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Helen Wilson

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***Beyond the Pink Ribbon:***  
***An exploration of the experience of self-compassion***  
***in Western Australian women survivors of breast cancer***

Thesis submitted for the degree  
Doctor of Philosophy

**2018**

Helen Wilson  
B.Bus (HRM); M.Couns.  
School of Arts & Sciences  
Discipline of Counselling  
University of Notre Dame Australia

## Table of Contents

<b>Abstract</b>	9
Statement of Authorship	11
Acknowledgements	12
List of diagrams and tables	15
Abbreviations used	16
<b>Chapter One: Motivation for the Study</b>	18
1.1 Professional motivation	18
1.2 Personal motivation and reflection	25
<b>Chapter Two: Introduction</b>	30
2.1 Overview	30
2.2 The heart of this study	32
2.3 The lens of self-compassion	34
2.4 Background to the study	35
2.5 Survival: Life beyond the pink ribbon	36
2.6 Personal resourcefulness: Being self-compassionate	42
2.7 Self-criticism and mis-communication	43
2.8 Living in the ‘long shadow of breast cancer’	44
<b>Chapter Three: Beyond the Pink Ribbon</b>	45
3.1 Overview	45
3.2 Cancer brings life changes	46
3.3 The public face of the ‘battle with breast cancer’	47
3.4 Beyond the pink ribbon	48
3.5 Survival: An urgent quest	49
3.6 Adaptation: Meeting a different self	51
3.7 Suffering and emotional distress	52
3.8 A phenomenon of anti-suffering	55
3.9 Transition: Survivorship and opening to self-compassion	57
3.10 Compassion	58
3.11 Self-compassion: Challenge and opportunity	59

3.12	The internal experience of self-compassion	60
3.13	Breast cancer and self-compassion-centred counselling	63
3.14	Significance for counsellors	65
3.15	Chapter summary	66
<b>Chapter Four: Literature Review</b>		<b>68</b>
4.1	Overview	68
4.2	Social constructions of breast cancer	70
4.3	The happiness imperative	75
4.4	Reality: Psychological sequelae of breast cancer	78
4.5	BC-related distress: Depression, anxiety and coping	79
	4.5.1 Inflammation, depression and risk of BC	83
	4.5.2 Diet, exercise and BC risk	84
	4.5.3 Anxiety and fear	85
4.6	Survival and the longer term: Life in the ‘long shadow of breast cancer’	87
	4.6.1 Seasons of survival	92
	4.6.2 Self-blame and self-criticism	95
4.7	Emotional suffering and wellbeing in long-term survival	99
4.8	Self and other relating	104
	4.8.1 Self-relating	104
	4.8.2 Other relating	108
4.9	Stress, breast cancer and relationship	110
4.10	A new beginning	112
	4.10.1 Post traumatic growth	112
4.11	Psychosocial interventions	117
4.12	Creative arts for personal enquiry	126
4.13	Compassion and self-compassion	129
	4.13.1 Self-kindness and self-compassion	131
	4.13.2 Fear of self-compassion	132
	4.13.3 Being mindful: A path to self-compassion	133
4.14	Self-compassion: Transformation and the self relationship	134
4.15	The body and self-compassion: Self-care and body changes	139

4.16	The contribution of counselling to emotional wellbeing and mental health	141
4.17	Chapter summary	144
<b>Chapter Five: Methodology and Research Methods</b>		146
5.1	Overview	146
5.2	Research question	148
5.3	Purpose of the study	149
5.4	Significance of the study	149
5.5	Strategy and design	150
5.6	Epistemological stance	150
5.7	A social constructionist perspective	152
5.8	Feminist methodology	155
5.9	Knowledge generation	158
5.10	Theoretical framework	159
5.11	Phenomenology	161
5.12	Interpretative Phenomenological Analysis	162
5.13	Historical factors for a phenomenological perspective	163
5.14	Bracketing	163
5.15	An Heideggerian perspective	165
5.16	Hermeneutics	166
5.17	Participants	168
	5.17.1 Participant recruitment	168
	5.17.2 Sampling and sample size	170
	5.17.3 Saturation of themes	170
	5.17.4 Inclusion criteria	171
	5.17.5 Phases of participation	171
5.18	Data collection	172
	5.18.1 Instruments and procedures	173
	5.18.2 OtSC sessions	174
	5.18.3 PRP sessions	174
5.19	Participant observation	175
5.20	Data analysis	176
	5.20.1 Analysis of semi-structured interviews	176

5.20.2	Opening to Self-Compassion (OtSC) sessions	178
5.20.3	Personal Reflection Program (PRP) sessions discussion	178
5.21	Protection of participants	179
5.22	Credibility	179
5.23	Chapter summary	181
<b>Chapter Six: Findings</b>		183
6.1	Overview	183
6.2	Women survivors of BC	184
6.3	Findings from women recovering from BC	187
6.3.1	Response to diagnosis	187
6.3.2	Survival and the meaning of life	193
6.3.3	Support	198
6.3.4	Cognition and functioning	205
6.3.5	Putting myself first: Adjusting priorities	209
6.3.6	Emotions and personal growth	213
6.3.7	Relationship with my body	219
6.3.8	Self-worth, self-blame and BC	224
6.3.9	Unexpected benefit: The gift of cancer	228
6.3.10	Self-compassion	233
6.3.11	What women need	242
6.3.12	Section summary	245
6.4	Findings from significant others	246
6.4.1	Confrontation with the disease	248
6.4.2	Being the strong one	251
6.4.3	Disorganisation and unrest	254
6.4.4	Turbulence and treatment	256
6.4.5	Caring for ourselves	259
6.4.6	Her self-image	261
6.4.7	Intimacy, sex and sexuality	263
6.4.8	Emotional support	266
6.4.9	Grief and talk of death and dying	270
6.4.10	The meaning of self-compassion	274
6.4.11	Back to basics	277

6.4.12	The future	279
6.4.13	What might help	281
6.4.14	Section summary	282
6.5	Findings from counsellors' reflections	283
6.5.1	Bearing witness	287
6.5.2	Passionate work: Not putting band-aids all over the place	290
6.5.3	Personal challenge for counsellors	292
6.5.4	Physical changes and being real	294
6.5.5	Youth, sexuality, death and dying	297
6.5.6	The chaos inside	301
6.5.7	I'm different but what does that mean	302
6.5.8	Self-blame	304
6.5.9	Time to heal and grow	305
6.5.10	Self-compassion	306
6.5.11	Survival and reconstructing life with a toolbox	310
6.5.12	Section summary	311
<b>Chapter Seven: Discussion</b>		314
7.1	Overview	314
7.2	Relationship with self and after-effects of BC	320
7.2.1	Restoration of emotional functioning: The psychological self	327
7.3	Emotional and personal growth	332
7.3.1	Emotions and wellbeing	334
7.3.2	A different perspective	336
7.4	The desire for self-nurturance	336
7.5	Unanticipated benefits: The gift of cancer	338
7.6	Personal Reflection Program sessions	339
7.7	Participant observation: OtSC and PRP	343
7.8	Relevance of self-compassion: Finding self, saying no	344
7.9	Significant others and the shared journey	346
7.10	Willing witnesses: Counsellors' perceptions	351
7.11	Chapter summary	354

<b>Chapter Eight: Relevance of Self-Compassion for Counselling</b>	356
8.1 Overview	356
8.2 Relevance of counselling and SC for BC survivorship	361
8.3 Counselling for BC survivors	362
8.4 Change and transformation	364
8.5 The art of counselling	365
8.6 Self-compassion and the professional counsellor	369
8.7 Chapter summary	370
<b>Chapter Nine: Implications for Counselling Practice and Training</b>	371
9.1 Overview	371
9.2 Counselling with BC survivors	373
9.3 What has already been offered: What can be offered	375
9.4 Survival and readiness to explore self-compassion	379
9.5 Implications for counsellor training programs	380
9.6 The place of self-compassion training	385
9.7 Chapter summary	386
<b>Chapter Ten: Limitations and Future Research</b>	388
10.1 Limitations	388
10.2 Suggestions for further research	391
10.3 Chapter summary	393
<b>Chapter Eleven: Conclusion</b>	395
11.1 The current situation	395
11.2 The future: Emotional wellbeing and the aging survivor	396
11.3 The women in this study	397
11.4 Survival and self-compassion	398
11.5 Conclusion: Revisiting the aims of this study	400
<b>Appendices</b>	403
List of appendices	403
Appendix 1: Information letter for participants	404
Appendix 2: Informed consent form	406



Appendix 3: Interview schedule:	
Women survivors of breast cancer	407
Appendix 4: Interview schedule: Significant others	409
Appendix 5: Interview Schedule: Counsellors	410
Appendix 6: Observations from Session 1:	
Personal Reflection Program	412
Appendix 7: Images of art responses by women survivors	417
Appendix 8: Summary of researcher's personal Reflection	
Journal summary	425
<b>References</b>	<b>433</b>

## **Abstract**

Using a phenomenological lens this qualitative study explored the experience of self-compassion in self and other relating in Western Australian women breast cancer survivors (BCS). A purposive sample of 17 participants were drawn from women aged between 35 and 70 years of age who had completed treatment for primary breast cancer and had been disease-free for a minimum period of 12 months. Participants were asked to take part in an in-depth semi-structured interview. Additionally, eight participants interviewed engaged in three, one-hour *Opening to Self-Compassion* sessions and three, four-hour sessions (12-hours in total) of a *Personal Reflection Program*.

Data was gathered using one-on-one semi-structured interviews with three participants who each were a significant other (e.g., spouse) in the life of a woman with breast cancer. Three counsellors working with BCS were also invited to take part in a semi-structured interview. Interpretive Phenomenological Analysis (IPA) was used to analyse data from all interviews. The *Opening to Self-Compassion Sessions* and *Personal Reflection Program* were analysed using a participant observer method. Major themes identified that BC survivor participants had difficulty prioritising their needs over needs of others, and only post-BC began to consider their own needs. Through a focus on physical survival BC had brought a realisation of personal resourcefulness previously unrealised. Self-compassion was not well understood and a number of participants reported concern about being judged as selfish. Interviews with Significant Others revealed challenges in witnessing their wife's physical illness and emotional distress as well as attempts to retain a sense of normality in life. Counsellors interviewed reported experiencing a deep state of compassion when working with BCS.

This study makes a contribution to enhanced understanding of ways women living with long-term after-effects of breast cancer relate with themselves and their body. This study also provides valuable information on whether self-compassion can help ease emotional burdens of survivorship. The question is whether self-compassion can support healthy mobilisation of intrapersonal resources and support reduction in post-treatment anxiety and depression in survivors of breast cancer. The findings make a valuable contribution to the design and delivery of psychological interventions for BCS. In particular the relevance and implications of inclusion of self-compassion training in counselling interventions for BC survivors is highlighted.

## **Statement of Authorship**

I affirm that this thesis is entirely my own work, and contains no material previously published or written by another person, except where due reference is made in the thesis, and it contains no work which I have previously presented for an award of the University or any other educational institution.

Helen Wilson

23 May, 2018

## **Acknowledgments**

With much gratitude I acknowledge the women who so willingly shared personal stories of their experience of breast cancer and living beyond the pink ribbon. Without their generosity and support this research would not have been possible. During the years of this project what kept me going was the knowledge that through our connection I was a privileged ‘holder’, for a brief while, of part of their personal stories. Completion of the project is a means for me to give back and honour the richness and depth they have added to my life. I think of these women often with gratitude and affection and to this day carry a mental picture of each one as they told their story. My wish for their lives is that they flourish and continue to be nurtured by their own strength and resourcefulness.

I would also like to acknowledge the three men who were absolute in their commitment to supporting their wives through breast cancer. Their unique perspectives on the experience of living through BC with their wife contributed a broader vision to this project and challenged and extended my thinking. I am extremely grateful for their genuineness, openness and their help.

The three professional counsellors whose generosity of spirit, practice wisdom and wealth of knowledge and experience helped me understand more of the human side of my research are women whom I deeply appreciate and admire.

Each person on the supervisory team brought a unique expertise and perspective that blended seamlessly into the planning and implementation of this study. The process of bringing this thesis to conclusion involved surrender of what often seemed at the time like precious ideas I hoped I could simply secrete somewhere in the text and not lose. Letting go of the way I thought I wanted the thesis to be helped me find the way it could be.

To my supervisors: Dr Jacqui Dodds who offered incredible input about what self-compassion and being compassionate meant. Jacqui's support and enthusiasm for the project kept me on task. Her patience when life got in the way of my progress was very much appreciated! As an experienced and respected psychotherapist and PhD Cum Laude Jacqui provided inspiration to me to continually improve the level of critical thinking and to approach scholarly writing about breast cancer with discipline, creativity, and mindful awareness. Jacqui has been an exemplary model and a resource about the experience of self-compassion, breast cancer, and the experience of writing a PhD thesis. I am forever grateful for her wisdom, skill, and support.

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Professor Martin Philpott provided solid mentoring in the early days and helped keep my thinking stabilised when I would drift off course. His mentorship has been invaluable to me.

I dedicate this thesis to my partner and my children. To a wonderful life partner, Mark Pearson, who had an unwavering belief in my capacity to complete a life-long dream, thank you for sharing my life, for nourishing meals that would somehow appear without any fuss or fanfare, for your guilt-free house cleaning, and for always relating to me with a compassionate heart and mind. Your trust in me and your love helped me finally believe in and love myself.

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## **List of Diagrams and Tables**

Diagram 1: Elements of the literature review	70
Diagram 2: Seasons of Survivorship	93
Diagram 3: Revised model of Seasons for Survivorship	93
Diagram 4: Seasons for Survivorship	94
Diagram 5: Essential ingredients for SC relating with self and others	134
Diagram 6: Elements of the research process	146
Diagram 7: A 5-step process of theme identification	184
Diagram 8: Associations between elements of healthy relating	361
Table 1: Participant groupings	169
Table 2: Demographic data for PRP group participants	185
Table 3: Major themes from women participants	186-7
Table 4: Demographics of significant others	247
Table 5: Major themes from interviews with significant others	248
Table 6: Counsellor participants	284
Table 7: Major Themes from counsellor interviews	287



## Abbreviations Used

BC	Breast cancer
BCS	Breast cancer survivor/breast cancer survivors
ET	Expressive Therapies
EWB	Emotional wellbeing
FoCR	Fear of Cancer Recurrence
ILS	Inner life skills
IPA	Interpretative Phenomenological Analysis
OtSC	Opening to Self-Compassion
PRP	Personal Reflection Program
PTG	Post-traumatic growth
PWB	Psychological wellbeing
SC	Self-compassion
SO	Significant other

Note: The term ‘breast cancer survivor’ (BCS) has been used throughout this thesis to refer to women in the study. It is acknowledged that only one of the women, of the 17 interviewed, had passed the five-year post-treatment mark whereas others ranged from 1 – 4 years post-treatment. This means that the women interviewed were each in the early stage of responding or reacting to treatment for BC. Use of the term BCS has been applied because it is a commonly used term in the literature. In their study into improving BCS psychological outcomes and quality of life, LeRoy et al (2018) took the stance that cancer survivorship begins at the time of first diagnosis of cancer. Their perspective is in line with that expressed in the USA by the National Coalition for Cancer Survivorship (<https://www.canceradvocacy.org/news/defining-cancer-survivorship/>). The term BCS was also one agreed upon by the women and Significant Others in this study. In interview the women said they did not want to be defined as either a victim, or a person still battling cancer. They regarded themselves as cured, a survivor – a person who no longer had breast cancer. Women participants objected to the phrase ‘living with cancer’ as they did not want to be stigmatised by a

label. Overall, there was no consensus reached about a term that would best describe the women and so the term BCS was one to which all participants agreed.

Universal agreement about the term ‘survivor’ has, so far, not been reached.

Research has identified that once the 5-year survival threshold has been crossed a majority of women treated for BC resume the social and work-related functions of their pre-diagnosis life. Resumption of life in a ‘new normal’ does not however mean that self-compassion lacks relevancy for survivors of BC.

# **Chapter One**

## **Motivation for the study**

The exploration of self-compassion (SC) and development of this thesis has been motivated from two main sources: one professional, one personal. Each of these motivators, in equal measure, stimulated my interest and provided personal energy to embark on the task of presenting the narratives of women's experiences of self-compassion as survivors of breast cancer (BC). The journey through this thesis has been as much a deeply personal, emotional one as it has been an academic one of discovery through research.

### **1.1 Professional motivation**

At the outset the aspiration to take on higher degree research was motivated by a desire, as a professional counsellor and counselling educator, to better understand and learn more about the ways people navigate through their emotional experience of a life-threatening or chronic illness. Many planned conversations, as well as meet-over-coffee chats with a range of academics, counselling colleagues, and women survivors of BC, created a vessel for refinement of the embryonic ideas swirling through my mind. Listening to others talk about their experience of embarking on a significant piece of research, as well as listening to the narratives of cancer survivors, allowed me to concretise thoughts and ideas. From these conversations, questions formed around what it was that helped survivors of BC cope with post-treatment life. This then became the central focus for my work.

The concept of having a pro-active, self-aware individual take up the role of effective monitor and manager of their own health could be regarded as integral to favourable outcomes from a medically-oriented care perspective. However, a persistent question revolved around evidence from research literature, as well as anecdotally, that indicated not all breast cancer survivors feel competent, energetic enough, or ready, to assume responsibility and ownership for ‘driving’ positive post-treatment change.

At the outset of this project self-compassion was a relatively new term applied to Western psychological conceptualisation of self and other relating. Neff (2003) was a pioneer in formal research into self-compassion as a protective factor in relation to psychopathology. Findings in a significant number of quantitatively-based studies on self-compassion have relied on Neff’s (2003) Self-Compassion Scale in either the full or abridged version of the measure. To assess self-compassionate relating through numerical scores may not tell the full story. Therefore it seemed valuable to gather women survivors’ stories of self-relating, and their perception of what it would mean to be self-compassionate. The usefulness of collecting narratives specifically about self-kindness arose out of questions about the potential for increased awareness of the benefits of inclusion of effective self-compassion strategies in therapeutic work. Findings from a study of self-compassion in a University student sample led to a proposed model of the links between self-compassion and wellbeing and self-coldness and personal distress (Brenner et al., 2018). Of particular interest in that study was the authors finding that “women reported less self-compassion and greater self-coldness than men” (p. 353). Importantly, health behaviour and adherence to medical regimens has been shown to be associated with the capacity for self-compassion (Terry & Leary, 2011). Increased self-compassion has been cited as having an important role in mental health in the aftermath of stressful life events (Scoglio et al., 2015), as well as facilitating healthy responses to living with chronic illness (Brion, Leary & Drabkin, 2014; Dunne, Sheffield & Chilcot, 2016). Therefore, the notions of self-compassionate self-relating as well as fear of self-compassion became particularly relevant for women vulnerable to mental health challenges as a result of, or pre-existing, diagnosis and treatment for breast cancer. Although much of the research into SC had found positive benefits it was considered important to explore the lived realities of self-relating post-BC.

At the beginning of this project, literature searches indicated that focused attention had not yet been paid to the influence of self-compassion as an emotional regulation strategy for Western Australian women living in the aftermath of breast cancer. For women to be able to more positively influence their self-relationship through an intervention such as self-compassion hinted strongly at a potential to manage stress and negative psychological sequelae. In turn, being able to manage stress responses could have important implications for positive effects on immune system functioning for survivors of breast cancer.

The experience and understanding of survivorship, the process of ageing for a woman's body, in addition to effects on close relationships, became the starting points of my enquiry. Optimistic though the current survival rate is for women diagnosed with BC, survivors will continue, across the long term, to experience psychological and physical sequelae. To me this highlighted the potential for emotional and developmental needs to silently slip from social and individual consciousness when women progressed from being a patient to the long-term task of being a survivor.

I began to wonder what might happen to authentic joyfulness and a sense of flourishing in life in the process of self-restoration after a woman had completed her medical journey through BC? I wondered if patterns of negative self-evaluation hindered the capacity of some survivors to be able to offer themselves the same emotional support they would willingly give to others. A query also arose in my thinking, about the effect on immune system functioning for the person with a chronic illness, from less than positive, or even toxic, self-relating. From these considerations a question emerged about whether there might be a missing ingredient to positive psychological recovery. What seemed clear was that any intervention or strategy would need to be helpful for women to give emotional kindness and generosity to themselves during their survivorship. At the same time any psycho-social intervention needed to be able to avoid becoming an imposition of additional emotional, psychological and social demands. The key to unlocking this doorway seemed to lie within an exploration of the relationship a woman had developed with herself and with her body prior to BC and how she related with herself post-BC.

In thinking about ways that could support and promote healthy psychological outcomes throughout survivorship, it felt critical to first arrive at a clearer understanding of the non-medical, non-disease aspects of the lives of women who had completed treatment and were living with the label of ‘survivor’. At the same time I found myself fascinated by the pink ribbon culture that had seemingly enveloped breast cancer. My thoughts were drawn to consider ways in which the relationship with self, and relationships with significant others, may influence restoration of those relationships post-treatment. In addition, could lack of self-compassion lead to negative distortion in processing fear of cancer and of personal evaluation of risk of recurrence. A 21<sup>st</sup> century heightened awareness of the prevalence of BC, in conjunction with trends toward commercialisation of BC survivorship could mean a person with low self-compassion may feel some pressure to align themselves with a perspective on BC recovery that might not be psychologically healthy.

My aim was to conceptualise a trajectory that could lead from a position where a woman might encounter persistent negative self-blame, to a state of being self-compassionate and, then ultimately to a capacity for effective self-care and self-soothing. I thought about the limitations life histories can impose on the direction of psychological adjustment to challenge or crisis. These ideas were still in the formative stage when I came across a television program featuring Kristin Neff. Watching the program piqued my passion for non-pharmacological ways that would support emotional regulation and reconnection with inner life skills, joy, and a stable sense of psychological wellbeing. Within a matter of weeks I had located Neff’s construct of self-compassion (SC) (Neff, 2003) and the ‘adventure’ had begun.

In my exploration to uncover a broader concept of human relating, Neff’s work on the topic of SC (Neff, 2003), with its central idea of relating with ourselves with a greater focus on a wiser and more affectionate self-relationship, provided an invaluable link. Neff’s (2003) concept was that encouragement of the key elements of SC involved compassionate relating with oneself, self-kindness, acknowledgement and aware acceptance of the imperfection of human existence, along with conscious quarantining of habitual self-judgment. The construct of SC offered an invaluable concept to support emotional agility in a broad range of people. Prompted primarily

by those early writings of Neff (2003) in the first decade of the 21<sup>st</sup> century, a significant amount of literature has since been generated on the topic of SC and its usefulness as a means of emotional regulation.

Self-compassion was a concept that seemed extremely straightforward in its explanation, but that could bring challenge in its application and practice. I wondered if its simplicity masked the value for people whose personal resourcefulness may have been blanketed by criticism from those around them, and who then may have struggled under the weight of ruthless self-criticism. It felt as though Neff's conceptualisation of SC delivered a resolution to my wondering about a missing ingredient in the existing strategies that support human wellbeing and promote sustainable mental wellbeing. SC appeared to offer an ideal trail that I hoped would lead inexorably to a reconnection with and maintenance of self-warmth, self-understanding and compassionate communication with self and with significant others. My strong belief was that SC had the great potential to help cancer survivors emotionally thrive - rather than simply survive.

As a concept, SC excited my professional mind and nourished my personal enthusiasm. My interest in SC led me automatically to the question: what is the experience of self-compassion in women with BC who are survivors of breast cancer? My question was further intensified by the apparent potential to explore ways to robustly live as a cancer survivor without self-judgment. My questioning then led me to consideration of the personal resources of women, and ways in which those resources might hinder or help individual resilience in the face of adversity.

To understand women's experiences and to hear the voice of women about what it was like to be a survivor, it seemed essential to uncover more detail about the essence of self-communication and the nature of the relationship with their body and their feelings. Therefore, initial self-questioning focused on whether a sense of personal goodness and value, for the person whose life trajectory was now inextricably linked with a chronic illness, could be enhanced through a compassionate self-relationship. The second question I faced was whether relating with self in a compassionate way would have a positive influence on relating with significant others. Additionally, there was the growing question about what specific

personal resources might provide a sense of recovery of an inner state of overall ‘goodness’ as opposed to feelings of ‘failure’ in body, mind and feelings. In response to these ideas, the sometimes often obscured power of women’s voices became a strong guiding principle.

At the outset, the concept of SC as presented, looked as though it could aid the creation of a post-BC personal narrative characterised by greater self-congruence. The task was for me to discover more about the larger context and realities of the lives of women survivors of BC. This undertaking heralded acknowledgement of the desire and need to gain reliable knowledge about women’s actual experiences of relating with themselves before and after BC.

From understanding more about the self-relationship for survivors of BC the hypothesis was that more could be discovered about the most prevalent influences that shape their relationships with significant others post-BC. As a result of a distillation of these ideas about the nature and essential ingredients of relating with the internal and external relational environments, the relationship with self became a central focus around which other aspects of relating revolved.

From my reading and personal engagement with SC, integration of the central elements of the practice of SC offered beneficial, yet gentle, means of engaging a woman’s self-healing potential. The resources that foster self-healing and soothe intense emotional states activated by fear, anxiety, helplessness or powerlessness can get trapped in unproductive negative thinking. Presented in the literature as a resource for ongoing self-awareness and mindful maintenance of mutually nourishing relationships, SC sparked my thinking about living life in the shadow of BC. For many survivors this is a life that would be expected to extend for the normal life span - well beyond the threshold of the much-desired post-treatment five year survival point.

Research has highlighted depression and anxiety as the most prevalent post-treatment issues for women with BC. My thinking was that when suddenly catapulted into the vortex of BC, a woman, and her family, are instantly faced with issues of mortality, recovery, survival, sexuality, dependency, financial strain, and



the demands of caring for family. The process of grieving for a past way of life that suddenly becomes non-existent, and the ever-present concern about survival, and how to cope in an uncertain future, now created a clear tapestry of emotional and psychological challenges women faced post-BC. My focus was not on identifying physical wear and tear as a result of a negative self-relationship. Mine was not a cause-and-effect interest. My interest was to consider and question whether SC might restore lost communication with self, body and others, and support emotional agility through a more flexible and healthy self-relationship. What the concept of SC could offer was a model of self-guidance to help create a vision of a future renewed self who could embrace emotional wellbeing.

The path of self-compassion offered the potential to significantly alter, in a positive sense, unproductive results from habits of shame, guilt, and lack of self-worth that may have persisted lifelong. Research had indicated that some survivors of BC find themselves unable to step back and gain psychological ‘distance and perspective’ on what happened as a result of their diagnosis. Previously effective in creating and managing life, they may now find themselves overwhelmed by stress. They may feel helpless and blame themselves, or feel helpless and want to blame others.

Research into SC provided evidence of an effective way to foster ongoing personal growth and development through the simple task of self-kindness rather than the path of achievement being forged through habitual harsh self-criticism. From the literature on SC, indications were that the construct offered a significant basis for deeper personal reflection that could lead to healthy self-restoration at times of distress or confusion. Despite evidence that increasing self-compassion was a powerful facilitator of positive affect, individuals high in self-criticism had been found to resist or fear receiving compassion from others as well as fear of being compassionate to oneself (Gilbert, McEwan, Matos & Rivis, 2011). This meant deeper reflection on the influence of self-criticism on one’s capacity for being open to social and emotional bonds with others. An incisive review of my own habit of resistance to being cared for by others occurred during the time of listening to, digesting, and interpreting the life stories entrusted to me by the women who participated in this study. Consideration of the human capacity to be self-

compassionate, fear of compassion for self, and resistance to feeling compassion from others was a constant companion throughout this PhD quest.

## **1.2 Personal motivation and reflection**

The distinction between the strongly evaluative nature of the concept of self-esteem as opposed to the kinder stance of SC provided a key that unlocked significant personal revision of my long-held perfectionist traits (Neff, 2003). For me, SC became an invaluable influence on my passage through this thesis. SC became an overarching mechanism for conceptualising conscientiousness, revising my intrapersonal dialogue, reviewing interpersonal relating, and investigating any blind spots I might hold around potentially ‘gendered’ perspectives about women, relationships, and BC. The women in this study were the ones who generously and gently help me explore these personal questions in greater detail.

The process of talking about, thinking about, researching, and writing about women and BC has, for me, been a richly textured journey. So much has happened during evolution of this study. Some of the more notable markers have been the weddings of my children, work-induced separation for almost two years from my partner, two interstate moves of home and work, packing up and moving house a total of five times, the unexpected loss of two much-loved relatives to cancer, reconnection with a half-sister adopted out at birth, the birth of four grandchildren, and, for good measure, a very real question for my sisters and I about the BRCA1 gene identified in a living female family member who had survived breast cancer.

One of the most outstanding personal features of these past years has been the very great privilege of being a listener to, and holder of, personal narratives of a group of women BC survivors. This thesis has enabled me to get to know eight amazing women who have each taught me so much about compassion. In addition I was fortunate to have the honour of being able to interview an additional group of nine women survivors. These nine women made a very significant contribution to my comprehension of what diagnosis and treatment meant for them.

The time spent with each and every woman who took part in this study was invaluable in getting as close as possible to an understanding of the challenges of BC

survivorship. The women were patient, gracious teachers and ‘guiding lights’, especially the eight who took part in the Opening to Self-Compassion (OtSC) sessions and the Expressive Therapies Personal Reflection Program (PRP). Each of these personalities, and the interviews and groups they attended, drew me closer to deep reflection about how we experience self-compassion, what being self-compassionate means, how self-compassion can add to the richness of life, in addition to understanding fear of being self-compassionate.

The *Opening to Self-Compassion* (OtSC) sessions had the purpose of providing time for the women to come together, address topics that they may not openly discuss with family, and begin to form safe relationships with each other. My focus was that those relationships would then be ones in which they could feel trusting and safe enough to give voice to their experience. This would mean that during the *Personal Reflection Program* (PRP) sessions, this smaller group of women would likely be willing to explore at depth their experience of BC, and share their unique narratives of needs, desires, and motivations for life post-BC. Three one-hour OtSC sessions were also a time for women to orient themselves to the topic of SC and consider their reaction or response to the idea of being compassionate to oneself. The format for both the OtSC and the PRP was created with flexibility in mind. The women’s responses to questions posed in the OtSC sessions were used to form a basis for the direction of group discussion during the PRP sessions.

From my encounters with the women and my evolving relationship with research, the hope is that my own experience has been a useful guide for me in how to *be* for people, not only those who have survived cancer, but for people who encounter a personal struggle to feel kindness and forgiveness for themselves.

For several decades I had been fascinated by phenomena of persistent pre-ordained negative cognitive, and emotional, conceptualisations that companion us in life. In my life these negative conceptualisations dictated how I was able to respond to myself and others in times of stress, loss, or emotional strain. Despite extensive personal therapy to repair events and relationship experiences from my past, I am able to confess that despite healing well from my past, the lived experience of how to be compassionate to myself continued, sadly, to remain somewhat elusive.

In hindsight I can see that SC was definitely a mystery to me. My conviction was that compassion was an outward act entirely focused on giving to others. I wanted to believe that simply thinking well of myself and being of service to others filled my basket of self-compassion. However, attempts to think well of myself carried the constant risk of reprisal and unforgiving negative self-evaluation from an internalised negative and highly critical self. Whatever life goal I set myself was considered by my inner judge to have fallen short of some imagined benchmark. The accompanying sense of abject failure left a deep void in my relentless desire to reach a sense of peace. I wanted to enjoy feeling peaceful about who I was, but this needed to happen in a realm of genuine self-acceptance. The roadblock in my psyche remained one of inability to feel genuine self-acceptance. Some years of personal therapy improved my self-esteem, facilitated healthier self-acceptance, brought a balance to my life, and a more positive way of relating with the outer world. But welcome as these changes were, being persistently kind and gentle in my relationship with myself remained elusive. In my thoughts and feelings self-kindness seemed to endure as an intellectual concept that was vague in its everyday application.

Discovering a small but unmistakable breast lump at age 22 was not good news to me. Just six short weeks from my wedding day, a prompt visit to my GP to discuss the lump resulted in an urgent late afternoon hospital check-in with surgery booked for early the next morning. Even though my GP had not mentioned the word cancer, my thoughts immediately went there. Within 24 hours I had gone from concern about the colour of bridesmaids bouquets to wrestling with my fear of death, and deeper questioning moments about what the future might hold. Employed at that time by an insurance company I had access to myriad medical reports and so had an awareness of the ominous potential of finding a breast lump. The spectre of death, or serious illness that might still result in death, felt a sudden, heavy burden.

The words I did not want to hear, the ones that wove my worst fears into a terrifying tapestry were delivered by a well-meaning nurse as I was prepped for surgery. In a rather knowing voice she told me that once the doctor was 'in there' he might have to take the whole breast or both breasts, depending on what he found. Stunned, gagged silence and violent retching all the way to the operating theatre was

my only response. There was no peace of mind despite the powerful anaesthetic that eased my physical self into a state of unaware sleep.

Only now as I look back can I recognise that the choice not to disclose this experience to anyone except my soon-to-be husband probably came from an extraordinary lack of warmth, understanding and compassion towards myself. There was no conversation with my GP. Surgery to remove the lump was scheduled for Friday and I exited hospital early Monday morning before the doctor did ward rounds so I could arrive at work on time. I wanted to ignore my experience and simply get on with life. Fortunately for me the eventual outcome was positive and no further medical intervention was needed.

The principles of life that I had absorbed - primarily from teachers in my school days that began with Year 1 when I was just four years old - lacked a foundational theology of hope, optimism, beauty, freedom, and grace. In place of these principles, I had translated what I was told in to constant negative self-evaluation for fear of not measuring up to what I realise now was an impossible goal.

Somewhere around adolescence I developed what I would call a 'phobic response' to the disease called cancer. I never fully understood why that was so, but looking back believe it emerged from the death of a much loved grandmother whom I expected would live forever. When confronted with the "C" word the feeling that gripped my body was cold, silent, terror. I could barely stand to say or hear the word. Any mention of cancer made me feel vulnerable to inevitable attack from a swiftly silent, deadly foe. It was a feeling I struggled to hide. But I felt shame at this failure to cope, a failure of what I thought was my usually resilient nature.

My emotional immobility at the mere mention of cancer was exaggerated. I knew this at an intellectual level. Despite this, I grew adept at hiding any hint of fear on the outside, while internally I remained unable to control the dread of cancer catching up with me. My fear was compounded further a few short years later when a close work colleague died of stomach cancer. At twenty years of age she had, only a few months earlier married the love of her life. Her death seemed desperately unfair and I wrestled with the 'why her' question. As a result cancer became, for me, an

indiscriminate, insidious, and capricious nemesis, lurking relentlessly in the shadows of life, waiting to claim its next victim.

It seems obvious now that cancer did catch up with me. But not in the way I had anticipated. In 2011 and 2012 the experience of facilitating group counselling with women who had survived breast cancer proved to be the place where I was both confronted by the thing I feared most and nourished by the thing I feared most. Inspired by women in those groups their wisdom taught me to be with them in a way that helped me regard their encounter with BC as what I would call a form of ‘pregnancy’ – a privileged time of taking the role of a type of patient midwife able to witness the re-birth of each woman’s own self. The Self that emerged after BC often, but definitely not in all cases, presented a revitalised sense of life.

As a therapist I have been privileged to witness the life benefits for those clients who have developed compassion for themselves. The tension for some clients as they separate the fear of selfishness from what it means to treat themselves with kindness has been profound. For some the fear of being selfish had kept them in servitude to out-dated attitudes that denied a flourishing in life.

The process of inquiry I have set about with this research is one that seeks to combine careful methodical process and analysis with knowledge from the heart. I hope the final document reflects the heart and soul of how women have found compassion for themselves as they navigated their way through the challenges of living beyond the pink ribbon.

## **Chapter Two**

### **Introduction**

#### **2.1 Overview**

Breast cancer (BC) is an old disease faced by women across centuries (Olson, 2002; Verrill, 2009). An extraordinarily complex disease (Downs-Holmes & Silverman, 2011; Vuong, Simpson, Green, Cummings, & Lakhani, 2014) BC strikes at the very core of womanhood (Cromptvoets, 2003; Galgut, 2007; Rubin & Tanenbaum, 2011). This form of cancer challenges notions of both what the female breast symbolises for a woman, and what it has come to represent in society in general.

The female breast has a nutritive function as an object of nourishment and human kindness, evidenced in the suckling role (Boyd, 2001; Levin, 2006), and at the same time female breasts are objectified and portrayed as a prime source of sexual fantasy and desire (Boyd, 2001; Galgut, 2007; Levin, 2006), the purpose of which is often represented in the media as something to be looked at, played with, and enjoyed by people other than the woman herself (Duvall, 2014).

One of the profound difficulties for a woman diagnosed is that loss of, or significant change, to one or both breasts presents a highly visible challenge to her sense of self (Cromptvoets, 2003). Her identity as a woman is confronted, and post-treatment the BC survivor can be faced with disturbance to her sense of “femininity, sexuality, and of herself as ‘normal’” (Cromptvoets, 2003, p.137). She is no longer her emotional self either. The question of self-value arises in relation to whether a woman is drawn to conform with socially endorsed ideals of both physical

attractiveness and external looks promoted as beauty and femininity in women (Moore, 2010). BC is not a cosmetic process (Van Der Wiel, 2013). Nothing remains the way it was before the words ‘it’s breast cancer’ enter a woman’s emotional orbit. Past traumas can be triggered at any time throughout her BC experience, not just during diagnosis or medical treatment (Galgut, 2007), and de-rail a desire to remain hopeful and untouched by the trauma that is BC.

When a woman feels as though her body has failed or betrayed her, her sense of personal value and attractiveness suffers because the body does not ‘live up’ to the standard set by either the woman herself, or her perception of the expectations of a positivity-g geared society. Those expectations are that a woman, in her young years, needs to be physically attractive, feminine, energetic, sexually active, and able-bodied (Sulik, 2011; Trusson, Pilnick, & Roy, 2016). Living with breast cancer can mean the outlook for life feels bleak at times, and both hope and confidence can fade to a vague shadow of their former ‘selves’.

In the life-defining moment of receiving a BC diagnosis, a flood of decision-making, emotional and psychological stress, and choice of treatment, changes a woman’s sense of personal meaning (Documet, Trauth, Key, Flatt, & Jernigan, 2012). Her hopes, dreams, expectations and future-oriented plans are rapidly swept away. The complexity of BC is that long after a formal treatment regime concludes, the negative after-effects of having had this disease continue to destroy a woman’s instinctive expectations of wellness as she experiences disruption to her physical, emotional and spiritual well-being (Elsheshtawy, Abo-Elez, Ashour, Farouk, & El zaafarany, 2014).

During recovery and re-integration into life post-treatment, personal identity can be subsumed under the label of being a BC survivor. Some women lament this identification; others may feel overwhelmed by the tasks of survivorship; others may marshal their personal resources to do battle. Rather than judge self as a failure, or feel the need to ‘do’ more, be different, or become engaged in making unhelpful comparisons with other women who may be esteemed by society for their ‘battle’ against BC, self-compassion highlights a means of moving through the experience of a life-threatening illness in a self-kind and self-sustaining way (Neff, 2003).



The landscape of older life can be radically redefined as the words ‘breast cancer’ and ‘survivor’ begin to intrude or dominate a woman’s identity, her sense of purpose and meaning as age advances and she becomes one of the older women living with the after-effects of BC.

In terms of emotional and psychological well-being the concept of self-compassion (SC) as hypothesised by Neff (2003) provides significant insight into a way post-BC women can be supported to navigate the inevitable stressors associated with the diagnosis, treatment, recovery process and survivorship. Three central components of self-compassion make this an appropriate and valuable topic for investigation in relation to the post-treatment experience of Australian women who have survived BC.

The capacity to relate with oneself in a kinder way elicits a “softer, friendlier relationship with physical discomfort and difficult feelings” (Germer, 2009, p.67). In short, being self-compassionate provides a self-protective strategy that could buffer against the negative impact of having had BC. Development of a more accepting, less critical, habit of relating with oneself has been identified as able to facilitate an ability to discern how to relate with oneself in ways sensitive and open to emotional, physical and spiritual needs (Akin, 2014; Alma, 2008; Alma & Smaling, 2006; Dodds, 1999). The outcome for women living with BC could be expected to be the ability to gently counteract ingrained self-criticism, self-blame, self-judgment. The hope would be that minimisation of an internal self-denying dialogue could create a mindful, self-affirming connection between body, feelings and mind. In the face of increased rates of diagnosis and increased years of survivorship, fostering compassionate communication with self and others affords a valuable tool for self-acceptance (Germer, 2009) to guide a survivor through the intricacies and nuances of living long-term post-BC.

## **2.2 The heart of this study**

In this study it was found that despite the idiosyncratic nature of the journey each participant had made through and beyond BC, their narratives combined to highlight common experiential ground by way of similar emotional reactions, and mutually experienced thoughts and behavioural responses. Clearly, the process for

women includes universally occurring ingredients - such as response to diagnosis, decision-making and treatment options, post-BC medication, in addition to the nature of the relationship with self and with significant others. In this study significant others reported a 'roller coaster ride' of emotions while trying to "be strong". They spoke of learning to live in the moment, of changes to their life, and positive changes in their relationships. Counsellors interviewed spoke of being the ones whose work required them to "bear witness" to the physical and emotional suffering of their clients who were BC survivors. Putting aside their personal response to the suffering they witnessed, these professional helpers spoke of their committed desire to help women survivors find "nourishment from within" themselves.

Bearing in mind the predominance in social consciousness of the nature of BC along with fear-based assumptions about the level of susceptibility to the disease (Galgut, 2007; Moore, 2010), this study examined whether an attitude of self-compassion could influence the way a woman communicates with herself, the way in which she nurtures herself, and acknowledges and attends to her physical and emotional needs, and the way in which she communicates her needs to others. This study looked at the nature of the relationship women living with BC have with themselves, their body, and with significant others. In particular, this research explored women's understanding and experience of self-compassion.

Increased numbers of BC survivors means the focus for those diagnosed with BC is now much broader, with current treatment directions not confined merely to awareness and prevention, or to the medical processes involved (Schernhammer, Haidinger, Waldhör, & Vutuc, 2009). Treatment in the 21<sup>st</sup> Century includes not simply a more open dialogue on the medical aspects of the disease, but over recent decades has included greater awareness of the psychologically and socially disruptive effects of BC and the impact on long-term survivorship (Meneses & Benz, 2010). This awareness has been matched by acceptance of new ways to understand and engender psychological well-being of women diagnosed with BC (Schernhammer et al., 2009).

Using a phenomenological lens, this qualitative study focused on emotional well-being in West-Australian women with breast cancer (BC) and specifically

investigated ways in which women survivors of BC understood the idea of self-compassion, and experienced self-compassionate relating with themselves, their body, and with significant others. At the heart of this study was consideration of whether counselling with a focus on compassionate communication with self and others could assist women to develop and nurture self-kindness for themselves and their body.

A purposive sample of 17 participants was drawn from women aged between 35 and 70 years of age who had completed treatment for primary BC and had been disease free for a minimum period of 12 months. Participants were women living in the Perth metropolitan area of Western Australia. They were invited to take part in an individual, in-depth semi-structured interview, followed by three one-hour focus groups. Once all interviews were completed, participants were invited to engage in three four-hour sessions (12-hours in total) of a specially designed Personal Reflection Program based on an expressive, creative arts approach to enhance self-discovery. The focus of the program was raising awareness of self-kindness and self-nurturance.

Data was also gathered using one-on-one semi-structured interviews, from three participants who each were a significant other (eg. spouse) in the life of a woman with BC. In addition, three counsellors who had worked with women with BC were invited to take part in a one-off, individual, semi-structured interview.

### **2.3 The lens of self-compassion**

Self-compassion (SC) has been defined as a conscious process of turning compassion inward towards oneself so an emotionally supportive self-relationship can replace a blaming, condemning, self-critical one (Gilbert, 2009). An emotionally supportive relationship is one that enacts a flexible attitude towards oneself when experiencing emotional pain, and has an awareness of one's life as meaningful (Neff, 2011; Neff, Kirkpatrick, & Rude, 2007; Pauley & McPherson, 2010; Yarnell & Neff, 2013). Consistently demonstrated in research data as "negatively correlated with measures of depression, anxiety, self-criticism and rumination" (Pauley & McPherson, 2010, p. 130) evidence has indicated that being self-compassionate facilitates resilience and coping (Leary, Tate, Adams, Allen, & Hancock, 2007). Positively linked to social connectedness, self-determination, and feeling

interpersonally connected to others (Neff, 2003), available evidence has found that self-compassion is integral in development of an adaptive strategy for emotion-organising and generation of positive emotions that foster psychological well-being (Akin, 2014; Zessin, Dickhäuser, & Garbade, 2015). Focused on the “emotional stance that individuals take towards themselves when faced with an experience of failure or suffering” (Neff, Hsieh, & Dejjitterat, 2005, p. 265), self-compassion has been found to contribute to stable patterns of emotional regulation (Leary et al., 2007; Neff, 2003; Neff, Kirkpatrick & Rude, 2007; Germer & Neff, 2013) in addition to reduction of symptoms in PTSD (Kearney et al., 2013), to a decrease in functional disability in defence personnel with symptoms of PTSD (Dahm et al., 2015), as well as less reduction in a tendency to engage in avoidance strategies related to unpleasant or distressing experiences (Thompson & Waltz, 2008).

#### **2.4 Background to the study**

Cancer is an unanticipated trauma that does not present as an encapsulated event. A complex disease that can be overwhelming, feared and stressful (Tallman, Altmaier, & Garcia, 2007), cancer brings pain and suffering on a number of levels. Being diagnosed with and treated for cancer confronts and challenges a person’s view of how life was expected to unfold (Dodds, 1999; Donovan-Kicken & Caughlin, 2010; Duric et al., 2007; Schulz, 2006). What characterises the experience of life with cancer is a sense of isolation from life as it was previously known, unreality about the current situation, as well as a persistent sense of having some unexpected limitations imposed on one’s emotional and physical life (Dodds, 1999; Duric et al., 2007; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Schulz, 2006).

In recent decades evaluation of treatment regimes for BC have challenged once routine application of aggressive treatment such as the radical mastectomy (Anderson, 2014; Harbeck & Gnant, 2017). There remains, however, general awareness that when a mastectomy becomes the option to achieve an optimal outcome, a woman undergoes irrevocable alteration to her body and her life (Little et al., 1998). Less well understood is that even without the need for a mastectomy, once diagnosis is made and treatment begins, suffering for the woman survivor becomes an experience of the whole person, not just of the body or a part of the body

(Crompvoets, 2003; Galgut, 2007; Przewdziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-Bilinski, 2013).

Amidst unpleasant emotions generated by confrontation with diagnosis of breast cancer, a woman is 'called' to urgently engage in and manage complicated interactions and negotiations with professionals in the medical domain (Bristow, 2002). There are a range of medical interventions to be navigated, such as chemotherapy, radiation therapy, possibly surgery, and hormonal treatment, each with their own type of side-effect (Arman & Rehnsfeldt, 2003). The resultant tension between the need to respond to a range of stressors that require cognitive acuity, self-perceptiveness and the need to consider relational functioning. Additionally, a woman may be faced with a range of social and economic and employment demands (Acitelli & Badr, 2005; Kayser, 2005) that add a more stress-inducing dimension to the process of absorbing the existential question with which she has been confronted.

## **2.5 Survival: Life beyond the pink ribbon**

Beyond BC it is essential to consider how best to create and plan emotional support that seeks to optimise women's personal resources for psychological and emotional well-being throughout survivorship. Several significant factors combine to underpin the value of exploring an individual's personal coping mechanisms and their approach to living with BC as a chronic illness. In general, Australian women can now expect to live longer and healthier lives than their counterparts of several decades ago. However, rises in population numbers brings an associated rise in the reported incidence of BC (Johnston, 2014). Australians diagnosed with BC have a 90% chance of surviving at least 5 years beyond diagnosis (Australian Institute of Health and Welfare [AIHW], 2017). Enhancements in contemporary medical technologies now offer an increasingly positive prognosis for the future of significant numbers of women diagnosed with BC (Johnston, 2014).

Women with a history of BC currently comprise the largest and most prevalent group of cancer survivors (Brennan & Houssami, 2011; Ganz et al., 2002; Knobf, 2007; Smith, Singh-Carlson, Downie, Payeur, & Wai, 2011). These increased survival rates beyond initial treatment mean larger numbers of women will expect to look forward to longer life post-treatment for BC (Gilbert & Procter, 2006; Pieters,

2009). This means significant numbers of women will need to continue to meet the ongoing physical and emotional adjustments required for living with the legacy of a chronic illness such as BC (Przezdziecki et al., 2013). Some survivors of BC will become long-term users of ongoing remedial medical treatment, as well as users of resources focused on emotional and psychological wellbeing (Esteva & Hortobagyi, 2008; Lijovic et al., 2008; Robb et al., 2007; Worden, 1989). This would be especially so for older women survivors who may develop concurrent co-morbidity, or have a pre-existing disease or mental health issue when diagnosed for BC (Pieters, 2009). Given that extended years of survival is now a critical issue for living in the aftermath of BC, it would be normal to expect that women will seek greater understanding and information about what to expect for their future and how they can cope as they experience cancer's lingering consequences (Harris et al., 2009; Worden, 1989).

Aging can no longer be associated solely with increasing physical frailty and a legacy of personal losses (Pieters, 2009). Issues related to longevity in survivorship become even more critical for a woman as she encounters challenges associated with the aging process (Mehnert & Koch, 2008; Robb et al., 2007). This means extended knowledge and understanding of the emotional experience of survivors of BC is useful to ensure the quality of available psychosocial support post-BC meets the needs of a woman as her years of survivorship extend into the future. There exists a need for a range of emotion-focused and problem-focused interventions to be considered when devising best practice for older women with a chronic illness. Emotional responses can change as a person ages, and anxiety and depressive mood linked to fear of cancer recurrence (FoCR) has been said to reduce in an older BCS (Vahdaninia, Omidvari, & Montazeri, 2010; Frazzetto et al., 2012; Champion et al., 2014). Yet, lifelong symptoms associated with BC have been found to persist and impact quality of life (Champion et al., 2014). This means that regardless of whether progressing age means a BC survivor becomes more 'accepting' of changes to her body and its functioning, or becomes less vocal about any disruption to life that BC-related symptoms can bring, problems of living with BC are compounded by age (Champion et al., 2014).

Once treated for BC the risk of recurrence remains persistent across the life-span for many women. Some research has found that a cancer-free existence for a woman living with BC has been shown to be predictive of positive adaptation and better quality of life (Brown et al., 2002). However, the term cancer-free differs somewhat from the term ‘disease-free’. A cancer-free survivorship brings with it challenges associated with psychosocial, physical, and spiritual wellbeing (Brennan & Houssami, 2011; Pieters, 2009). While a woman may emerge from treatment cancer-free, recent research has suggested that short-term and long-term positive outcomes of adjuvant therapy treatment that involves chemical control of the disease may have variances in the time lapse needed to gain a guarantee against risk of recurrence (Jatoi et al., 2015). This time factor could be of particular importance as women BCS age and for whom amelioration of negative emotional states and stress could prove important for their ongoing physical wellbeing (Graham, Christian, & Kiecolt-Glaser, 2006; Mehnert & Koch, 2008).

Some evidence points to a significant number of BCS living with anxiety arising from fear of recurrence (Custers et al., 2015). To be disease-free then would mean finding ways to live free from anxiety-based bias toward FoCR. Research has indicated that women with a prior history of depression may be particularly susceptible to BC-related fear of recurrence (Janz et al., 2014). Past trauma (Galgut, 2007) and “past experience of stressful ... life events” have been “associated with the length of the disease-free interval in women with metastatic breast cancer” and regarded as indicative of the “possible long-lasting effect of previous life stress” (Palesh et al., 2007, pp. 233-239). These findings have clinical implications that call for consideration of self-compassionate relating as an intervention to lessen the impact of post-treatment anxiety or self-directed negative thoughts and feelings.

The promise of a disease-free existence is not the only factor to be considered in the aftermath of treatment. Survival across the short or long term may bring expectations from the woman herself, as well as from significant others, of a reasonably rapid restoration of her family, social or community roles, and resumption of a fulfilling existence (Dodds, 1999; Sulik, 2007). Challenges include personal functioning, resumption of sexual intimacy, short or long-term limitation in physical activities, increased prevalence of future development of chronic disease, return to

and maintenance of employment (Becker, Henneghan, & Mikan, 2015; Pieters, 2009). Issues related to restoration of lifestyle for the whole person, not just the person who has been ill, become important for psychological wellbeing (Robb et al., 2007; Schapira, 2014; Stergiou-Kita et al., 2014). The work of balancing care for the self alongside care for the needs of others generates for survivors the task of how relational harmony can be maintained. The effort required by this balancing act has been found to be less intense in a person who engage a self-compassionate response when encountering negative situations (Yarnell & Neff, 2013).

Recurrent personal and social challenges to psychological adjustment to living with BC as a chronic illness are commonly reported as a significant risk factor for later development of pervasive experiences of depression and anxiety (Robb et al., 2007). In addition to the increase in reported incidence of BC, and increased likelihood of survivorship, there are cultural and social constructions that surround the BC experience. For example, a positive thinking imperative may prevail in the social and familial world of the survivor. On the face of it, evidence offers useful insights into SC and its capacity to make significant alteration to the way a person responds to criticism, blame and failure. This then provides compelling reasons to explore whether it is appropriate for clinical approaches in post-BC-treatment psychological care to be refreshed or extended to include the teaching of Neff's (2003) construct of self-compassion. From the evidence provided by disciplined research, exploration of SC as a valuable construct on which to base development of psychosocial support mechanisms, as well as view inclusion in training of professional helpers, appears to be an appropriate focus for counsellors and mental health care specialists.

Findings from research literature on both BC and on SC (reviewed in Chapter 5) revealed that development of self-compassionate intra-personal skills to encounter distressing thoughts and emotions brings the opportunity for personal decision-making to be guided by what a person thinks, feels, and needs. For women, this perspective contrasts a viewpoint that they are often guided more by concern for what others think, feel or need. In line with literature on patient empowerment and care for the person with a chronic illness (Bulsara, Ward, & Joske, 2004), support for a woman to develop an interactive, inseparable self-relating system characterised by



self-acceptance, kindness and compassion, engenders healthy tolerance for distress and motivation to greater self-care (Pauley & McPherson, 2010). Reduction in personally-hostile, critical self-dialogue is to stabilise and sustain a woman's sense of personal empowerment during times when she experiences mixed emotions and finds it difficult to describe and express how she feels (Vigliotti, 2010).

Personal empowerment offers the experience of optimism and positivity to BCS, and has been reported to provide a sense of control or mastery over the experience of illness (Bulsara et al., 2004; Furzer et al., 2014). Being determined to find a way forward and having a sense of personal empowerment during all stages of an illness (Bulsara et al., 2004), can suggest a valuable interface with the central aspects of the construct of SC. A significant intersect between these two concepts would likely occur in a person who had developed a capacity to engage in acknowledgement and willing acceptance of their illness, and who also experienced that illness as a catalyst for hope rather than despair (Bulsara et al., 2004).

To include SC as a positive approach in the range of responses to BC-induced distress, the spotlight first needs to focus on how a woman may already employ 'mentalising' tools that help her interpret, resist, or make sense and meaning of her own and others experiences. Mentalising has been defined as awareness of and being able to perceive our own and others' thoughts from either what is observed or what is inferred (Brüne & Schaub, 2012; Franks & Whitaker, 2007). Usually regarded as a positive 'tool' that aids self-management of emotional discomfort (Launay et al., 2015), it may be possible that the same skill of mentalising has the potential to also provide a distracting and inhibiting defence mechanism. A distinctive feature of mentalising is the notion that humans are able to make inferences about thoughts and feelings (Launay, et al., 2015). What complicates this simple idea is that conclusions reached by an individual may not always be correct. In consideration of BC survivorship, mentalising may be the very 'skill' that could aid avoidance of dwelling on the emotional content of an illness experience, or alternatively, aid symptom self-management so as to cope with existential concerns by suppressing any inner emotional chaos (van der Kolk, 2014).

Substantial research has been dedicated to the impact on health of negative emotions, and the contribution of depression and anxiety to poor health outcomes (Ganz et al., 2002; Robles, Glaser, & Kiecolt-Glaser, 2005). There is currently a growing body of research that focuses on positive emotions and the contribution psychological constructs play in immune functioning and health (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002; Reiche, Nunes, & Morimoto, 2004).

Management of symptoms and adoption of coping mechanisms can offer a sense of control and short-term relief as a woman moves from the threat of cancer to the fear of recurrence (Vigliotti, 2010). While a locus of control has been argued to determine how a person adapts to adversity (Arraras, Wright, Jusue, Tejedor, & Calvo, 2002), the problem remains that attempts to keep control over disruptive psychological reactions may end up circumventing the ability to ‘metabolise’, or internally resolve, emotional distress. Habitual methods of coping through cognitive, emotional or behavioural disengagement (e.g. suppression and rumination, obsessive focus on detail), that have, until the ‘arrival’ of BC, aided management of emotionally stressful life events become unproductive post-treatment. Unfortunately, in survivorship these habits may become the ‘skills’ that continue to be used to over-regulate cancer-related distress in the hope of a more positive emotional outcome.

The relevant argument here is that when maladaptive emotional and cognitive processes remain unaddressed these become the major influences on a woman’s ability to cope and maintain wellbeing (Vigliotti, 2010). This means a survivor may find themselves unable to take action that could alter the nature of a negative self-relationship. Women who survive BC also may challenge two dominant narratives: what it means to her to be both a woman and a survivor of BC. Post-treatment the risk is that without the ability to develop healthy internal mechanisms to encounter and stay with difficult emotions a survivor may find themselves unable to utilise those same emotions to effectively evaluate information coming from a range of external and internal sources.

Emotions are a way we provide information in our interactions with ourselves and our social world (Leung et al., 2014). Our emotions have been said to serve as social signals (Hareli & Hess, 2012). Access to a broad emotional range, and in

particular the ability to express negative emotions has been considered important for psychosocial wellbeing (Lieberman & Goldstein, 2006). Restriction on emotional expression in BCS has, for some decades, received specific attention especially in relation to emotional wellbeing and positive improvement in adaptation to BC (Lieberman & Goldstein). The risk is that to avoid emotional awareness or expression of negative emotion so as to avoid physiological and emotional overload threatens to negatively influence the potential for positive adjustment to a traumatising event (van der Kolk, 2015). On the other hand, emotional awareness would be anticipated to result in the capacity for a care-giving outlook in self-to-self relating, for instance, and being able to generate feelings of compassion and warmth towards oneself when feeling anxious or threatened.

## **2.6 Personal resourcefulness: Being self-compassionate**

Evidence suggests that self-compassion is integral in development of an adaptive strategy for emotion-organising and generation of positive emotions that foster psychological well-being (Akin, 2010). Therefore, this study explores whether the concept of self-compassion, or the lack of it, is a significant factor in hindering or transforming emotional healing from the suffering associated with the experience of BC.

A central argument in this study is that development of a self-compassionate relationship with oneself will actively encourage a mindful and gentle shift away from any unconscious tendency to avoid or deny our emotional pain. Integral also is the idea that SC can eradicate the inclination to engage in coping mechanisms that emphasise a need to control emotional responses and avoid difficult feelings (Germer, 2009). For the woman recovering from treatment for BC, attempts to ignore her own suffering might in the short term lead her to coordinate efforts to make a premature return to a 'situation normal' way of living. However, such a focus could be detrimental to her psychological health over the long-term. Accordingly, a fundamental premise underlying this study is that conscious mobilisation of personal resourcefulness and self-efficacy in a self-compassionate way would be an invaluable personal capacity for providing relief from traits of perfectionism, self-reproach, self-condemnation, the burden of shame or isolation, or fear of negative evaluation.

To support a woman to be able to organise, understand and cope with the emotional challenges of BC, it is important to understand the nature of the experience for those who add BC to their list of life events. For the woman who is required to participate in the complexities of decision-making and health care as they live in the long shadow of treatment for BC, self-compassion may provide an important function in the creation of positive adaptation. Of interest is what intrapsychic processes interfere negatively with relating with oneself in a self-compassionate way.

## **2.7 Self-criticism and mis-communication**

A harshly critical relationship with self is revealed in cognitive distortions such as attribution of blame for events to oneself, feeling misunderstood, rumination, or unrelenting 'shoulds' and 'musts'. Self-criticism has been positively linked to depressive symptoms whereas self-compassion has been negatively linked with depressive symptoms (Zhang et al., 2017). Therefore it is important to be able to distinguish between a kinder self-relationship and being critical of oneself. The 'inner critic' is the name given to a manifested inner voice that sounds and feels normal to the person. In effect the inner critic interferes with one's psychological functioning and forms part of various psychological disorders (Stinckens, Lietaer, Leijssen, 2013).

When communication between survivor and caregiver is replete with misinformation, misinterpreted and misread messages, or if the way of communicating with oneself is characterised by anxiety, or harsh or unrealistic expectations, fear of negative evaluation, or a tendency to de-press essential truths about who one is, then it would not be surprising relational functioning could end in less than satisfying outcomes. When internal experience is rife with negative self-evaluation, self-judgment, neediness, and self-criticism these tendencies create barriers to healthy communication both within the self and in relationship with significant others (Campos, Besser, Ferreira, Blatt & Glazer, 2012; Leary, Tate, Adams, Allen & Hancock, 2007; Neff, 2003; Neff, Kirkpatrick & Rude, 2007; Stinckens et al., 2013).

## **2.8 Living in the ‘long shadow of breast cancer’**

The personal, financial and social cost of an illness such as BC makes clear the value of the search for ways to help women develop a self-compassionate attitude that will facilitate healthy intra- and inter-personal relating for living with the physical, psychological and psycho-social consequences of BC. Findings in studies such as those by Bettencourt, Molix, Talley, Schlegel, and Westgate (2008), Dodds (1999), and Low, Stanton, Thompson, Kwan, & Ganz, (2006), have highlighted the need to continue exploration into ways to diminish distress and support positive personal adaptation to living with the insecurity that BC imposes on people’s lives (Midtgaard, Stelter, RØRth, & Adamsen, 2007).

For a woman who experiences a serious health challenge such as BC, post-treatment psychological care that would encourage development of self-compassion could add constructively to her life after treatment in what appears to be a fundamentally effective and positive biomedical health-care model. The biomedical model offers care for the physical realities of life and it is only in recent years the profession has been prompted to offer compassionate, holistic responses to the psychological and spiritual needs of BC survivors (Dossey, 2007). Therefore, an essential step to take is extending clinical understanding of how SC could enhance psychological wellbeing for the mental realities of life for women experiencing negative late effects of BC and its treatment.

## **Chapter Three**

### **Beyond the Pink Ribbon**

#### **3.1 Overview**

This chapter takes a brief look at issues that will be discussed in greater detail later in the body of this thesis (see Chapter 7). Psychosocial issues that accompany BC are reviewed from the point of view of their power to define and dominate a survivor's personal wellbeing and identity, from diagnosis through to end of life.

Continued advances in research and medical science means BC has become a condition that women of any race, class and creed in this 21<sup>st</sup> century can be anticipated to survive (Geffen, 2010). Advances in early detection and in treatment procedures in Western medical practice and research offer women with an early-stage diagnosis of localised or regional BC a more optimistic outlook than for other forms of cancer (Rowland, 2008). Despite advances in management of the disease, those same life-saving, risk-reducing treatments have a negative influence on physical, emotional and psychological well-being (Kukar, Watroba, Miller, Kumar, & Edge, 2014). This means that while increased numbers of women with BC will go on to lead a relatively normal life post treatment for BC, to do so will necessitate accommodation of the physical adjustments and emotional demands required for living with BC as a chronic health condition (Kukar et al., 2014). Although there may be a statistically similarities in the incidence of BC in women in industrialised societies (Parkin & Fernandez, 2006) each woman encounters a unique psychological journey (Dodds, 1999).

### **3.2 Cancer brings life changes**

Delivery of a diagnosis of cancer was once considered an almost certain death sentence generally accompanied by uncertainty about how long the person had to live, or the way in which the disease would progress (Dodds, 1999). For the person diagnosed with and treated for cancer the experience can be a traumatic one that generates intense emotional and psychological distress (Lindsay, 2009).

Now acknowledged as “a form of chronic condition with many unknown after-effects from treatment” (Loh, Packer, Chinna, & Quek, 2013, p. 331) BC is not an encapsulated event. It is the experience of navigating a disruptive, dynamic, uncertain journey through a series of linked stages (Elmir, Jackson, Beale, & Schmied, 2010) that will continue through life. Predictably, those stages move from diagnosis that results in active medical treatment and may include surgery, through the quest for physical survival, transition to survivorship, and on then for the balance of life. Through each of these “seasons of survivorship” (Leird, 2010) a woman diagnosed bears the burden of physical, emotional, psychosocial and spiritual disruption (Fischbeck, Maier, Nehring, Beutel, & Weber, 2012; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). Survival brings with it the need for surveillance of the needs of survivors (Kukar et al., 2014). A survivor may be assessed as cancer free however, they are not free of the problems that accompany having had cancer (Miller, 2009).

The journey of BC is one of moving from initial identification of a lump, a feeling of un-wellness, or in some cases, a very surprising result from a routine mammogram or visit to a GP, to a situation that requires a woman to plot a thoughtful course through significant and demanding objectives. Those objectives include the need to respond to the initial diagnosis, decide on treatment options, complete treatment, manage both recovery and the desire to restore personal functional abilities, and at the same time maintain optimism and hope for the future (Brown et al., 2002; Dodds, 1999).

Currently, women diagnosed with BC have the right to collaborate with specialists about treatment options, can increasingly influence decisions about their needs for reconstruction, and ultimately make more informed choices about the

direction of treatment for themselves. However, similar to others who are diagnosed with another form of cancer, BCS have had no pre-diagnosis preparation for the shock of confirmation they have a life-threatening illness. Nor do they have any preparation for processing the rapid changes that take place once a diagnosis is made. At the time of diagnosis the woman may not have felt ill, or she may not have noticed or acknowledged breast or bodily symptoms that would indicate a serious problem.

### **3.3 The public face of the ‘battle with breast cancer’**

Breast cancer as a ‘social commodity’ has become a high profile disease that has as some of its ‘champions’ celebrities who encourage women to become empowered through knowledge and understanding of their body. In addition, well-known sporting identities who have lost loved partners to the disease, and film stars who have the disease, can promote aggressive action to avert a feared potentiality. Encouragement to fight against BC can provide women with motivation and a sense of power over an illness that crosses all social and political boundaries. Optimism and BC survivorship seem to make a ‘happy couple’, so why would we not celebrate the ‘marriage’ of these two? Yet, when connected to BC, the optimism imperative (Gibson, Lee, & Crabb, 2014) becomes a subtle, concerning, yet powerful enculturation of women, and Western society in general.

Creation of a ‘culture’ around BC happens through focused media coverage of the disease and the prevailing discourse about survival rates. However, subscribing to the desire of others for a woman to be optimistic about a positive outcome may not always be the healthiest direction for her to take. Fighting the fight, waging an ongoing war on cancer may mean a woman feels compelled to take personal responsibility for their survival (Gibson et al., 2014). The less than positive side of being optimistic could mean women become overly fearful of their body letting them down, or to feel a sense of failure if they do not maintain a recommended health care regime. Being optimistic, while socially sanctioned, can impose a restrictive ideal women may try to live up to in ways that are not psychologically healthy for them (Gibson et al., 2014).



### 3.4 Beyond the pink ribbon

In Western society a growing interest in personal displays of compassion has been taking place over the last two to three decades (Gibson et al., 2014). The symbol of the pink ribbon has become a powerful symbol of breast cancer awareness (Vineburgh, 2004). Activism in relation to BC emerged in the late 1980's (Gibson et al., 2014; Moore, 2010), and since the early 1990's the pink ribbon has become synonymous with awareness of breast cancer. It is important, here, to acknowledge the significant and crucial work done by awareness campaigns such as the National Breast Cancer Foundation the McGrath Foundation and Avon Cosmetic's Avon Million Crusade, among other organisations, in raising much-needed funds for research and BC support, and for providing Australian women with improved access to vital information about breast care and health. Clearly, as a result, "the way in which breast cancer is socially understood and personally experienced" has been redefined (Gibson et al., 2014, p. 2).

It is important also, to highlight that "the iconic attitude promulgated by pink ribbon culture (i.e., positive outlook, uber-femininity, warrior behaviour, collective rallying, survivorship) actually ignores men and isolates those women who have doubts, value gender neutrality, are private and ... are dying." (Hall, 2013, p. 280). Gibson and her colleagues (2014) have highlighted the concerning interpretation that BC awareness campaigns may in fact contribute to maintenance of sexualised views of women and unrealistic assumptions of what being feminine means.

In terms of extending awareness to more politically-driven action, Moore (2010), in her book *Ribbon Culture: Charity, compassion and public awareness*, refers to what she identified as a ribbon culture, developed within Western society, that can confuse raising 'awareness' with actual understanding of diseases for which ribbons are donned. Moore referred to the sociological implications of the now popular practice of public displays of awareness of issues of social and political justice or injustice. The result, Moore proposed, has been a 'commodification' of compassion. This has happened within a cultural climate where empathy has become associated with, and often becomes a replacement for, authenticity of experience (Moore, 2010).

In the desire to be seen as socially responsible, aware, and supportive of fund-raising for BC important considerations are missed. We need to also be aware of ways pink ribbon awareness, while productive and indispensable, may inadvertently contribute to a BC survivor believing that positivity and being proactive is the most socially sanctioned stance to adopt. Included in the optimism imperative is a sense that, for a woman, personal attractiveness includes two uniformly proportioned breasts. In the social world breast reconstruction provides a BCS a means by which they can fit back into the 'norm'. In some cases reconstructive surgery might mean that women have an opportunity to create what might be considered an 'even better or more perfect' stance. The BCS faces a social world that presents a confusing 'face' to BC. On the one hand BC awareness is promoted and on the other hand women may find themselves encouraged to conceal both distress and physical indications of their 'one – or no – breastedness' (Rubin & Tanenbaum, 2011).

Pink ribbon awareness campaigns may also unwittingly promote stereotypical beauty ideals, exclude from focus women who do not fit the stereotypical image of white, middle-class females with access to, at least regular, health care (Gibson et al., 2014). This is where Neff's (2003) concept of self-compassion could be explored to assess its potential to contribute significantly to efforts to reconstitute physical and emotional well-being post-BC. Counselling care and therapeutic interventions that cultivate increased SC as a means to reduce overall self-judgment and over-identification with negative rumination can help survivors of BC to reach a place of new life or healing that is authentic and integrative. In that process the very self-system that may have contributed to negative adaption to survivorship can be gently dismantled and eventually replaced, by the survivor, with a healthier self-relationship.

### **3.5 Survival: An urgent quest**

Current trends in medical 'consumerism' have indicated heightened demand for the person who becomes a patient to have greater access to more specific information about their health needs (Geffen, 2010). The person seeking medical advice or services is no longer a passive recipient of standardised care (Geffen, 2010,

p. 106). Whole-person multidimensional care models will include a broader range of services sensitive to the needs of the individual.

A benefit of advances in medical science is that specialists in the field of oncology now have access to vast amounts of information that increase awareness of the debilitating effects of post-treatment depression and anxiety. The hope is that this may lead to greater understanding that psychosocial care is necessary and beneficial throughout the long-term of survivorship, not just in the immediate post-treatment or end of life phases of the disease.

In conventional BC medical treatment regimes, front-line life-saving defences such as screening, surgical procedures, radiotherapy and drug treatment take precedence in planning for and achieving survival. Treatment for BC is a multidisciplinary approach that includes medical and surgical oncology and psycho-oncology (Thavarajah et al., 2015). For positive physical outcomes there is significant current and past research to substantiate the accepted argument that survivors of BC are primarily dependent on appropriate use of proven pharmaceuticals (Paskett et al., 2009). Provision of adequate education about living with the after effects of the disease, as well as about ongoing self-management have been considered useful for active engagement of survivors in maintaining personal wellbeing. Psycho-educational interventions have also been found effective in accelerate the reduction of negative affects which present and the completion of treatment (Dolbeault et al., 2009).

In the necessary push to arrest negative evolution of the disease and create optimal opportunity for physical survival, the importance and significance of psychological wellbeing and compassion for self as a critical element in both physical and psychological recovery must not be overlooked (Dossey, 2007). Therefore, this study concerned itself with a survivor's personal wellbeing when an illness that has generated a very real and present threat to life becomes a life-long companion. The challenge is that the combination of psycho-educative strategies and powerful pharmaceuticals are not always able to provide the answers for meeting psychosocial needs for those living with the after effects of BC.

The essential adaptation to and integration of life changes that a BCS makes in order to accommodate the after-effects of a life-threatening illness can become burdensome, emotionally testing and lengthy (Low et al., 2006). The BC recovery pathway is most commonly one of immediate reliance on the biomedical model. For women diagnosed, joining with the biomedical model may be lifesaving, or may provide an extended lifespan beyond what would have been possible without medical intervention. Physical survival takes urgent priority over any other consideration.

### **3.6 Adaptation: Meeting a different self**

Because the oncological clinician's first and only responsibility is to treat the disease the biomedical response to cancer is not designed to either support or explore a survivor's long-term emotional needs (Dodds, 1999). The biomedical response is equipped to concentrate on physiological repair and is a system not intended nor designed to provide assistance with the processing and containment of psychological experiences generated by ongoing uncertainty or existential distress (Kissane, 2014).

Medical science has made major life-saving inroads into the evolution of effective treatment and immediate post-treatment care (Geffen, 2010). However, recovery and restoration of psychological wellbeing also involves complex variables that include existential concerns that revolve around death and dying. Among these variables are factors such as the risk of personal demoralization (Kissane, 2014), aversive orientation to emotional experiences, and post-BC self-care as well as resumption and maintenance of relationships within family and social networks. Other variables include adaptation to a changed body image, re-establishing a sense of meaning, reconciling a pre- and post-cancer identity, encountering physical, emotional and spiritual stress, and, ultimately, a simultaneous encounter with both life and death (Sattman-Frese, 2009; Schaefer-Schiomo & Atwood, 2009; Tallman et al., 2007).

The elements of survival capable of producing uncertainty are echoed in research that indicates diagnosis, treatment and living with breast cancer across the long-term can increase the potential for distress in a range of aspects of life such as a woman's somatic, psychosocial and spiritual experiences (Bitsika, Sharpley, & Christie, 2010; Bower, Ganz, & Aziz, 2005; Low et al., 2006).

### **3.7 Suffering and emotional distress**

In Western society the prevailing dialogue surrounding mental health is such that subjective distress may be more commonly regarded both as an enemy of health and as something to be managed, or even eradicated, disguised as expeditiously as possible (Rubin & Tanenbaum, 2011). The impact of such a perspective is to effectively obscure the potential for emotional distress to serve as a ‘teacher’ from which a person could learn and grow. In an effort to regain a sense of control, prevent re-traumatisation through recurrence of the disease, or to combat feelings of helplessness, a BCS may join with a social world paradigm that works to either avert emotional suffering or numb a felt sense of emotional ‘dis-ease’. This means the mechanism of self-defence normally engaged to achieve protection against distress then becomes the same process that ends up turning against the survivor and increases their psychological vulnerability.

Occurring across a number of psychosocial dimensions the psychological consequences for some BCSs include feelings of confusion, uncertainty, confrontation with mortality, identification as a BC survivor, personal dignity, body image and functioning, limitations in life choices, and a degree of separateness or alienation from those aspects of social life a survivor was familiar with prior to BC (Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010). Given the potential for an anxious, fearful and stress-laden response to the life-penetrating news that one has cancer (Curran, 2011; Dodds, 1999), post-treatment there is also a plausible claim that the overall result for some survivors means they begin to exhibit symptoms of distress that mimic Post Traumatic Stress Disorder (PTSD) (Kornblith et al., 2007).

As a physical and emotional condition, the concept of suffering is often experienced as inconvenient, undesirable, and uncomfortable. It exposes vulnerabilities and challenges notions of expectation, as well as our concepts of the meaning of life (Arman & Rehnsfeldt, 2003). And yet, suffering, while sometimes traumatic and always unwelcome, also offers unique access to a turning point in life. A journey through suffering could be conceptualised as providing a doorway to personal transformation through acceptance of the challenges that suffering brings (Baník & Gajdošová, 2014). The BC ‘doorway’ is one that ‘users’ would likely not

want to re-visit despite the potential for growth and transformative affect to effect significant, change ‘for the better’.

Since cancer is a multifactorial disease, psychosocial care for the BC survivor (BCS) also needs to be viewed through a multifactorial lens. The uniquely personal way in which each woman constructs her BC experience highlighted attention that could be paid to personality factors, her interpretation of illness, her perceptions, her personal explanation of causality, her style of intra- and inter-personal communication, and the way in which she has responded to stressful life events. While personality factors may influence how a woman responds to her diagnosis and treatment, no association has, however, been found between incidence of BC and personality traits and expression of emotions (Bleiker, Hendriks, Otten, Verbeek, & van der Ploeg, 2008). The findings from Blieker and colleagues (2008) indicate that BCS can feel confident that their personality factors have not influenced the arrival of BC.

Negative self-judgment persistently directed at our “inner thoughts, feelings, intellectual attributes” has a corrosive effect on personality and has been “strongly correlated with a range of psychopathologies” (Long et al., 2009, p. 1849). The relevance of self-criticism for BC is that an internal commentary pre-occupied with focusing on one’s faults and mistakes has been found to generate similar physiological consequences as negative evaluative comments made to us by others (Gilbert & Irons, 2005).

Prior to addressing the different ways BC affects emotional functionality and wellbeing, it is important to consider that personal issues do not sit in isolation to each other. An interactive relationship between current personal issues and past experiences of illness, attachment style, the nature of close relationships, and the legacy of trauma or abuse can negatively affect a survivor’s framing of their experience. Pre-morbid psychological characteristics and the coping style of the survivor have been found to positively or negatively influence quality of life (Brunault et al., 2016). Age-related factors in non-metastatic BCS have also been cited as variables that negatively bias quality of life in survivorship. For example, emotional distress in a younger BCS may be related to loss of fertility or femininity,

body image, pain, and FoCR (Brunault et al., 2016). FoCR means any lumps, bumps, or times of simply ‘not feeling well’ can generate fear of a return of the disease.

For some women, self-esteem may be invested in a (personal) perception of how attractive they are perceived to be by others. In that case well-being may become contingent on maintaining an ideal standard that is perceived women in general set for themselves. For other women, self-esteem may be the by-product of unquestioning adherence to roles allocated in internalised sex-role stereotyping and complex power relations (Romeo et al., 2017). Additionally, conformity to culturally acceptable displays of emotion can preserve a person’s sense of self-esteem – at least momentarily.

The capacity to reframe a BC experience in a positive way has been found to lessen emotional distress in surgical BC patients, whereas self-blame and ruminative self-focus have been linked to passive or avoidant coping and associated with elevated emotional distress (Kim, Han, Shaw, McTavish, & Gustafson, 2010). The BCS who has high self-blame, low self-acceptance and feels isolated in her suffering are more likely to adopt avoidant coping strategies (Brunault et al., 2016; Kim et al., 2010). This means that therapeutic interventions tailored to BCS’ individual psychological factors that can either perturb or promote resourcefulness and self-reassurance.

Opening to more informed understanding of the variant influences on psychosocial survival for each woman post-BC, means being open to the emergence of a number of questions. One key question centres on what psychosocially-relevant factor could aid long-term maintenance of overall emotional equilibrium without risking: a) one’s emotional life becoming something that needed to be avoided, or at best, subdued; or b) one’s emotional expression becoming unnecessarily intensified in a way that exacerbates distress. These questions required thinking about the nature of a woman’s post-cancer relationship with her body, with herself, and with significant others, alongside what a woman feels she would need to maintain healthy personal relating throughout survivorship.

Therefore the focus of this study is to explore whether SC would be a useful and appropriate skill that could help women BCS nurture themselves, and assist them to optimistically navigate the inevitable stressors associated with diagnosis, treatment, recovery, and particularly, the ageing process. A benefit of being self-compassionate would be to increase the awareness of BCS that so-called ‘negative’ emotions are a natural part of the reactions to cancer, and provide a means of understanding their experience without judging development of, or vulnerability to, cancer as failure on their part.

### **3.8 A phenomenon of anti-suffering**

While, in general, feeling compassionate could be regarded as an agreeable experience, the very act of witnessing or of being present to another person’s suffering can generate feelings that are experienced in the observer as uncomfortable or unpleasant (Condon & Feldman Barrett, 2013).

In the wake of emotional disruption the tendency in Western society has been to promote a point of view as seen through a ‘lens’ of anti-suffering. To alleviate emotional suffering professional helpers are often expected to dispense expertise, recommend what should be done, provide strategies, and give authoritative guidance (Mearns & Thorne, 2013). The implication is that promoting a ‘stay with it and work through it’ perspective would be considered out of step with a ‘grin and bear-it’ viewpoint that has a stronger investment in a person ‘moving on and staying strong’. Coping mechanisms that ‘encourage’ a BCS to withdraw from “uncontrollable aversive changes in one’s environment” may at first be seen as “adaptive and thus ‘healthy’ ... but may become symptomatic of clinically severe depression” (Bitsika et al., 2010, p. 180).

Relevant to the dichotomy between an attitude of staying with it or an opposing attitude of moving on, staying strong, Markell (2002) has suggested that the transformative power and value in staying with and understanding our emotional suffering is the starting point for physical and emotional health. Similarly, Siegel (2009, pp. 156-157) stated that “emotion is a window into something changing” and that emotional integration of the personality is “at the heart of well-being”. When trauma, anxiety, or depression, activate a rigid but familiar response to



uncomfortable emotional states the resultant “unstable affective outbursts, intrusive thoughts, impulsive behaviours” deny the person access to an undistorted, kinder self. The argument from Markell (2002, p. 27) speculated that:

*It is through experiencing the strange flora and fauna of our inner life, which can disturb or frighten us or bring us to great love for others and true compassion, that the healing tendencies of the psyche begin to guide our lives.*

What Markell (2002) theorised was that adverse life experiences, given expression in the process of therapy, have the power to bring emotional healing and simultaneously generate beneficial and positive psychological outcomes. The outcomes proposed by Markell have been reiterated in the writings of Greenberg (2012, p. 697) whose clinical work and research leads to the conclusion that emotions are both “our greatest friends and at times our worst enemies”. These outcomes could be observed as a coming together – a coherence – in our emotional state: a state in which there we can be mindfully aware of our emotions, and the way in which they shape our perceptions, can be informed by them, and less driven by emotional reactivity.

Therefore, a therapeutic process of emotional transformation involves development of, and active engagement with, a capacity and willingness to encounter difficult feelings. The goal as proposed by Markell (2002) is not just to allow suffering to guide our lives in general, but to actively transform and integrate experiences of suffering and illness. If women survivors of BC are to be encouraged to stay with and process difficult feelings in what ways might they be appropriately and sensitively supported? What are the benefits, and what are the resources they need, or have, to feel nurturance through the process, and to ultimately build the skill of being able to nurture themselves and flourish in life?

The problem of emotional distress is likely to be addressed by the individual through various forms of defence by creating an imaginal and positive reality that becomes a place of refuge. Alternatively when the situation feels overwhelming a person can move into a substitute world of addiction (Sieff, 2008) whether that

addiction is food, substances, or another form of distancing oneself from the harsh realities of life. Self-medication, addiction, creating an imaginary positive reality, or professionally through application of more potent psychopharmacology, may only create a result of less likelihood of confident self-reassurance and self-integration.

### **3.9 Transition: Survivorship and opening to self-compassion**

When faced with adversity some people respond in ways that bring transformation, personal growth and significantly changed ways of relating with self and others (Durkin & Joseph, 2009). Examples of this have been reported in investigations by Dodds (1999) whose research with cancer patients in Western Australia analysed “how people diagnosed with cancer came to define and redefine their illness” (p. iii). Dodds (1999) focused specifically on “prominent discourses of healing and illness” and found that participants in her study regarded cancer as putting them on notice to significantly adjust their life direction and their relationship with themselves and with significant others (p. iii).

The optimistic outlook for a disease that Olson (2002) classified as “a horror known to every culture in every age”, makes the study of living with BC as a chronic or critical illness an important field to explore, particularly for the profession of counselling. Expanded understanding of the psychological issues that positively or negatively affect the relationship with self, and the world around a BC survivor, makes it incumbent on professional health carers to extend the capacity of existing programs and support services to offer appropriate, sensitive assistance.

With regard to emotional and psychological wellbeing, the concept of self-compassion appears to offer significant insight into a way support for BCS can help her navigate the inevitable stressors associated with diagnosis, treatment, recovery and the ageing process that comes with life post-BC. In practice this means that incorporating a focus on SC into psychosocial interventions and support services will require more than an extended list of treatment techniques to a skills-based repertoire for professional helpers (Mitchell, Murray, & Hynson, 2008).

The transition from being a cancer patient to a cancer survivor can initially be greeted with relief (Holland & Lewis, 2000). However, once unconfined by demands

and routines of a treatment regime, a BC survivor may experience uncertainty about whom she will now turn to for advice and support (Bessen et al., 2014). Furthermore, some women may feel inhibited around asking for help with intimate details of personal functioning, whether that be from a cancer support group, cancer care agency, a local pharmacist, or her immediate family.

### **3.10 Compassion**

Compassion for oneself has been linked, in recent studies to a number of positive life outcomes including reduction in experiences of low self-worth, depression and anxiety (Neff, 2003; Neff, Hseih, & Dejiththerat, 2005; Terry, Leary, Mehta, & Henderson, 2013). A specific definition of compassion and what might be observed in someone who is compassionate is, in one particular sense, not simple to describe in a clear and succinct language frame. Compassion may be defined in a number of ways. Contemplative traditions may refer to compassion as the wish to alleviate the suffering of others (Lutz, Brefczynski-Lewis, Johnstone & Davidson, 2008). In health-care professionals compassion has been aligned with enhanced empathy (Sinclair et al., 2016). Sometimes correlated with acts of selfless service (Neal, 2000), other authors posit that compassion is a mutually beneficial emotion that nourishes both giver and receiver (Kagan, 2014; Morse, Bottorff, Neander, & Solberg, 1991; Morse, Bottorff, Anderson, O'Brien & Solberg, 2006).

Compassion may often be thought of as a virtue, characteristic of heroic, larger than life people whose acts of service we could never, in reality, hope to emulate. Goetz, Keltner and Simon-Thomas (2010, p. 351) defined compassion as “the feeling that arises in witnessing another’s suffering and that motivates a subsequent desire to help”. Described also as “a mixture of love and sadness” (Seppala, Rossomando & Doty, 2013, p. 428) compassion could be said to be the intrapersonal experience of “recognition of suffering and the desire to help one who is suffering” (Goetz et al., 2010, p. 351). There is emerging evidence that confirms the very act of being compassionate brings significant benefit for an individual in terms of both their mental and physical health (Seppala, Rossomando & Doty, 2013).

The task to understand what the experience of compassion means for a particular person is not simple. In this respect language can become reductionist with

the power to diminish or negate the depth of an experience. It may feel easier to give compassion to another person through acts of kindness and generosity than to direct that same compassionate response toward oneself (Pauley & McPherson, 2010). The language of contemporary self-help processes may mean the words compassion, kindness, self-acceptance, self-forgiveness and self-compassion unfortunately become vehicles for a well-worn catalogue of clichéd interpretations. The integrity of what being compassionate means can get lost in rhetoric and overlooked in practice.

Despite the definitions, the meanings ascribed, and much-desired perception that we are now a more ‘aware’ society, awareness may not of itself result in deeper understanding of personal suffering or the suffering of another (Moore, 2008). Increased information and intellectual awareness are not tools that necessarily promote healing. They do, however, provide a starting point past which we must move in order to attend to individual needs for self-acceptance.

If compassion relates to the delicate undertaking of being able to suffer with another (Goetz, Keltner & Simon-Thomas 2010; Kagan, 2014; Young-Eisendrath, 2008) then the question to be answered is how we can better understand the intra-personal experience of compassion.

### **3.11 Self-compassion: Challenge and opportunity**

The significance of the construct of self-compassion for this study lies in its contribution to developing healthy attitudes to self and well-being through creation of a direct orientation to self-kindness and self-care rather than harsh judgment of oneself (Leary et al., 2007).

To consider whether self-compassion could be a significant feature of positive adaptation to living with BC it is important to first understand factors that negatively affect post-treatment emotional well-being. The distinctive psychosocial challenges of diagnosis and treatment for BC include anxiety and depression (Andreu et al., 2012; Burgess et al., 2005; Miller & Massie, 2006; Montazeri et al., 2001), shock, self-blame and self-criticism (Bennett, Compas, Beckjord, & Glinder, 2005; Dafter, Greenwald, & Block, 2006; Else-Quest, LoConte, Schiller, & Hyde, 2009; Friedman et al., 2010), shame (Bell, 2014; Hill et al., 2011), psychological stress

(Nekolaichuk, Cumming, Turner, Yushchyshyn, & Sela, 2011), stress in the process of returning to a ‘normal’, post-treatment body image (Przezdziecki et.al., 2013; Zimmerman, Scott, & Heinrichs, 2010), personal psychological agency, and for couples the renewal of sexual intimacy (Fobair et al., 2006), and the way in which a cancer diagnosis and treatment impacts on relationships in general (Dodds, 1999; Sperry, 2010). These factors may be ones that have their onset as a result of diagnosis and treatment, or, in the case of depression and anxiety, could be indications of a pre-existing vulnerability (Hill et al., 2011).

When ‘compassion’ is added to the word ‘self’ the overall perception of the concept of compassion becomes altered. Extending the word compassion to include the ‘self’ (i.e. self-compassion) may generate an internal struggle in the self-to-self relationship. What happens is an internal struggle can occur between preconceived notions of the negative evaluation of selfishness as opposed to the more socially acceptable – and admired – acts of selflessness. The dynamic tension between being kind to self and being selfish raises an important question. The cautionary question is whether, when confronted by painful, intense feelings, or adverse life circumstances, traits such as complacency, selfishness, and perhaps even narcissistic behaviours, mean selfishness can be mistaken for, or can masquerade as, self-compassion.

The concept of self-compassion gives rise then to another question about what happens for a woman post-BC in her experience and witnessing of her own and other survivors emotional processing. Defined as an internal mechanism that can replace self-blame, self-condemnation and being self-critical with a compassionate relationship with self, self-compassion has been found to enhance contentment with life (Gilbert, 2009). Research studies that have explored SC have suggested to direct associations with “social connectedness, emotional intelligence, happiness, optimism, agreeableness, extroversion and personal initiative” (Neff, 2011, p. 5).

### **3.12 The internal experience of self-compassion**

With a foundational principle of compassion for all life forms, SC is characterised by a capacity for gentleness, acceptance of, and kindness to self (Neff, 2003). That is, SC seeks to foster a healthy orientation to the self and to relating with others (Gilbert & Procter, 2006). Positively linked to adaptive self-regulation (Terry

& Leary, 2011), SC requires an individual to develop the ability to adopt a self-perspective that can accept that mistakes and disappointments in life are a very normal part of human existence. Furthermore, SC calls for a capacity to observe, experience and stay connected to feelings without identification with those feelings to the extent that they become foremost in a person's mind (Neff, 2009).

Self-criticism is characterised by a punitive and self-denigrating dialogue and has been associated with psychological difficulties (James, Verplanken, & Rimes, 2015). This means a self-critical person is likely to fear loss of self- and other-approval, has negative cognitive appraisals of self, and is hypersensitive to perceived criticism (Powers, Koestner, Zuroff, Milyavskaya, & Gorin, 2011). Fear has been said to relate to threat of ridicule or rejection, fear of being shamed, or being found lacking in some required skill or capacity (Sagar, & Stoeber, 2009). Reflection on the idea that as humans we are essentially flawed beings (Neff & Germer, 2013) generates, for some people, fear, resistance, and shame. Entrenched, repetitive, and distorted ways of looking at and experiencing ourselves and the world, create perceptions that obscure self-efficacy, resourcefulness and creative potential.

A healthy level of self-criticism can be useful as a motivator to assist in striving to 'getting things done' or pushing oneself to 'do (or be) better'. A certain level of self-monitoring could be regarded as the strength that provides safety in relationship. What this means is that judicious awareness of behaviours and thoughts guides our actions in ways that mean we are approved of and liked by others. The difference between healthy and unhealthy self-criticism seems to rest on whether relentless self-reproach emerges from fear of not being approved of or liked by others, or self-criticism is a means that provides constructive self-encouragement to act and think in a self-congruent and authentic way.

Excessive negative self-criticism, or self-critiquing, can be generated in instances where a BCS takes on personal responsibility for the burden of her illness at the same time as her emotional and physical resources are needed to generate sufficient personal endeavour for her ongoing survival. Research has determined that when a person is able to counteract self-punishment with self-acceptance the anticipated result would be the ability to provide self-reassurance (Fisher & Exline,

2010). In terms of thoughts and behaviours what having the capacity to offer genuine self-reassurance means is that this aspect of self-compassionate relating would be expected to reduce the burden of negative self-criticism.

Therefore, what would it mean if self-criticism could be transformed into an effective resource to adjust, positively, the condition of our thoughts and the direction of our behaviours? Rather than being regarded as an ‘ailment’ necessary to expel from the conscious mind, or to overwrite with positive self-talk, self-criticism, viewed through a different lens, could also be a constructive resource to sustain personal motivation (Kurman, 2003). The benefit of positive transformation would, ideally, reduce a tendency for continuing to make avoidable mistakes, or make decisions that are unproductive for our wellbeing (Gilbert & Procter, 2006). The result of fostering self-criticism as an effective rather than ineffective reaction to stressful demands is a capacity to pursue and achieve a meaningful goal. For example, a goal for a survivor of BC might be to structure life in a way that enhances a zest for living without placing them at risk of cancer recurrence.

Acceptance of the argument that self-criticism, of itself, not become tainted with a negative viewpoint (Gilbert & Procter, 2006) begs the question of how we might distinguish a healthy, positive form of self-criticism from more life-denying automatic negative self-criticism. With research providing evidence of the human potential for self-healing after loss (Mancini & Bonanno, 2009) the scope of self-discovery supported through the presence of a skilled counsellor could extend a way for hearts and minds to open, and help dissipate the corrosive effects of self-criticism, shame or guilt.

Despite identified negative effects on quality of life, relationships, physical well-being, and self image, psychological distress as a result of BC can go unrecognised and under-reported (Cancer Australia, 2011; Seok et al., 2010). Paradoxically, effective and beneficial progress in less radical treatment techniques can mean the challenges of living with BC become invisible or taken for granted. The shadowy side of advances in medical technology and scientific understanding of the workings of the human body is that the use of invasive procedures and expensive technology may be unquestioned.

A woman's recovery and restoration of her pre-breast-cancer identity has been said to be compromised by a demeaned sense of value of her body to herself and to others, of feeling that a physically altered body significantly reduces her personal attractiveness and femininity. Described as both an emotional insult and an assault on a woman's femininity and fundamental sense of self (Moore, 2010; Sheppard & Ely, 2008), BC and its treatment sequelae can destroy a woman's instinctive expectations of health and wellness.

Other quality of life factors that a woman with BC must contend with include alteration in sexual functioning and responsiveness (Dizon, 2009; Gilbert, Ussher, & Perz, 2010; Sheppard & Ely, 2008), surrender of control to a biomedical system, reduced margins of personal autonomy and control (Williams & Irurita, 2005), and significant challenges in returning to normal life, renewing social contacts and, for those in spousal or partnered relationships, re-establishment of intimacy (Little et al., 1998; Navon & Morag, 2004) and consideration about any sexual side-effects in survivorship (Graziottin & Rovei, 2007; Pillai-Friedman & Ashline, 2014).

### **3.13 Breast cancer and self-compassion-centred counselling**

The transformation of human emotional suffering and adverse life disruption is at the heart of counselling practice. With skilled support from professional helpers restoration from psychological fragmentation takes place in troubled hearts and minds. To work collaboratively with another person to bring about positive transformation is the essence of counselling as a helping profession. At the same time, being able to bear witness to the suffering of others is an essential trait in a counsellor, especially those counsellors working with clients who present with issues related to death and dying (Kirchberg, Neimeyer, & James, 1998), or those whose personal life experiences mean they are vulnerable to stress working with BCS. The well-known caution about the effects on counsellors of prolonged exposure to suffering calls for vigilance about maintaining the skills of connection and detachment (Benoit, Veach, & LeRoy, 2007). For client and counsellor, the therapeutic space can offer a 'stilling' and 'quieting' time for both mind and body. It offers a unique, short-term relationship based on the fundamental premise of offering openly caring and compassionate relating.



More than the sharing of cognitive information or a focus on cognitive and behavioural processes, counselling is an experience of confirmation for a person seeking emotional support. Through the counselling process the person can feel more certain of themselves, can feel as though they matter, and ultimately develop a more confident construal of self (Christopher & Maris, 2010; Teyber & McClure, 2011). Then, they are able to contribute more positively to their own wellbeing, and to the wellbeing and mental health of the community as a whole.

Contrary to popular perception, the task of counselling is more than a mere extension of the innate human caring bond (Neukrug & Schwitzer, 2006). For some the process will involve an exploration of the origins of their deepest longings and their impulses (Young-Eisendrath, 2008). Yet others may feel confronted and disturbed by conscious acknowledgement of a sense of limited control over the more challenging circumstances of their life. Understanding subjective distress and how to work effectively to help people untangle the mysteries of their lives are both central to a counsellor's capacity to effectively promote change (McLeod, 2013). Counselling offers a client the unique opportunity in a special environment to become a researcher of the phenomena of their own emotional life.

The collaborative counselling relationship provides a facilitative experience in which "the client is able to renew already existing personal resources, and augment them with new learning" (Cooper & McLeod, 2011, p. 35). The collaboration between counsellor and client helps the client find a level of self-acceptance previously untapped, in addition to the means to make positive life choices. This means that while the therapeutic alliance does not represent the entirety of benefits from undertaking counselling, it does provide a unique opportunity for a person to reconnect with and renew pre-existing, unexplored personal resources that become integral to a process of recovery. Recovery allows release from experiences that have significantly disrupted a client's sense of being in their immediate world. The short-term, intensive relationship created between client and therapist does, however, offer a definite source of transformation and enrichment for both participants (Neukrug & Schwitzer, 2006; Teyber & McClure, 2011).

### **3.14 Significance for counsellors**

Alongside extension of psychosocial support programs, there is the ongoing demand to enrich the personal capacity of professional helpers to sensitively and appropriately create conditions that promote emotional healing and engender hope. Paradoxically, counselling is the very process whereby a client is moved in a gentle, supportive manner toward exploring and becoming aware of the very suffering they have tried to medicate away, ignore, overlook or discount. In practice, the ability of a counsellor to be empathic and have the capacity to experience compassion is likely to be found through unconscious identification or alignment with a client's self experience (Cunningham, 2005). Similar sentiments are echoed by a Buddhist nun and scholar, Pema Chödrön, who commented that the practice of being compassionate, and offering compassion to others, is likely to confront us with awareness and fear of our own emotional pain.

Counsellors and professional helpers may find themselves faced with clients who enter the therapeutic process with a long term illness (Schaefer-Schiomo & Atwood, 2009), an uncertain outcome, and, in many instances, a progressively downward-oriented life trajectory. Training as a counsellor may not have prepared a skilled helper adequately to take on the role of working with and supporting, not only women with BC, but with clients who have an illness that is progressive and potentially fatal. Valuable skills are those that help a counsellor be able to distinguish between a person's experience of living with a chronic illness such as BC, the emotional impact of the likely trajectory of the illness, and the meaning they draw from their experience of illness (Schaefer-Schiomo & Atwood, 2009). Additionally, psychosocial challenges adjusting to life as a BC are not all necessarily centred within the person of the survivor.

Professional helpers benefit from increased knowledge and understanding of interpersonal and intra-personal relating, of complex issues that encroach on attitudes and perceptions of the body, and of overall psychological recovery and emotional well-being for women living with BC (Fossey, Harvey, McDermott, & Davidson, 2002). It is important for counsellors to be cognisant of ways to support women diagnosed and treated for BC to enhance their quality of life and manage the

psychological side effects of medical treatment as they process their transition into survivorship.

This study considers the usefulness of self-compassion as a personal faculty that offers women who have had BC the capacity to engage in encouraging, safe, open and honest expression of their emotional experience within their intra- and interpersonal relating. Thinking positively is not enough. Counsellors, particularly, are well placed to encourage and promote self-compassionate attitudes in people experiencing the vicissitudes of living with chronic illness. Implicit in this study is the potential to foster development of effective counselling strategies to encourage greater awareness of self-compassion and promote counsellor sensitivity to a woman's relationship with her post-treatment body and her relationship with significant others.

### **3.15 Chapter summary**

Research projects provide evidence from which policies, practices, and effective service delivery can be reviewed to assess what strategies and interventions are currently working well for BCS (Fossey et al., 2002). Systematic analysis of what is already perceived to be effective affords the prospect of being fluid, flexible, and imaginative in attitudes about the direction of enhancement of self-understanding, self-kindness and warmth in both the client as well as in the professional helper.

This chapter has provided an overview of the dynamics that emerge in living with the aftermath of BC. The outline of some challenges of living as a BC survivor gives an entre into the antecedents to psychological distress. Additionally, the conversation is begun about self-compassion as a way in which women could be supported to relate with themselves in such a way as to improve quality of their emotional life during their BC recovery experience as well as across the years of survivorship.

Extending current understanding of the psychological issues that positively or negatively affect the relationship with self and with the social and emotional world as experienced by women living in BC survivorship, makes ongoing review and assessment of psychosocial support for BCS a useful and essential path to follow.

The implication is that a philosophical, conceptual, and therapeutic practice framework for counselling strategies that would gracefully ‘arrest’ the inevitable consequences of harsh self-judgment, without creating yet another way an inner critical voice can continue to judge would be supportive for women, post-BC. The aim would be to foster a happier and hopeful approach to life for those survivors whose capacity for emotional self-healing is temporarily trapped. Whatever the level of social standing, self-esteem, power or powerlessness, so-called deficiencies in education or position, or cultural complexity, the construct of self-compassion seems to be a resource that can constellate an internal, and sometimes disconnected ‘mosaic’ of symptoms, emotions and needs.

## **Chapter Four**

### **Literature Review**

#### **4.1 Overview**

This chapter presents a review of literature relevant to the core areas of this study. Specifically, Neff's (2003) concept of self-compassion (SC) presented as a pathway to enhanced self-awareness and healthy self/other relating for female breast cancer survivors (BCS). Literature reviewed in this chapter offers a fundamental outline of the emotional trajectory of diagnosis and treatment, the prevailing ideas about women's lives beyond the initial treatment phase, the challenges inherent in aging for the person with a chronic illness, as well as an exploration of self-compassion as a strategy for emotional regulation. Literature that has discussed cancer-related mental health issues has been reviewed in addition to literature where the focus has centred attention on the purpose and meaning a woman ascribes to her BC experience. Exploration of BC in this thesis has been written from a viewpoint of the psychosocial impact and resultant psychological processes.

An extensive range of literature is available that has already explored women's lived experience of BC. Contemporary and recent research has been conducted using quantitative methodology as a way to catalogue the implications of life post-BC for women, and their families (Andreu et al., 2012; Hopko et al., 2015; Kyranou et al., 2013; Sohl, Levine, Case, Danhauer & Avis, 2013). Additionally, there is also a considerable body of qualitatively-focused literature available relevant to the construct of SC as applied to a range of psychologically-based conditions (Arch et al., 2014; Baker & McNulty, 2011; Breines & Chen, 2012; Breines et al., 2014; Forti, 2011; Kreiger, Altemstein, Baettig, Doerig, & Holtforth, 2013; Neff, Hsieh, & Dejitterat, 2005; Zhang et al., 2017). Qualitative research into lifestyle

changes, and reactions to those changes as a result of having breast cancer has previously been conducted with Australian women by Bitsika, Sharpley and Christie (2010). That research found that women with BC often reported “a common coping strategy of avoidance or escape similar to depressive symptomatology” (p.179). The specific topic of whether SC could be of benefit to alleviate self-coldness and self-criticism in the lived experience of Western Australian women survivors of BC, has not, as yet, been the subject of a qualitatively-driven research project. The outcome of such a study will carry implications for counsellors, counsellor training, as well as for the design of interventions for survivors of BC.

Literature reviewed suggested strongly that in the longer term BC survivorship carries a silent, but undeniable, threat of cancer recurrence and a terminal diagnosis. Co-morbidity and increasing loss of personal physical and psychological functioning in the aging female survivor accompanied that silent threat. Findings from research state that a range of aspects of life could be expected to become increasingly difficult and non-negotiable as a woman survivor ages.

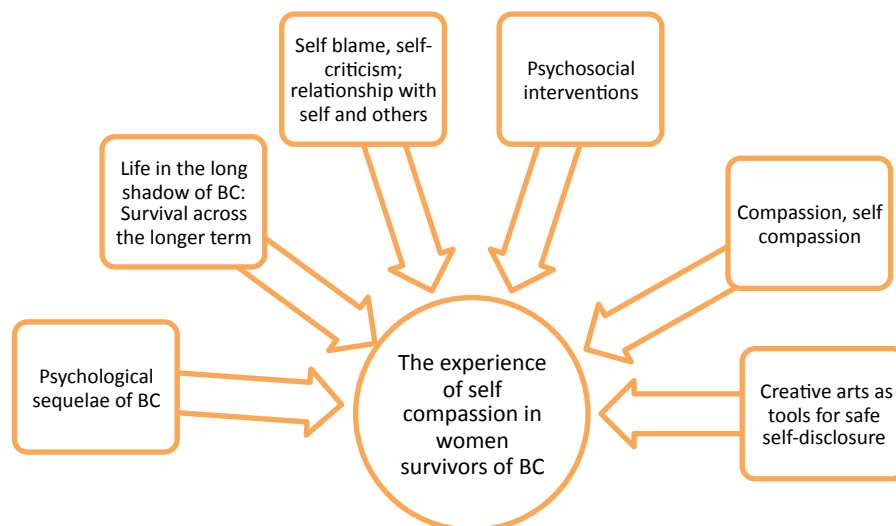
Research into the concept of self-compassion (SC) has been reviewed to identify the potential of an association between the experience and practice of SC, and amelioration of psychological distress for those women who experience negative after-effects from treatment for BC. Examination of the personal cost of living with the experience of emotional suffering and threat has guided the review of literature relevant to compassion and SC. To further consolidate the direction of this study, research has been included that deconstructs the concept of SC and explores a comprehensive overview of the value of SC as a support for positive personal growth specifically in relation to a number of health-related issues.

Literature on previously trialled psychosocial interventions has also been reviewed. In addition, literature relevant to the concept of post-traumatic growth as a facilitator of reduction in post-treatment stress and subsequent positive psychological adjustment and functioning.

A ‘core’ group of participants in this study (8 of the original 17 women who were interviewed) engaged in three 1 hour Opening to Self-Compassion sessions.

Some months later the 8 women met to engage in three 4-hour sessions of a Personal Reflection Program that utilised a range of creative arts activities. The creative arts activities were used as a way to foster personal enquiry about the self-relationship, as well as encourage more ‘intimate’ discussion of personally-held ideas about self-compassion.

The central elements of this review have been braided together from a range research into psychosocial factors experienced as an after-effect of diagnosis and treatment for BC. In addition, research that has identified SC as integral to emotional wellbeing was reviewed to gain a sense of the overall research picture surrounding SC. To place the literature in context, an overview of the social constructions of cancer and the psychological sequelae of BC open this review. The focus then moves to specifics of life in the ‘long shadow of BC’, and in particular, the negative influence of self-blame and self-criticism on self and other relating. Psychosocial interventions already tested have been reviewed to develop a map of the territory of psychological support available for BCS. The concepts of compassion and SC are discussed along with research indicating the influence on personal and social functioning. Diagram 1 sets out the main elements of this literature review.



**Diagram 1: Elements of the literature review**

#### **4.2 Social constructions of breast cancer**

An accepted social construction of an illness such as cancer is that the disease is an enemy to which the person diagnosed is victim, is afflicted by or, must battle

against (Petersen & Benishek, 2001; Petersen, Heesacker, & Schwartz, 2001). The way people relate with, talk about, and discuss BC can sometimes be directly linked to an escalation in personal fears or hopes related to a disease that remains a significant life disruption. The term ‘cancer’ makes a powerful statement that society has historically equated with impending death (Little et al., 1998). The social construction of BC has been said to be influenced by the context in which it occurs (Thorne & Murray, 2000). The disease of BC was once thought to be a malfunction in a woman’s reproductive organs (Olson, 2002; Thorne & Murray, 2000). In the main, male medical professionals attended to women’s bodies. In the earliest manifestation of BC treatment regimes those bodies were regarded as harbouring the female trait of emotional frailty and reproductive organs were viewed as the culprit in the genesis of the disease (Thorne & Murray, 2000). This original perspective served to create a stereotype of a woman with BC as ‘victim’ to the disease (Gibson, Lee, & Crabb, 2014).

Early treatment specifics for BC with radical mastectomy as the primary treatment method for disease eradication meant a woman was left physically disfigured (Olson, 2002; Thorne & Murray, 2000). The social construction of this form of cancer was that it was a destructive force that often meant mutilation and, most likely, succumbing to the disease (Galgut, 2007; Olson, 2002; Thorne & Murray, 2000; Verrill, 2009). Changes in public discourse, women’s illness experience, and importantly, treatment regimes for BC, emerged from both medical research and social movements in the latter part of the 20<sup>th</sup> Century. As a result women’s expectations and experience of a diagnosis of BC was altered from that of “tragic victim to heroic survivor” (Klawiter, 2004, p. 845).

Despite that transition from victim to survivor, women with BC remain confronted with the need to make necessary and urgent choices and decisions about their ongoing health care. Additionally, contemporary social constructions of the female breast concentrate on the importance of this aspect of a female body as a significant attribute for intimate relationships and body image (Li, Gao, Yu, Zhu, & Cao, 2017). The attitude that breasts are critical to personal attractiveness to others has lent weight to the argument for breast reconstruction as a painful means of restoring the body to its pre-surgery form (Gibson et al., 2014). The outcome for



women may be that treatment decisions are shaped by what the outcome of their decision might mean for others.

Another distinctive current social construction of BC highlights the social imperative for early detection as a means of reducing the number of women diagnosed receiving an unexpected negative BC prognosis (Gibbons, Groarke, Curtis, & Groarke, 2017). Breast self-checks empower women to be pro-active in monitoring their breast health. However, the difficulty is that self-checks, necessary as they are, form a secondary defence 'system' rather than a preventive mechanism. The seeming contradiction can be that a woman may become stressed and feel something she has or has not done makes her responsible for a negative result to a mammogram. In short, the woman may blame herself for whatever has 'gone wrong'. It is as if resistance, or 'failure', to carefully check her breasts continue to thwart more informed understanding of how a woman processes the psychological reality of diagnosis and survival of breast cancer (Galgut, 2010). Furthermore, in her book *The psychological impact of breast cancer: A psychologist's insights as a patient*, Galgut (2010) points out that while social convention is that a woman's breasts are hidden from view, paradoxically a diagnosis of BC means that nothing is sacred. For example, in routine mammography and once a BC diagnosis is made, a woman's breasts inevitably become no longer her own, but objects for inspection (Galgut, 2010).

In contemporary and recent media BC has been elevated to cultural prominence (Bell, 2014) with this disease 'carrying the banner' for positive survival statistics. Breast cancer survivors are portrayed in a sanitised version with what is in line with a persistent discourse around what femininity or being female should look like (Bell, 2014; Koczwara & Ward, 2015; Moore, 2010; Sulik, 2011). To add to the socially presented image of the BC survivor, celebrity status has been afforded the prospect of survival of the disease with several high profile personalities lending weight to the increased visibility of a BC survivor as synonymous with youth, beauty, and freedom (Bell, 2014).

Reporting on her investigation of interviews with 32 Canadian men and women about how they make sense of their cancer experience within their social,

political and cultural context, Bell (2014) explored “ways in which dominant discourses on cancer mediated their experiences” (p.58). The conclusion reached by Bell was that BC survivorship may have now become a socially-driven cultural conception that leads to some degree of invisibility of individual struggles and personally-imbued responses to BC. Oversimplification of women’s unique experiences of BC may in turn lead to an oversimplification of thinking about what psychosocial supports are needed. The woman for whom post-treatment depression, fear and anxiety become constant life companions may feel alienated. Their perception may be that it is acceptable or appropriate to speak openly about feelings of vulnerability and fear that would go against a mainstream positive view of survival (Kaiser, 2008). This means distress may be underestimated for those BC survivors whose ‘version’ of survivorship does not match the new ‘norm’.

Koczwara and Ward (2014) offered an extension of the findings from Bell’s research and concluded that some BC survivors may have access to greater socioeconomic resources with which they can make contributions that support greater visibility of survivorship. These authors also highlighted the rapid development of effective treatments and the subsequent increase in numbers of survivors as contributing to the public perception that BC can be overcome, that treatment “can be successful and longevity (and therefore a future successful life) can be assured” (Koczwara & Ward, 2014, p. 343).

Amongst health care professionals, families and friends, negative reciprocity can automatically inhabit cancer communication and actively block expression of fears and concerns by a cancer patient (Razavi et al., 2002; Sheridan, Sherman, Pierce, & Compas, 2010). Semi-structured interviews informed by the Critical Incident Technique were used in a study by Canzona and colleagues (2016) to identify communication behaviours in health care providers that either helped or hindered interactions with BC survivors on the topic of sexual health issues. The study findings emphasised the importance of language used in communicating with BC survivors as well as highlighting negative outcomes when a survivor perceived there was a lack of care, knowledge or investment in the process of communication (Canzona et al., 2016).

The social and cultural constructions of breast cancer have, in more recent times, been challenged by social movements (Klawiter, 2004), as well as by women who have had BC, who reject, or interpret differently, the identity of survivor (Cheung & Delfabbro, 2016). In addition, there are some BC survivors who wear proudly the scars of their mastectomy. The term 'survivor' can appear to be something of an all encompassing term under which can become grouped all women for whom the disease is not fatal. However, the title survivor does not allow for the unique experience of the individual (Kaiser, 2008). The survival-oriented culture that currently surrounds BC may limit their willingness to express existential fears and concerns. The evidence shows that even if the disease has been eradicated, women treated for BC will live with the after-effects for the remainder of their life.

Social constructions of illness and illness experience have shaped public discourse and personal responses to a disease such as BC. A shift since the 1970's in the power differential between the medical professional and their patient, has, however, provided women greater participation and alternative pathways for treatment. Greater acceptance of women's choice not to conceal physical 'evidence' of a breast cancer experience has now created a 'space' for a different framing of breast cancer and breast cancer survivorship. Change in the way women relate with their illness means empowerment for those living with BC would include a process involving some form of self-reflexive action (Porroche-Escudero, 2014).

In adapting to challenge and change, both brain and body are reported to experience overload (Charney, 2004), and despite a desire by women with BC to focus on wellbeing, anecdotally this is reported from counsellors and psychotherapists as often not the case. Women with breast cancer are no longer invisible in the public domain. Without opportunity, however, to engage in reflection and review of their self-experience there are limits to enabling some women to increase control over their illness experience and ultimately improve their psychological wellbeing (Porroche-Escudero, 2014). The optimal outcome would be adoption of a health-focused lifestyle that included along with sustainable change in personal attitudes and processes for maintenance of a healthy body-mind-feeling connection.

What remains to be explored in more detail is the nature of the personal relationship a woman has with herself and her body, and how self-coldness or self-kindness might influence relationships with an illness experience, with significant others, and with a woman's lived environments.

### **4.3 The happiness imperative**

A question raised in the literature relates to the impact on psychological functioning of long-term negative or positive affect. In particular, for survivors, concern and fear about recurrence of cancer has been cited as a common by-product of treatment and recovery, and has been associated with heightened distress and negative affect among BCS (Custers et al., 2015; Lichtenthal et al., 2017). In a seminal study of cancer recovery Dodds (1999) used Collaborative Group Enquiry to explore whether participants in the study regarded cancer as an indicator that change was required, or presented a wake-up call to examine one's lived environment. Dodds (1999) concluded that while chronic stress was nominated as a catalyst for cancer by many participants in her study, the "dominant perception was that healing could be evoked by personal change" (p. 155). Furthermore, her study findings pointed to the experience of "serious illness and suffering" as an "impetus for great spiritual and emotional growth" (p. 148).

Vitry (2010) has written about the tendency in current medical discourse to situate depression as a health issue with a biomedical explanation that has a pharmacological resolution. This author comments that "the medicalization of human suffering and the promotion of positive thinking as the moral normality" may result in a lack of 'voice' for the uniqueness of emotional suffering for women survivors (p. 32). Imperatives for women to subscribe to a populist notion of the power of positive thinking, and therefore reflect a socially desired identity as 'optimistic hero' in the 'war' on BC may end up denying survivors the opportunity to undergo the personal growth from facing challenges inherent in survivorship (Vitry, 2010).

The evidence for adoption of positivity as a useful ally in women's efforts to defeat BC has been challenged with the argument that quietly managing despair, and holding secret, negative thoughts would actually be unhelpful and counterproductive for women in the wake of BC (Ehrenreich, 2009). The argument from Ehrenreich is

in line with writings from authors such as Sulik (2011), Moore (2010) and Porroche-Escudero (2014). Sulik maintained that the pink ribbon movement in Western culture may have served to obscure more demanding realities of what women actually need for psychological wellness when they face enduring, and at times extreme, emotional concerns. Moore (2010) used in-depth interviews and a questionnaire to gather data in her exploration of cultural meanings ascribed to the wearing of ribbons as a sign of social support for charitable causes. Those interviews brought insight to perceptions of public awareness and the public sense of compassion for women living with BC. Porroche-Escudero (2014) argued that greater awareness of BC has empowered women to become proactive in reducing the incidence of terminal BC through early testing. However, at the same time, increased awareness of BC may become a catalyst that fuels fear (of being diagnosed) as much as empowerment for women to be active participants in early detection of BC. A societal focus on supporting a positive response to BC survival may in fact result in the unnecessary constraint of meaningful articulation of a woman's authentic self as a survivor (Moore, 2010). Another conclusion drawn from research by Porroche-Escudero was that BC awareness campaigns that unwittingly deliver fear-based messages may unnecessarily dis-empower women who would assume full responsibility for their breast health.

Early studies on BC survivorship reported that women who responded with fighting spirit or with denial were less likely to encounter BC recurrence (Greer & Morris, 1978). However, direct correlations between positive coping styles and reduction in risk of cancer recurrence were not supported in a systematic review of studies that had researched association between psychological coping styles and cancer survival (Petticrew, Bell, & Hunter, 2002). The findings from the study by Petticrew and colleagues did not support claims of a link between increased chance of survival and mental attitude highlighted the necessity for the person with cancer not to feel pressured to sanction particular coping strategies in the hope of enhancing their chance of survival. An important conclusion from these researchers is that the imperative to think positively may mean the cancer survivor ends up trying to manage an increased psychological burden.

A pilot study to develop a questionnaire that would provide an assessment tool for gauging frequency of distress from negative and positive anticipatory thoughts in women in Canada about to undergo chemotherapy for BC has been conducted by Gilbert and colleagues (2016). One of the findings in that research was the report of a high incidence of belief amongst participants that a positive attitude was an essential ingredient in fighting the disease. What this means, and has been reported by these authors, is that women may fear accommodating or expressing negative thoughts and emotions (Gilbert et al., 2016). Although the study focused on women who had not yet completed their treatment regime, there are implications to consider in relation to suppression of negative thoughts and feelings in BCS. The powerful social norm of thinking positive may end up disempowering women's capacities to examine in greater detail their self-relationship.

Evidence from the field of psycho-neuro-immunology has found that chronic stress is likely to impair biological functioning (Subnis, Starkweather, McCain, & Brown, 2014). The arguments posited by researchers in that field validate the view that what happens in the mind affects the body. For example, research in the field of psycho-immunology has claimed that an individual's psychology can exert a profound effect on their physiological processes (Diamond, 2010). However, it would be plausible to expect that the psychological sequelae from having BC would not be uniformly negative. This becomes an important factor in assessing a woman's response to fear, distress and uncertainty generated by living with BC. Every woman has a culture with uniquely personalised aspects that affect the way she will respond to life, particularly in the aftermath of BC. Previous life experiences, values, behaviours, socio-economic factors and personality factors have each been reported as affecting the way an individual responds to BC (Mystakidou et al., 2008; Wendling, 2016).

Awareness of the influence of social movements, popular culture, and activism, and the way those 'environments' can envelop the BC experience, help improve understanding of social structures that shape and contextualise a woman's experience of the illness. The impact of greatly increased positive medical outcomes for women diagnosed appears to have been matched by social forces that engender conversations that focus on optimism as a significant strategy for wellness. While

there is substance to that view, the downside is that not all BCS benefit from that view. A presumption that women need to sustain optimism sounds simple, but may serve to deny a safe psychological space in which they feel able to explore fears and concerns about the realities of what it means to live with an emotional and physical legacy from BC.

#### **4.4 Reality: Psychological sequelae of breast cancer**

Fundamental to exploration of self-compassion as a valuable ingredient in psychological strength and EWB, is firstly an understanding of the psychological consequences of BC and survival across the short and longer term.

There is acknowledgment of extensive contemporary research covering a broad range of perspectives on the immediate impact of BC on a person diagnosed, as well as psychosocial issues that emerge after completion of treatment (Arman & Rehnsfeldt, 2003; Cappiello, Cunningham, Knobf, & Erdos, 2007; Razavi et al., 2002). Contemporary research into cancer and/or BC has addressed topics that include anxiety and depression (Deshields, Tibbs, Fan, & Taylor, 2006; Hill et al., 2011; Hopko, Clark, Cannity, & Bell, 2015; Kyranou et al., 2013), body image, and attitudes and perceptions about self (Bitsika, Sharpley, & Christie, 2010; Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016), intimacy and sexuality (Naaman, Radwan, & Johnson, 2009; Taylor, Harley, Absolom, Brown, & Velikova, 2016), interpersonal relating (Bolger, Foster, Vinokur, & Ng, 1996; Harris et al., 2009; Mackenzie, 2014), BC and personality factors (Bleiker, Hendriks, Otten, Verbeek, & van der Ploeg, 2008), stress and survivorship (Dodds, 1999; Lebel, Rosberger, Edgar, & Devins, 2008), dietary factors (Vance, Campbell, Mccargar, & Moutzakis, 2017), distress and chronic illness (Kenen, Ardern-Jones, & Eeles, 2003; Wendling, 2016), hidden suffering (Arman & Rehnsfeldt, 2003; Wendling, 2016), and the inter-relationship of mind and body, particularly in relation to processes with personal and spiritual growth (Dodds, 1999; Mystakidou et al., 2008).

A study by Low and colleagues (2006), in three different geographic sites in the United States of America, found that while women living with the aftermath of BC could be expected to encounter stressful events post-treatment, their overall personal distress could be expected to diminish over time. The authors of that study

highlighted that coping through cognitive, emotional, or behavioural disengagement was detrimental to long-term adjustment, whereas coping through active acceptance, seeking social support, emotional expression, or other approach-oriented coping strategies predicted diminished distress over time (Low et al., 2006). In contrast, a recent study with young Asian American women found that after treatment, women “worked to find ways to use their experience as a transformative one and also to develop more positive coping skills including expressing emotional vulnerability and reaching out to others” (Yoo, Sudhakar, Le, & Levine, 2017, p. 43). The results of studies into emotional coping styles, emotional regulation and depression and anxiety in BC survivors have identified that positive and adaptive types of coping strategies support better quality of life, however, implicit internal processes also influence emotional regulation (Marroquín, Czamanski-Cohen, Weihs, & Stanton, 2016; Paek, Ip, Levine, & Avis, 2016).

#### **4.5 Breast cancer-related distress: Depression, anxiety and coping**

When contemplating the range of negative after-effects of BC, depressive mood and clinical depression are the sequelae that immediately come to mind. Diagnosis and treatment for BC brings greater exposure to a multitude of psychological factors including increased susceptibility to depression (Bitsika et al., 2010; Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2012), anxiety (Hill et al., 2011), doubts self-worth, adaption to a changed body image, sexual identity, function and relationship (Dizon, 2009; Gilbert, Usher & Perz, 2010; Krychman & Katz, 2012), disharmony as well as activation of strengths in family relationships (Corney, Puthussery, & Swinglehurst, 2016; Coyne, 2013; Wolf, 2015), and disruption to a sense of personal attractiveness (Ganz & Hahn, 2008; Silva, Moreira, & Canavarro, 2012). Research evidence has confirmed that BC amplifies a survivor’s vulnerability to psychological distress (Carvalho et al., 2014; Reich, Lesur, & Perdrizet-Chevallier, 2008; Wang et al., 2014). A review of the literature by Pinto and de Azambuja (2011) established that the most reported symptom presentations, in psychological terms, included “fatigue, insomnia, depression, cognitive dysfunction, reproductive and menopausal symptoms, and lymphedema” (Pinto & de Azambuja, 2011).



A review of relevant literature brings visibility to differences that exist between in what generates post-BC related emotional distress. For example, the rigours of treatment and a woman's uniquely individual physical and emotional response to her illness generate differences in psychological outcomes (Arman & Rehnsfeldt, 2003). In relation to that range of psychological outcomes there is evidence to suggest that depressive symptomology is a common stand-out response following treatment for BC.

A study with women with BC in Romania proposed four factors as culprits for post-treatment emotional distress. Those four elements centred on physical changes believed to impact directly on a woman's loss of femininity: undergoing a mastectomy, a change in body structure, and self-image (Enache, 2012). The argument in that study proposed that women who underwent surgical removal of one or both breasts would experience a "sense of inferiority, shame, social isolation which correlated with the feeling of loss of femininity" (Enache, 2012, p. 127). In Enache's findings depression post-BC was believed to be caused, in part, by social isolation directly related to participants' lowered sense of self-esteem (Enache, 2012).

Depression or depressive symptoms post-BC have been found in some studies to be long-lasting (Reich et al., 2008). In addition to a complex interface between factors that lead to psychological distress, evidence confirms that survivors of BC themselves also experience varying levels of distress as they progress through survivorship (Burgess et al., 2005; Carvalho et al., 2014). The psychological outcome is a derivative of the combination of a multi-factorial situation blended with a highly personalised response.

Statistically significant levels of depression and anxiety have been reported in Australian women with early-stage BC (Cancer Australia, 2011). Figures cited by Cancer Australia (2011) and Cancer Forum (Beatty & Kissane, 2017) highlighted that anxiety and depression have been identified as the two most prevalent mental-health issues for women with BC. These findings reflect similar findings by researchers in the United Kingdom (UK) whose investigation into risk factors for depression and anxiety in women with early BC (five years after diagnosis) served as

a reminder that compared to the general female population, the incidence of anxiety as well as clinically significant depression was markedly higher for women with early breast cancer (EBC) (Burgess et al, 2005, p. 4).

Hegel and colleagues (2006) also reported that at least half of the participants in their study had “clinically significant distress levels” or were assessed as “meeting criteria for a psychiatric syndrome” (p. 2930). Major depression and PTSD emerged as prevalent in women participants in that study, with evidence that both conditions had a significant and negative influence on participant’s psychological functioning (Hegel et al., 2006).

A significant decrease in the “prevalence of clinically important depression and anxiety” was reported by Burgess et al (2005, p. 1). What Burgess and her colleagues found was that over a period of 5 years the incidence of depression and anxiety reduced from nearly 50% of women with early BC in the first year to 15%, for women in remission, in the fifth year (Burgess et al., 2005). Their study, involving 222 women living in the UK, recognised that the first year after diagnosis and treatment was a critical time for women with either early stage or advanced BC to receive focused social and emotional support. Findings from a later study in which 236 women in Lebanon took part in an investigation into the incidence of depression and anxiety in the immediate post-BC phase (Hegel et al., 2006) were consistent with previous research (Burgess et al., 2005).

A meta-analysis of 78 studies with a combined total of 11,948 participants reviewed both primary and secondary coping categories in women with BC as predictors in the relationship between coping strategy and the experience of positive or negative affect. The identified variables that influenced the effectiveness of a woman’s coping included “cancer stage, treatment, disease duration” (Kvillemo & Bränström, 2014, p. 1). In their review of literature on coping strategies employed by women post-BC what emerged was “acceptance, positive reappraisal and fighting spirit were associated with lower levels of negative affect” (Kvillemo & Bränström, 2014, p. 17). In contrast, those authors also identified that when a woman post-BC engaged in emotional avoidance and disengagement as a coping mechanism this led to diminished well-being and overall health.

Research evidence lends weight to an argument that the experience of clinically important psychological distress associated with BC can be expected to dissipate over time (Vahdaninia, Omidvari, & Montazeri, 2010). Some research has argued that the overall prevalence of depression in women with BC has now fallen to within the range of 10 – 25% (Fann et al., 2008). Despite the argued fall in the incidence of ongoing depressive symptomology, yet another study reported a figure of at least 10% of women diagnosed as being susceptible to development of a major depressive disorder (Nekolaichuk et al., 2011).

Overall, the findings of Fann (2008), as well as Nekolaichuk and colleagues (2011), confirmed the ongoing risk for persistent emotional distress. However, it is important to acknowledge the idea that not all negative psychological aftermath appears to be persistent and residual over the longer-term. The reduction of the prevalence of depression by the fifth year post-BC to around a 15% mark predicted by Burgess et al (2005, p.1) amplified the expectation of positive survivorship and positive return to normality in life. However, the hypothesised gradual subsidence of depressive symptomology as proposed by Burgess et al (2005) may coincide with proximity to the 5-year survival threshold. As a woman moves closer to passing that important milestone without BC recurrence she may experience some release and relief from living with fear of recurrence. Taken optimistically, any forecasted contraction in frequency and duration of depressive episodes could indicate that, over time, the number and severity of episodes of depression and anxiety post-BC could be expected to inevitably diminish to the point where levels arrive at a statistic consistent with the occurrence of depression in women in the general population.

Although ample data exists that confirms an increased susceptibility to depression and anxiety as part of a BC experience (Fann et al., 2008; Seok et al., 2010) research has argued an opposing position cannot be confirmed. That opposing position has argued that no direct causal link between pre-existing depression and development of BC has yet been convincingly established (Pössel, Adams, & Valentine, 2012). In line with research findings that particular chemicals used to arrest the advance of BC may also be implicated in the emergence of depression in women survivors of BC, a quantitative study by Cvetković and Nenadović (2016) interviewed 87 participants ages 30 – 78 to “determine the frequency of depression

among patients with breast cancer” (p. 344). The findings illustrated that a “statistically significant difference was noticed between the degrees of depression of cancer patients with regard to age” with occurrence of depression decreasing to 15% a year after diagnosis (p. 345). The argument from this research maintained that “depression is significantly more often recorded with BC patients receiving the first cycle of cytotoxic therapy when compared to the patients suffering from the same disease that are receiving their second round of treatment” (Cvetković & Nenadović, 2016, p. 345). Findings from that study imply the need for further research into any link between life-saving medication, used to inhibit the growth of cancer, and the onset of depression in survivors of BC.

#### **4.5.1 Inflammation, depression and risk of BC.**

Inflammation in the body is a complex, multi-factorial process and as such is not a focus for this research. However, research from a physiological perspective has raised an argument about a symbiosis between depressive symptoms and elevation of inflammation (Zunszain, Hepgul, & Pariante, 2013). Cancer, including breast cancer has been included in the range of illnesses identified as vulnerable to exacerbation by inflammation, therefore links between psychological functioning and inflammation require mention (Krishnamoorthy & Honn, 2006; Lippman, 2016). Evidence of a biochemical link between inflammation and depression and the impact on immune functioning is important when considering psychosocial interventions for BC (Lippman, 2016). Understanding the pathogenic role inflammation has on the evolution of BC, particularly the role of pro-inflammatory cytokine genes that “induce sickness behaviour with symptoms overlapping those in clinical depression” (Sotelo, Musselman, & Nemeroff, 2014, p. 16), suggests further research in this area to specify the magnitude of the effect elevated levels of inflammation have for women survivors of BC could assist with screening and treatment for depression post-BC. Furthermore, the physiological and psychological mechanisms that precipitate a disease such as cancer – or cancer recurrence – require consideration so as to preface psychosocial interventions that may assist in enhancing immune function.

Any suggestion of there being a link between a stress-induced increase in inflammation in the body, and risk of cancer recurrence means it is important to

consider amelioration of stress in the aftermath of BC to impede disease progression and the risk of recurrence. Suggestions that negative mental states are one factor responsible for an exacerbation of inflammation (Kendall-Tackett, 2009) and changes in the physiological regulatory system may mean elevated risk of adverse health outcomes (Keyes et al., 2013). While the focus of this thesis is not chemical componentry of the body-mind connection, a significant point of discussion about the effects of psychological distress and BC survivorship is whether reduction of psychological distress could improve the course of certain inflammatory diseases ... and therefore decrease risk of cancer.

Connections have been made between the consumption of diet high in fatty acids and a link to increased inflammation in the human body as a precursor of greater vulnerability to depression (Maes & Smith, 1998). Links have also been made between diet and weight gain, risk factors and poor prognosis in BC populations (Dal Maso et al., 2008; Koo, Seo, Cho, Kim, & Choi, 2016) and diet and improved BC survival (Beasley et al., 2011). Investigation into whether any association exists between SC and dietary habits has found SC to be a “protective factor against stress-induced inflammation and inflammation-related disease” (Breines et al., 2014, p. 109). The study findings suggest that “individuals who are higher in self-compassion may be buffered from increased inflammation following unfamiliar psychosocial stress” (p. 113).

#### **4.5.2 Diet, exercise and BC risk.**

The relationship between environmental factors such as diet and BC risk has pointed to obesity as a significant risk for development of BC and poor prognosis after diagnosis (James et al., 2015). Concerns and beliefs about links identified between dietary factors, weight gain and risk of recurrence of BC has been reported anecdotally by participants who took part in the study being reported in this thesis. Greater attention to diet and exercise aimed at reducing BC recurrence in survivors has been the subject of recent research (Augustin et al., 2017; Kushi, Kwan, Lee, & Ambrosone, 2007; Pierce et al., 2007). It has been argued that while weight gain during or after BC can have a negative effect on prognosis, positive lifestyle changes such as increasing physical activity can bring benefits such as self-perceived satisfaction with appearance as well as overall fitness and emotional wellbeing

(Hamer & Warner, 2017). Diet would appear to be a BC risk factor with the ‘facility’ to be modified without surgical or chemical intervention. In particular, SC has been identified as having the potential to serve as a protective factor against disordered eating or eating pathology in women (Kelly, Vimalakanthan, & Miller, 2014).

A frequently accompanying and equally as debilitating condition to depression or major depressive disorder in BC survivorship also requires examination. From their review of the literature relevant to the relationship between physical illness and mental distress, Roy-Byrne and fellow researchers (2008) argued that anxiety disorders - in people with comorbid medical illness - had been less well studied than depression. When comparing mental health outcomes from a number of illnesses, including cancer, Roy-Byrne and colleagues claimed the existence of “robust epidemiological and clinical evidence” that referred to anxiety disorders as having “an equally important role” (2008, p. 208) as that of depression.

#### **4.5.3 Anxiety and fear.**

For a woman suspected of having developed BC, anxiety can result from delays in a confirmation of diagnosis, a missed diagnosis, or mis-diagnosis. Anxiety may have a negative effect on health-seeking behaviours (Fatiregun et al., 2016). A tendency in some cancer patients to ‘play down’ their anxiety or fear on the basis that those feelings are an “expected part of their diagnosis and treatment” (Roy-Byrne et al., 2008, p. 217) means there is a high need to identify anxiety disorders in BC survivors. Understandably, it is noted that reduction in occurrence of emotional distress would not be expected to occur for women diagnosed with recurrent BC. A 5-year observational cohort study by Burgess and colleagues (2005) highlighted the dilemma in recognition and treatment of post-BC distress, and therefore suggested intra-personal factors could be identified as likely to increase the risk of depression and anxiety for women with BC, in particular, those who “remain free of the disease in the year after the disease is diagnosed” (p. 3).

A study of 355 women in the UK, explored the question of whether anxiety and depression, commonly diagnosed following BC, were more accurately considered a recurrence of previous psychopathology (depression) or directly related to their current experience of BC (Hill et al., 2011). In contrast to the earlier study by

Burgess et al (2005), the study conducted by Hill and colleagues suggested that the incidence of depression and anxiety in women with BC was higher for women with a prior history of depression and anxiety. The claim was that for a certain number of women, depression and anxiety post-BC was a recurrence of a pre-BC predisposition to episodes of depression. In relation to the contribution of premorbid factors, the Hill et al study found that in women with BC “approximately 40% of patients with episodes of Generalised Anxiety Disorder were ... experiencing recurrences” of that anxiety (Hill et al., p. 1432). Rather than BC being identified as a catalyst for development of anxiety the evidence from the study by Hill and colleagues seemed to support the view that those women who had episodes of depression and anxiety prior to their diagnosis and treatment for BC were more likely to experience negative emotional disturbance post-BC.

A significant factor highlighted by the studies from both Burgess et al (2005) and Hill et al (2011) that cannot be ignored was the recognition of the complex interplay of factors that predispose a post-BC individual to experience ongoing psychological distress. Critical intrapersonal contributors to emotional distress such as self-blame and shame, often in addition to the interpersonal aspect of low levels of social support, have been cited in previous research (Burgess et al., 2005; Hill et al., 2011).

An investigation into the hypothesis that a link exists between antidepressant medication and increased BC risk, reached the conclusion that no support for a connection between the two was available in the literature reviewed (Reich, Lesur, & Perdrizet-Chevallier, 2008). This finding has implications for fear of recurrence for women survivors of BC who are prescribed antidepressant medication. The authors of the review acknowledged that cognitive attitudes of helplessness and hopelessness, hallmarks of depressed states as well as fear of disease recurrence, have been consistently argued as having a significant role in influencing emotional wellbeing in women with BC. An important caution consistent with that mentioned by Fatiregun and colleagues (Fatiregun et al., 2016) was that apart from the psychosocial distress experienced, depression can place a woman at risk of not complying with the medical care regime that offers her protection from recurrence (Reich et al., 2008).

Uncertainty about the future and an ever-present threat of death from recurrence generate anxiety and distress and predispose some women to “psychosocial problems and poor adjustment” (Ohaeri, Ofi, & Campbell, 2012, p. 419). What is clear is that for some time post-treatment a significant number of women continue to experience anxiety and depression (Kyranou et al., 2013). What this tells us is that despite optimistic survival statistics, across the longer-term, for some women who live with the sequelae of the disease the future will mean continual effort to meet the demands of physical and emotional adjustments required for living long-term with the legacy of BC (Boinon et al., 2013; Esteva & Hortobagyi, 2008; Lijovic et al., 2008; Robb et al., 2007b, p. 77; Worden, 1989).

Deficits in understanding the pre-determinants of more subtle elements of psychosocial distress can lead to an underestimation of the effects of BC on emotional wellbeing in long-term survival (Fann et al., 2007; Roy-Byrne et al., 2008). This means that without exploring and challenging current knowledge about the emotional and physical wellbeing of women survivors of BC their functioning can be unwittingly compromised or limited. In particular, the importance of detailed analysis and awareness of factors that influence emotional stability in BC survivorship highlights the need to understand the disparate elements of effective counselling and psychotherapeutic techniques that could reduce psychological distress post-BC treatment. Women survivors of BC whose depression is not appropriately and effectively treated may be at greater risk of poor psychological outcomes (Beatty & Kissane, 2017; Butow, Fardell, & Smith, 2015).

Perhaps the indication is that the nature versus nurture question continues to remain very much open in relation to causality between psychological distress and BC. For this current study the ‘nurture’ question is the sole focus of attention. What becomes important then is how women care for themselves post-BC and in what ways they nurture a renewed sense of identity other than through a label of BC survivor.

#### **4.6 Survival and the longer term: Life in the ‘long shadow of breast cancer’**

Personality and psychological factors, type of treatment and length of treatment have all been identified as significant in quality of life post-treatment for



BC. While medical treatment for BC has been revolutionised over the last four decades, what has not changed with the passage of time is the capacity for a diagnosis of BC to provoke a range of intense emotional reactions (Drageset, Lindstrøm, & Underlid, 2010; Souza et al., 2014). Optimistic and statistically proven outcomes from BC research that offer extended lifespan expectations for many women mean psychosocial wellbeing and the quality of life in the aging BC survivor has become an increasingly important and urgent consideration in health care (Repetto et al., 2003; Robb et al., 2007). Therefore it is likely older BCS will tend to have poorer physical health and health-related quality of life (Campbell-Enns & Woodgate, 2015).

One implication of the acknowledged capacity of BC to erode emotional wellbeing (EWB) with age advancement in survivors relates to the research-supported argument that emotional expression is inextricably changed, or, at very least, negatively influenced by a BC experience (Mehnert & Koch, 2008; Sachs-Ericsson et al., 2010; Frazzetto et al., 2012). Research evidence has supported findings that even past the five-year survival point post-BC, changes in emotional expression can materialise in ways that can be unproductive for mental and physical wellbeing (Dodds, 1999). The fact that there can be late-effect emotional change has important implications for the mental health of the BC survivor who may go on to live a full and long life.

An expected health statistic is that the incidence of cancer malignancies in a given population increases with age. With BC survival rates now extended to an expected 90% of those diagnosed (AIHW, 2017) this means older survivors face an increased vulnerability to comorbid conditions that come with advancing age (McCaskill-Stevens & Abrams, 2011). The challenges inherent in geriatric oncology were reviewed in 2007 by Malek and Silliman (Malek & Silliman, 2007). These authors pointed out that individuals who outlive the average age expectancy seemed to “have the highest odds of surviving even longer” (p. 215). A consequence of the findings in Malek and Silliman’s study is acceptance by society that older persons who are also survivors of BC are entitled to receive attentive medical care across the entirety of their life-span. These authors also highlighted the lack of available evidence (at the time of writing) that would provide greater knowledge and

understanding of cancer survivorship in older adults (p. 221). In focusing specifically on BCS however, Malek and Silliman (2007) highlighted the possible convergence of the side effects of therapy for BCS with coexisting health conditions. The authors highlighted the fact that what is not known is whether a diagnosis of BC can be routinely associated with “an increased burden of disease” (p. 221). The outcome of their review of the issues for older adults was that health care for this population necessitates attentive care in the monitoring of their health, particularly in relation to routine interventions such as influenza vaccination and routine screening for bone health and cancer other than BC.

The desire to re-engage with society and their previous social roles highlights the need for survivors of BC to be able to resume their life as an active, worthwhile and contributing member of their family and the larger community (Trusson et al., 2016). For some women, however, after-effects of the disease will continue to impose on their life “unwanted transformations and pain” (Piot-Ziegler et al., 2010, p. 480). What is important from the findings by these authors is that there will be survivors of BC may become continuing users of resources focused on emotional and psychological wellbeing (Harris et al., 2009; Worden, 1989).

A qualitatively-driven longitudinal study over 5 years that compared health outcomes and healthcare utilization by BCS older than 65 years of age, alongside a control cohort matched for age, geographic location and total co-morbidity burden, revealed that co-morbidity levels for BCSs over the five years of the research remained similar to levels found in women who did not have BC (Hanchate, Clough-Gorr, Ash, Thwin, & Silliman, 2010). However, review of participant data indicated that in the first year after diagnosis there was significant non-BC co-morbidity but this trend did not continue throughout the study. One conclusion was that BCSs visited their doctor more often than participants in the control group. However, this finding was presented not as an indicator that a survivor required higher levels of medical treatment, but as an indicator of their vigilance of follow-up health care. An important limitation reported by Hanchate and colleagues (2010) related to the volunteer status of participants in the study. Because BC participants had volunteered to join the research, the authors hypothesised that this could indicate the cohort taking part “may be healthier, or more prone to positive health behaviours, than other

survivors” (p. 1069). The reported outcome of the study was that patterns of disease burden and quality of health care in older BCSs “beyond the first year after breast cancer diagnosis” was found to be commensurate with women never diagnosed with BC (p. 1069). The findings suggested that survivors of BC who were categorised as ‘older’ were no more likely to make more use of health services than women in the general population. This finding does not mean that older women survivors of BC need less monitoring or care. Conversely, these women may have habitual patterns of delaying attention to their health needs through concentration on the needs of others.

Age can be anticipated to herald a reduction in quality of life that may complicate maintenance of cancer-free health. There is evidence to suggest, however, that older women survivors may not seek, or be adept at seeking, the physical or emotional assistance needed. A 7-year study by Clough-Gorr, Ganz, and Silliman (2010) that investigated the self-reported experience of persistent lymphedema in BCSs indicated that an older survivor might be less likely to report symptoms of this common complication from BCS than a younger BCS. Using telephone interviews to collect data, trained interviewers conducted interviews that averaged 45 minutes in length. A series of 9 interviews was spread across a time span of just over 7 years (87 months) and data was combined with medical record review three months after surgery (Clough-Gorr, Ganz, & Silliman, 2010). Implications from this research also pointed to the necessity to engage the older BCS in remedial measures that would assist maintenance of their health and wellbeing during survivorship in older age.

The study by Clough-Gorr et al (2010) added significance to findings from a study by Lo, Lin, Gagliese, Zimmerman, Mikulincer and Rodin (2010) that investigated whether age-related patterns in attachment security and wellbeing provide a protective effect of age against distress for persons with metastatic cancer. Three hundred and forty-two outpatients recruited to the study by Lo et al had a confirmed diagnosis of Stage III or Stage IV cancer (lung or gastrointestinal). A finding from this research raised the possibility that an older cancer survivor may be more adept at bearing the distress generated by the disease (p. 332). Reasons suggested for this capacity to bear distress included the age-related experience of attachment security from having maintained secure, close relationships. Age and the passage of time has been said to provide opportunity for spiritual growth and

meaning, reflection on life experiences, time to make sense of those experiences, and generate a sense of purpose (Lo et al., 2010). The findings support the impression that while older age, for the cancer survivor, can be a time of frailty and vulnerability (Bennett, Winters-Stone, Dobek, & Nail, 2013), it may also be a time when “new, adaptive capacities” are developed (Lo et al., 2010, p. 333). However, the researchers involved in the study voiced caution at interpreting their findings to mean that the older survivor can be judged as able to cope with the disease better than a younger cancer patient. Neither do the findings suggest that psychosocial care is less of a necessity for the older survivor (Lo et al., 2010). In contrast to the finding that the older BCS has the opportunity to make meaning and experience spiritual growth (Lo et al., 2010), in a study of 274 women survivors aged 70 and older, Robb and colleagues (2008) reported that BCS reported “significantly lower levels of life satisfaction, mastery and spiritual wellbeing” (p. 89). The indications are that care is needed to assess and address the psychosocial needs and emotional functioning of the older BCS.

A study of frailty in older BCSs analysed data from two exercise intervention trials with older adult BCSs (Bennett et al., 2013). A distinction was drawn in this report between BCSs who were healthy and could actively engage in an exercise program, and those BCSs whose health status was less positive. The findings indicated that cancer treatment may predispose a survivor to early-onset frailty. However, exact conclusions were not drawn because the design of the study was to analyse pre-existing data. The point being made was that attention be paid to evaluation for frailty and this should be routinely included in the assessment of wellbeing in the older person who has survived BC as a way to assess the impact of frailty on mental wellbeing.

Individual interviews with 21 women aged between 50 and 70 years of age, diagnosed with BC and awaiting surgery at a Norwegian university hospital, revealed that in the interval between diagnosis and treatment, participants in the study reported being able to offset a fear of death through self-generation of feelings of hope and optimism about survival (Drageset et al., 2010). Therefore, known positive survival rates for women with BC could be said to support confident maintenance of

feelings of hope and optimism as women face a disease that still carries the prospect of death (Drageset et al., 2010).

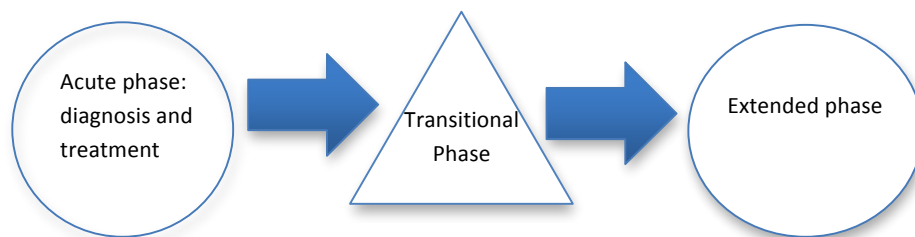
Reports from Norwegian women participants in the study by Drageset et al., (2010) indicated they processed emotional distress in one of two ways: to deal with [emotions] either by openness or by holding back (p. 149). What the study also uncovered was a tendency in participants to be aversive to feeling emotionally overwhelmed. This is an important finding in terms of EWB. In order to avoid ‘emotional overload’ each women in the study had formulated a method of managing their distress such that their unique personal needs and lifestyle could be accommodated (Drageset et al., 2010). Therefore the question becomes whether their ‘acquired skill’ of managing distress would be maintained for continued activation through survivorship. The participants in this study were at a very early stage in their oncological process (pre-surgery) and as such had not yet encountered the demands of survivorship.

A further study in 2011 identified that most women found it difficult to accept their BC diagnosis given that they did not feel unwell. Participants in that study also found the task of facing uncertainty about the future beyond surgery to be particularly difficult to process (Drageset, Lindstrøm, Giske, & Underlid, 2011). The findings in the study pointed to the women’s appraisal of their diagnosis as a significant factor in post-treatment adaptation to BC. Confirmation of a BC diagnosis with a plan for subsequent treatment seemed to catalyse both significant change and challenge in coping skills for a woman diagnosed with BC. Diagnosis required the woman to accommodate her reactions to both the threat of mortality and a very real potential of survival (Drageset et al., 2011).

#### **4.6.1 Seasons of survival.**

Finding ways to support restoration of a fulfilling psychological existence leads to earlier work in the 1980’s by Mullan (1985) who from his personal experience of cancer proposed three seasons of cancer survivorship. The term ‘survivor’ was preferred by Mullan to replace the inference of pathology in the words “victim”, “sickness” or “cure” (Cheung & Delfabbro, 2016). Mullan identified survivorship as commencing at diagnosis when the person is called to rethink their

life and rapidly make a range of adjustments to it (Cheung & Delfabbro, 2016). The framework proposed by Mullan indicated the initial shift from an acute to a transitional phase, and then to extended survivorship (see Diagram 2). A conceptualisation of survival from cancer as a transitional process that one moves through rather than a potentially stagnant life phase was revisited by Miller and colleagues (Miller, Merry, & Miller, 2008). Both models categorised the initial (acute) phase of survivorship as predominantly a medical phase – a time when medical professionals are heavily involved in the person’s care. According to both models, when this phase concludes, survivorship begins. It is after that time the person experiences withdrawal by, or involvement with, the medical enclave of BC and breast care specialists (Miller, Merry, & Miller, 2008).



**Diagram 2: *Seasons of Survivorship***

(Mullan, 1985)

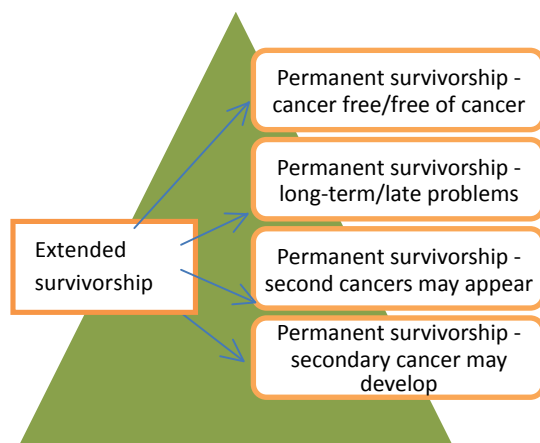
Mullan’s (1985) original model of survivorship was expanded to include a variety of states of longevity that survivors would encounter. The next figure (Diagram 3) illustrates an expansion of Mullan’s (1985) originally hypothesised seasons of survivorship. In this model, devised by Miller, Merry and Miller (2008), a permanent cancer survivor would transition through not three but four stages of survivorship that could include long-term remission from the disease.



**Diagram 3: *Revised model of Seasons of Survivorship***

(Miller et al., 2008)

In the transitional phase of the Miller, Merry, Miller (2008) model, the person moves from treatment to observation and monitoring of their emotional, social and medical adjustments. The extended phase relates to a ‘season’ in which a person may be monitored for recurrence or may be in complete remission from cancer. The addition of a fourth phase of permanent survivor would relate to the person who had survived cancer and was living cancer free or free of cancer but who may still encounter after-effects of treatment, and, of course, still lives with the uncertainty about development of second cancers. Characteristics of the fourth phase of permanent survivorship more accurately describe an anticipated, contemporary survival experience. Distinct categories of that permanent phase of survivorship (Miller et al., 2008) are shown in Diagram 4 (p.88). According to this representation of the seasons of survivorship a person in the third stage - extended survivorship – may then transition into four further, distinct categories that comprise the fourth stage of permanent survivorship.



**Diagram 4: *Seasons of Survivorship*** (Adapted from Miller et al., 2008).

In the light of 21<sup>st</sup> century improvements in cancer care, that include earlier detection and better treatment of the disease (van Londen et al., 2013) further consideration of the distinct seasons of survivorship has led to a contemporary perspective in which the term ‘cancer survivor’ is used to refer to a person living with the sequelae of the disease for the rest of life (van Londen et al., 2013). This definition from van Londen et al (2013) stands beside the previous work of Mullan

(1985) and Miller, Merry & Miller (2008) who defined permanent survivorship as a person who was eventually diagnosed as cancer free.

The perspective of the original models of seasons of survivorship has been echoed in the study by van Londen and co-researchers (2013) that promoted development of a multidisciplinary model of care for symptomatic BC survivors. A framework for cancer care proposed by these authors included routine screening for emotional as well as physical symptoms. Among other recommendations, these authors suggested the repertoire of post-BC care strategies be arranged to include non-pharmacological treatment options and psychosocial interventions that could support the expected increase in the population of BC survivors (van Londen et al., 2013). Consideration of non-pharmacological treatment options centres attention on the role of emotions in maintenance of beneficial quality of life, health behaviours, as well as adherence to healthcare routines.

Brien and colleagues (2014), guided by the framework proposed by Mullan in 1985, devised a survivorship program for a community-based oncology clinic in which care for the person begins as soon as possible after diagnosis. This more immediate activation of medical and psychosocial support for a cancer survivor is in contrast to Mullan (1985) and Miller and colleagues (Miller et al., 2008; Miller, 2009) who regarded the phase of survivorship as beginning only after medical treatment had ceased. One limitation of a proposed program for BCS was that initiating survivorship-focused visits in close proximity to diagnosis, and pre-treatment, may result in the woman having relatively little understanding of the reason, or need, for such a consultation. Authors of the report into that program highlighted that some cancer patients would not consider themselves survivors before medical treatment had begun (Brien et al., 2014). Optimal timing for offering support mechanisms would therefore be integral to successful outcomes both for a service provider as well as a cancer survivor.

#### **4.6.2 Self-blame and self-criticism.**

Every woman has a culture with uniquely personalised aspects that affect the way she will respond to life, particularly in the aftermath of BC. Previous life experiences, values, behaviours, socio-economic factors and personality factors each



affect the way an individual responds to BC (Mystakidou et al., 2008). Suggestion that what happens in the mind affects the body through the neuro-endocrine system presents a question about the likelihood of a mechanism by which psychological stress would increase the incidence of BC. For example, research in the field of psycho-immunology has demonstrated that an individual's psychology can exert a profound effect on their physiological processes (Diamond, 2010). However, reported findings from research with thirty years of follow-up provided "weak evidence of associations between high levels of self-reported psychological stress and subsequently increased rates of breast cancer ..." (Metcalf, Smith, Macleod, & Hart, 2007, p. 1064). However, if the psychological sequelae from having BC were to be found not to be uniformly negative across survivors of BC, this becomes an important factor in assessing how to support a woman BC survivor whose response to living with the aftermath of the disease is a state of masked or expressed fear, distress and uncertainty.

Fifty women being treated for a primary BC took part in a study in Portugal that explored vulnerability to distress from the combined effects of coping strategies and personality vulnerabilities (Campos, Besser, Ferreira & Blatt, 2012). In that study personality dimensions of neediness and self-criticism and their contribution to distress were examined. Findings from that study confirmed that both personality dimensions were risk factors for reactions of distress in women undergoing treatment. Neediness was, however, identified as the dimension more strongly associated with distress than self-criticism. The authors raised the point that this could mean threats to interpersonal relating would be higher for women exhibiting high levels of neediness. That threat was suggested to arise from potential associations with feelings of decreased, or little, support. In addition, Campos and colleagues highlighted a range of factors previously identified in research literature as associated with BC-related distress. Those factors included elevated levels of helplessness/hopelessness, anxious preoccupation, and low levels of fighting spirit.

Self-reproach may mean attribution of blame to personal failure to monitor and reduce stress levels prior to diagnosis. The relationship between self-blame, a capacity for self-forgiveness, and quality of life in women with BC was the subject of a study of one hundred and eight women in an out-patient breast cancer clinic

(Friedman et al., 2010). The results indicated that self-blame could be linked to mood disturbance and this could indicate poor adjustment to living with BC.

Self-criticism may also reflect a perception that the cancer is a result of the body 'letting me down', or that some recipe for wellbeing has been inaccurately interpreted (Dodds, 1999). A tendency for self-blame can revolve around a personal conclusion reached that BC was 'allowed' to develop (Galgut, 2007). Negative self-appraisal has been found to be further exacerbated if, in recovery, a woman measures her progress negatively against what she perceives to be more rapid, more positive progress made by other women with BC.

Thirty BC patients took part in a study in the USA involving a total of 172 patients diagnosed with lung, prostate and BC (Else-Quest et al., 2009). The hypothesis examined was whether "perceived stigma and self-blame would be associated with poorer psychological adjustment" (Else-Quest et al., 2009, p. 949). Research into a looking-glass-self model and a learned helplessness model, found that self-blame was "consistently linked to poorer psychological adjustment in lung, breast and prostate cancer patients" (p. 959). In that same research self-blame was identified as having the capacity to facilitate the relationship between "perceived stigma and psychological adjustment" (p. 959).

An expected finding in research into stigma, self-blame and psychological adjustment was that feelings of self-blame were not universal among people with cancer. Some women attribute their disease to their own behaviours, to family history, stress, fate, or chance (Dumalaon-Canaria, Hutchinson, Prichard, & Wilson, 2014). In cases where a person attributed the cause of their disease to their own actions or to their internal state there is evidence of poorer psychological outcomes. Authors such as Else-Quest and colleagues (2009) concluded that for people with any form of cancer, emotional support may be beneficial where it is "directed towards reducing or alleviating both self-blame and adjustment problems..." (Else-Quest et al., 2009, p. 962).

In a study exploring self-blame and psychological adjustment to newly-diagnosed BC, results indicated that anxiety and distress were directly related to self-

blame at three time points (4, 7 and 12 months) post-diagnosis (Bennett et al., 2005). Using as a base, the hypothesis from Janoff-Bulman's earlier work on attribution of self-blame in the time immediately following diagnosis (Janoff-Bulman, 1992), Bennet and her co-researchers (2005) argued that in the first four months post treatment attributing blame for BC to her own behaviours was not identifiable as a protective mechanism against a woman's poor psychological adjustment to BC. What the study results indicated for the 115 women who participated, was that in the year following diagnosis, distress, symptoms of anxiety and symptoms of depression were able to be directly linked to behavioural self-blame (Bennett et al., 2005).

Characteriological self-blame with its concentration on identifying a flaw in one's personal characteristics was regarded, in the literature, as having a more fatalistic element than behavioural self-blame (Bennett et al., 2005). This form of self-blame was also linked to symptoms of depression in women with newly-diagnosed BC. One hypothesis explored in the Bennett et al (2005) study posited that in instances where aspects of self-behaviour could be identified as causative this would result in an eventual easing of negative psychological adjustment to BC. Where the source of a problem could be attributed to actions able to be modified in the future then the hypothesis is that when a woman with newly-diagnosed BC attributed blame for the disease to her personal behaviour then she would have more control over the future direction of the disease. To be more concise, the belief in the individual would be that self-management would mean eradication of whatever personal behaviour was active in causation (Dodds, 1999; Sheikh & McNamara, 2014).

It has been argued that around the seven-month post-diagnosis mark, recovery from BC would come to be perceived by a survivor as a situation that was "controllable and therefore changeable" (Bennett et al., 2005, p. 313). Although the authors of that research did recommend further research into attribution of both behavioural and characteriological self-blame over a longer term of survivorship, they were able to establish that in the first year post-diagnosis, perceptions of personal control over BC or recurrence of BC were not influenced positively by attribution of either behavioural, or characteriological, self-blame. This means that it is important for professionals who support women with BC to understand how

attribution of blame to oneself relates to emotional distress (Callebaut, Molyneux, & Alexander, 2017).

Among other risks to wellbeing, negative self-judgement has been linked to increased vulnerability to clinical depression (Zuroff, Mongrain, & Santor, 2004). In the face of research that has argued convincingly against the notion that specific personality factors predispose a person to developing cancer (Price et al., 2001), curiosity remains about the extent to which negative emotions may contribute to poor psychological outcomes during BC survivorship (Lebel, Rosberger, Edgar, & Devins, 2008).

A relationship with the self, characterised by harsh self-judgment and habitual self-blame and self-criticism, denies a woman the experience of loving and gentle acceptance of herself. This finding by Forti (2011) highlighted an important task to develop ways in which women, post-treatment for BC, can enhance their awareness of their emotional reactions, can understand the nature of how they relate with themselves and others, and review how they cognitively conceptualise the challenges they face (Forti, 2011).

#### **4.7 Emotional suffering and wellbeing in long-term survival**

Breast cancer quickly becomes a highly medicalised illness (Schaefer-Schiomo & Atwood, 2009) in which a woman's body becomes an extension of the medical system with which she joins in her quest for recovery. Choosing to enter the biomedical system means a woman with BC surrenders control of her body and may feel as though she maintains only a slender margin of personal autonomy (Dodds, 1999; Little et al., 1998). At the same time, a woman with BC remembers what it was like to be healthy. She may regret or resent that this is no longer the case and may wish for a return to their previous healthy state. In a study of sixteen Australian BC patients, Bitsika, Sharpley and Christie (2010) found that the women experienced significant challenges in sustaining previous lifestyle activities. In addition, participants in that study reported an experience of a sense of loss because of their changed body image.

Although psychosocial issues have been brought to the forefront of BC survivor care, long-term support may still drift into centering mainly on medical aspects such as detection of recurrence or of new primary cancers (Virgo, Katherine, Catherine, Carrie, & Craig, 2013). Undoubtedly, discussion about cancer-related concerns activates difficult emotions (Kaptein, et al, 2015). The role of many women as emotion managers within family and social relationships (Yoo, Levine, Aviv, Ewing, & Au, 2010) means that women post-BC, may enter survivorship with a legacy of believing they have a responsibility not to place additional emotional burdens on loved ones or close friends. The perspective that openness and articulation of one's fears about recurrence and anxieties about an uncertain future will have a negative impact on others

An investigation into psychological comorbidity and health-related quality of life in long-term BC survivors involving 1,083 women in Germany with a mean age of 61 years, reported "consistent lower quality of life in breast cancer survivors ... years after diagnosis and treatment" (Mehnert & Koch, 2008, p. 389). Another finding in the study from Mehnert and Koch was that while "a relatively high percentage of breast cancer patients (62%) participated in a cancer rehabilitation program in Germany to regain physical and psychosocial functioning" (2008, p. 389), they also found that a certain percentage of those women also accessed "other forms of psychosocial support" (p. 389). Of interest in the study is the finding that a relatively low number - approximately 24% - of participants engaged with "other psychosocial support offers or self-help organizations" (p. 385). Among myriad reasons for limited engagement in psychosocial support offered it may be that as women age and their socioeconomic status, personal confidence and mobility decreases, there may be less understanding of and provision for their particular needs from cancer support services.

In recent decades there has been debate about the concept of there being an identifiable 'cancer-prone personality' (Eskelinen & Ollonen, 2011; Skinner & Fox-Francoeur, 2013). A recent study has referred to research conducted in the 1980's in which women diagnosed with BC were reported to have used self-descriptive terms such as "calm, easy-going, non-assertive, timid, and holding back anger" (Graves et al., 2005, p. 580). The issue highlighted by Graves and colleagues calls attention to a

tendency for women to desire to be thought of as a good person, and in doing so, to actively deny, repress, or internalize negative feelings. The role of emotional expression was addressed in an internet-based study that found BC survivors “who reported low social constraints and evidenced higher emotional intelligence tended to report less distress” (Schmidt & Andrykowski, 2004). Therefore, indications are that women may suffer higher levels of distress where their model for emotional expression has been culturally or socially guided by prohibitions around observable displays of distress. In addition to avoidance of outward demonstrations of negatively perceived emotions, women may consciously engage in selective processing of their emotions as a way to cope with and try to avoid thinking or talking about their BC experience (Schmidt & Andrykowski, 2004). Understanding the implications of the contrasting findings in studies about the influence on wellbeing of what has, in the past, been called a ‘cancer-prone personality’, is important in order to establish any direct and indirect effect upon the mental health of aging survivors of BC.

In a study of BC survivors at 3, 6, 9, and 12 months post-mastectomy surgery, women who engaged in emotional avoidance at the initial baseline subsequently reported lower levels of quality of life 12 months post-surgery (van de Wiel, Geerts, & Hoekstra-Weebers, 2008). The implication of using emotional avoidance as a coping strategy is that avoidance of uncomfortable or distressing thoughts and emotions has a negative inter- and intra-personal influence that results in lower quality of life. Factors significant to life adjustment as a BCS indicate that a woman’s response to BC could be pre-determined by factors that include their capacities for help-seeking, their social and economic environment, and personal resources, in addition to the meaning they make of the stressful event of BC.

A link between BC and emotional inhibition, prohibition on expression, or repression of emotional expression was not supported in a more recent study by Bleiker, Hendriks, Otten, Verbeek and van der Ploeg (2008) who found that “no psychologic risk profile was associated with the incidence of breast cancer” (p. 216). Similarly, in their Netherlands-based study that tested for an association between incidence of BC and personality factors such as anxiety, anger, depression, and anti-emotionality, Bleiker, Hendriks, Otten, Verbeek and van der Ploeg (2008) again

argued that their study revealed no statistically significant associations between BC and the personality factors targeted in their study.

In terms of self and other relating, and personality factors that may predispose a person to BC, the effects of childhood experiences and the impact of those experiences on mental health, and particularly development of depression and anxiety, is worthy of consideration. Experiences of severe cases of child abuse have been found to persist over the longer term and continue on into older age (Sachs-Ericsson et al., 2010). For the BC survivor whose self-concept remains linked to abuse enacted on her in childhood, and whose self-esteem is low, there is the potential for that combination of factors to have a negative influence on the way the woman relates with herself and others, in addition to her susceptibility to develop depression and/or anxiety. The combination of low self-esteem and legacy of childhood abuse appear to predict negative outcomes in wellbeing (Sachs-Ericsson et al., 2010). Coming to terms with early life events appears to offer protection for the older adult against negative effects of those events. However, unawareness of child abuse and low self-esteem in the older adult mean early life factors that negatively effect mental wellbeing of an aging BC survivor could also have a detrimental effect on length of survival.

To continue with the argument about emotional expression, in some cases a woman may choose to re-position her physical and emotional experience of BC to the background of her awareness, and, instead, privilege a narrative with a central theme of activation of personal strengths in a very pragmatic way. What is of concern, according to Sulik (2011), is the drive to redefine BC as “something manageable ... and restore a semblance of normality” (Sulik, 2011, p. 77). The risk is a focus on cancer-care strategies that overlook a deeper understanding of exactly what bio-psycho-social supports assist survivors to feel less emotionally dis-abled by BC. This would be especially relevant for women who encounter a sense of loss of control of their self and their body as they age and therefore navigate a long life post-BC (Sulik, 2011).

Living with BC as a chronic illness brings direct, daily confrontation with issues such as anxiety, depression, threat of recurrence, body image, death anxiety,

ageing, hope, empowerment, personal agency, in addition to the relationship with self and others (Livneh & Antonak, 2005). One argument put forward posits that the root of psychopathology can be found in personal confrontation with overwhelming emotions where the person experiences a felt sense of aloneness (Fosha, 2009). This argument leads directly to issues related to the negative and positive impact on long-term BC survivorship that then become critical factors in thinking through the multifactorial emotional experience of BC.

In the research literature some findings caution against the attraction to identify any “symmetry between personal characteristics and health” (Sloan, 2011, p. 897). Stating that “there is no relation between cancer and emotional wellbeing”, Sloan (2011, p. 897) commented on a historical tendency to link, in some instances, biological illness with mental health. What the findings in studies on personality factors and health from the last thirty years indicate is that the concept of a cancer-prone personality continues to be debated, and either contradicted, supported or questioned (Bleiker et al., 2008; Zozulya, Gabaeva, Sokolov, Surkina, & Kost, 2008). Research that gathers the perceptions of BC survivors themselves would be expected reveal valuable information applicable to survivors’ beliefs about causes and preventability, as well as extend observations of researchers about hypothesised connection/no connection between emotional functioning and perceived risk of cancer.

A growing body of research has been dedicated to the impact on health of negative emotions, and the contribution of depression and anxiety to poor health outcomes (Kiecolt-Glaser et al., 2002). Mitchell, Murray and Hynson (2008) argued that “when illness strikes, the person remains the same whole person, yet somehow everything is changed” (p. 80). Living with BC means personal distress can oscillate and escalate; attempts to generate sustainable optimism can become a daily challenge (Worden, 1989). Research in the field of positive psychology now focuses on affirmative emotions and the part that having a positive relationship with one’s self can play in immune functioning and health (Dodds, 1999; Kiecolt-Glaser et al., 2002; Segerstrom, 2010).



The reports gathered from personal consultations with women with BC, as well as from women participating directly in this study, were in line with findings in an investigation by Panjari, Davis, Fradkin and Bell (2012) which found that many women held the belief that “stress has contributed to their condition” (p. 725). An earlier 2001 survey of BC survivors in Canada had already revealed that 42% of women considered stress as the underlying cause of their BC. Another finding from that survey of BC survivors in Canada was that lack of recurrence was attributed, by 60% of participants, to having a positive attitude (Block, Dafter, & Greenwald, 2006, p. 123).

#### **4.8 Self and other relating**

A chronic illness refers to a health-related condition that can exist for an entire lifetime with considerable implications for the person’s relationship with their body and sense of self. In addition, the person’s ability to relate with significant others can be changed considerably (Kenen et al., 2003). When surgical removal of one or both breasts is medically indicated for BC this confronts a younger BCS with the dilemma about whether her partner will still find her attractive (Katz, 2011). People living with a chronic illness such as BC are often required to manage a range of symptoms or conditions that result from their diagnosis (Lindsay, 2009). It is the management of the condition or the range of symptoms that can significantly interfere with self and other relating.

##### **4.8.1 Self-relating.**

Significant others in a woman’s life may communicate to her that something she has either done or not done has led to the disease invading her body. This means responsibility for recovery from BC may be a burden a woman feels she alone must carry (Dafter et al., 2006). However, any attempt to apply uni-causal or overly self-critical thinking to reasons for this diagnosis ignores the complexities of reality, and may overlook any contribution by ‘ecological or biomedical realities’ (Dafter et al., 2006, p.125). Ecological or biomedical realities are not topics for deeper investigation and further discussion in this study, however, both are acknowledged as important considerations a BCS explore in the search to establish identifiable links for her diagnosis.

The crippling inhibitory affects of shame and guilt, and the relationship these have with attachment styles have been discussed, in part, in the light of client resistance to experiencing feelings from early faulty attunement with significant others – usually occurring during childhood (Neborsky, 2003, p. 294). Shame has been identified as a self-conscious emotion characterised by the feeling of distress experienced in response to a personally-perceived lapse, failure, indiscretion or misbehaviour (Candea & Sventagotai-Tatar, 2014). In writing about the transformation of human suffering, Young-Eisendrath (2008) has commented that “much of our suffering originates with our sense of separateness and fear, through our evaluations of ourselves and others” (p. 543). When the evaluation of self is relentlessly negative emotional suffering is exponentially increased.

While shame is a multi-faceted emotion with several possible intrapersonal origins, feelings of shame have been said to arise in the individual as a direct result of supposed public exposure of a personal action or experience (Combs, Campbell, Jackson, & Smith, 2010). However, the reasons for self-blame taking hold in the psyche of the BCS are more complex than simple attribution of negative self-evaluation and self-blame. In connection to the self-relationship for cancer survivors, internalisation of perceived stigma, self-blame or excessive self-criticism have been found to be negatively correlated with recovery from cancer (Else-Quest et al., 2009).

Breast cancer is likely to produce less self-blame than other forms of cancer. In the social construction of BC, it is a disease that carries less personal and social recrimination than other forms of cancer such as lung cancer (Bell, 2014). By contrast, BC is a now common disease that has been ‘normalised’ as far as is possible. Despite this normalisation a certain percentage of survivors still question whether there was anything they could have done to prevent the disease. Lingering doubts about cause and preventability of their BC means the presence of an added risk of adverse physiological and psychological consequences because of the persistence of a heightened stress response (Charney, 2004).

Discussion of prevention of BC leads to consideration of correlates that have been drawn between high levels of shame and disordered eating in women who are

highly sensitive to criticism and low status (Goss & Allan, 2009). It is plausible that a woman whose dietary habits are identified as a risk factor for BC, who is also self-critical, and sensitive to criticism may experience high levels of shame. Self-critical thinking has been identified as comprised of a tendency to ruminate, habitual self-criticism, and inhibition on expression of negative thoughts and emotions (James, Verplanken, & Rimes, 2015). Negative self-relating in the form of eating pathology has been addressed in this literature review in the section relating to self-compassion.

Post BC, self-doubt and self-criticism can activate a vicious cycle that generates over-optimistic demands on the self for a woman who experiences depression (Kempke et al., 2011). The findings from that study have relevancy in terms of a woman's recovery and experience of survival. That relevancy is related to the implication that a woman's recovery process is something she may view negatively by measuring herself against an internal perception that other survivors are making more rapid, more positive progress. She may also feel self-critical if her choice is not to take advantage of any of the range of psychosocial interventions such as behavioural programs, psycho-educative options, peer support groups, or complementary therapies such as art, music or dance. It could be surmised that women diagnosed with BC who choose not to avail themselves of routine medical treatment may result in her having to absorb, from others, negative responses about her choice. The outcome may be an increase in self-doubt and self-criticism that could go unattended.

Questions about the nature of the self-relationship give rise to the idea that SC as a skill for life could potentially mean that women BC survivors develop an identity that is able to maintain a sense of perspective in relation to personal suffering (Neff & McGehee, 2010). For women who experience increased and prolonged levels of negative affect, a congruent self-relationship based on a self-compassionate way of being with oneself could contribute a positive sense of meaningfulness for long-term EWB. Meaningfulness and flourishing in life relate to positive wellbeing ideally arise from an innate sense of self-worth and value of self post-BC, rather than from a sense of obligation or duty to others who want them to be well.

Friedman et al., (2007) reasoned that a person with a capacity for self-forgiveness or who engages in interventions focused on facilitation of self-forgiveness can activate a mediating dynamic that can foster healthy adjustment to living with BC. Neff (2003) had previously argued that adoption of a self-compassionate relationship provided a protective factor against emotional distress. In a study investigating self-compassionate self-regulation, individuals high in self-compassion were found to show less anxiety, and less depressed mood (Kelly, Zuroff, & Shapira, 2009). From this study, Kelly and her colleagues (2009) also suggested that people who were harshly self-critical and therefore impaired in their capacity for self-kindness could benefit from using positive affect to regulate their emotions.

An argument against making causal connections between negative personality traits and poor health conditions has been proposed by Sloan (2011). While Sloan's argument is an important one in relation to the dilemma of self-blame and cancer, to promote women's understanding of SC would provide the potential for them to activate, in a self-caring, non-critical way, personal resources. It is those personal resources that have been identified as helpful in developing greater capacity for self-nurturance and to alleviate symptoms of intra- and inter-personal distress, mood-disturbance and other health-related challenges that result from emotional distress (Dodds, 1999; Friedman et al., 2010).

Factors relevant to the relationship a woman has with herself need to be intricately explored to ensure that any reported decrease in episodes of depression and anxiety are not interpreted in such a way as to lead to underestimation or obfuscation of what happens psychologically for women post-BC. Less visible, but nevertheless critical is the need to understand existential concerns and offer appropriate support. Issues such as persistent concerns about the future, fears of disease recurrence, existential questions, increased levels of self-criticism, loss of hope, existence within a liminal space between who they were and who they are becoming, and the demand to maintain optimism, remain strongly associated with BC. What recent research has pointed to is that emotional support for women with BC must take into consideration both interpersonal and intrapersonal challenges.

#### **4.8.2 Other relating.**

In studies relevant to adjustment to a cancer diagnosis the focus is often on the perspectives and impact on the person diagnosed. This means that the experience, and contribution of the partner or family member to a survivor's adaptation to cancer can be overlooked. Women survivors of BC have close relationships with family members as well as with social networks. Many studies were focused on the impact of BC on married or committed, intimate relationships or on the effect of BC on external relationships such as the relationship a survivor has with the medical professionals (Wolf, 2015). While acknowledging the existence of a range of other significant, non-coupled, supportive relationship in the life of BCS, literature reviewed for this section will look through limited lens. Partners and families that encounter BC are challenged to find a collective language through which they can communicate with each other and the 'outside' world about what they are experiencing and how they are coping (Wolf, 2015).

Research leaves little doubt that management of a disease such as BC means the illness itself becomes a 'unit' to be integrated into the life of a couple or family. For the person diagnosed, energy for relating with a partner or family members may need to be redirected to cope with treatment and to relate with the processes that offer survival (Dizon, 2009). BC brings to couples and families a range of urgent profound decisions that can influence the direction of treatment or can shape the form of interpersonal relating. A woman's emotional wellbeing, relationship satisfaction and resumption of sexual expression can be influenced by the perception she forms of her partner's reactions to her post-BC (Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005).

The strength of interpersonal connection in committed pre-treatment relationships are confronted and challenged by the stamina required to navigate an unanticipated experience of shock, loss, identity reconstruction and redefinition (Navon & Morag, 2004; Worden, 1989). A study that reviewed video-taped psychological therapy sessions (among other measures) of thirty-three couples as a way to explore and understand the process of interpersonal forgiveness (Woldarsky Meneses & Greenberg, 2014) found that contrary to literature that views shame as a collapsing in on oneself, shame could have an adaptive function in reparation of

emotional disruption between partners. The process identified by these authors centred on the partner guilty of a transgression taking responsibility to reflect on suffering they had caused to a significant other as well as understanding that causing hurt to another causes hurt to self. Activation of empathy from the injured partner, and regret from the injuring partner, has been shown to foster a ‘softening’ in communication and approach-ability between the partners and is likely to result in them feeling re-connected with each other. This could mean the couple avoids becoming polarised and each regarding themselves as victim in the conflict. The notion of shame as an adaptive resource could be an important concept to embrace in provision of psychological support for BCS especially in working with distressed couples in their attempts to cope with the changes foisted on them by BC.

Distress generated by a diagnosis of having a chronic, life-threatening illness is felt not just by the person with cancer; distress is likely to also be experienced by family members of the person diagnosed and treated (Harris et al., 2009; Wolf, 2015). BC as an illness robs families of control over their lives and the family’s future. An individual’s response to forced change influences the way they interact with those around them (Mitchell et al., 2008). Therefore, coping strategies adopted by a BC survivor will also have an effect on partners and other family members. Couples will find that communication from the BCS (to their significant others) may be replete with language about control, survival, and the need for things to return to a pre-cancer normal (Wolf, 2015). After the personal dislocation as a result of BC, what takes place in survivorship is a prioritising of what holds greatest importance in life (Dodds, 1999). Family members close to the diagnosed person can in turn respond from their own sense of loss, as well as in reaction to changes in the relationship (Mitchell et al., 2008).

Using the BCSs perceptions of their partner’s reaction to their recovery from their cancer experience, data was gathered from 110 women who completed questionnaires that requested responses about their partner’s adverse reaction to scarring, sexual functioning, marital satisfaction, emotional distress and psychosexual adjustment (Wimberly et al., 2005). In that study, reciprocal relationships were found between variables in the study. The findings led to the conclusion that a partner’s emotional and sexual interest could be regarded as

precipitating the same response from the BCS. This means that when a BCS perceives a partner has a positive orientation towards her, and she also has a perception of sexual interest from her partner, as well as sensitivity in the partner to resumption of sexual expression within the relationship, then a survivor would be expected to enjoy greater satisfaction in the relationship post-BC (Wimberly et al., 2005) In regards to what assists the sexual relationship in a couple where one has BC, research indicates that the importance of the sexual relationship lies in the ‘perception of the partner’s desire for closeness and intimacy, rather than the sexual act itself’ (Wimberly et al., 2005, p. 309).

Access to appropriate treatment may bring with it financial strain that places an unexpected burden on the couple or family (Sperry, 2010). The nature of how women relate with their spouse or family and couples may also influence decisions they make in thinking about the financial cost of health care (Sperry, 2010).

#### **4.9 Stress, breast cancer and relationship**

Stress has been said to be experienced when feeling isolated from others and when a sense of dis-equilibrium invades a person’s innermost ‘world’ (Rybak & Decker-Fitts, 2009). As a result of that disruption to a sense of emotional balance, thoughts, actions and behaviours can form in response to that stress in an attempt to resume a feeling of equilibrium once again. Gaining the capacity to increase awareness and presence to stress in our lives has been identified as a key contributor to mental wellbeing (Cozolino, 2010). Being able to access and build on positive emotions and positive memories in times of stress has been said to lead to optimism for one’s lifestyle (Rybak, 2013).

Even without the added strain a BC diagnosis introduces, stress has been cited as posing a risk for couples’ relationships. Relationships suffer when stress affects the psychological functioning of one or both partners and its affects result in downward changes in psychological and physical aggression, the way a couple communicate with each other, and the level of their satisfaction with the relationship (Falconier, Nussbeck, Bodenmann, Schneider, & Bradbury, 2015). Falconier et al conducted their study with couples in Switzerland to examine “the ways in which stress from daily hassles affects partners’ individual and psychological and physical

wellbeing and their couples' relationship" (2015, p. 222). The results of this study indicated that assessing for major external stressors that negatively affect partners' stress levels and capacity to cope is an important part of therapeutic work with a couple whose relationship is in distress.

Relationships require effort – and they can bring stress and distress. The findings in the study by Falconier et al (2015) hold important implications for couples coping with BC because the nature of their relationship can offer a secure and supportive emotional environment that is helpful for the person diagnosed to regulate emotional distress. Conflictual communication within a relationship has been found to interfere with regulating emotions (Weihs, Fisher, & Baird, 2002). Much of the 'management' of the after-effects of the disease is likely to take place in the home even if the partner of the BCS is not directly involved in ensuring compliance with health behaviours or treatment adherence (Weihs et al., 2002). An example of conflictual communication would be if one person in the relationship exhibited a highly critical style of communication to their BC partner. This style of interaction may lead to polarisation or covert/overt hostility between the couple that in turn can lead to feelings of isolation and being unsupported in a BCSs quest to stay well, positive and optimistic.

The demands of multiple roles in which a woman functions has been cited as a factor that must be considered when reviewing women's susceptibility to stress that may instigate "mechanisms of diseases that result from allostatic overload" (Groër, et al., 2010, p. 185). Groër and her colleagues in the Women's Health Research Group at the University of South Florida College of Nursing highlighted that "the unique stressors experienced by women that are related to gender, social status, role, and development, along with differing responses to stress, gender-specific coping processes, and women's unique vulnerabilities to certain illnesses" (2010, p. 183) place women at risk. Evidence has pointed to that risk becoming exacerbated when allostatic load requirements are disproportionate to the ability of the body's systems to cope.



#### **4.10 A new beginning**

Elements identified in research on power and regaining control for BC survivors (Lawn, Delaney, Sweet, Battersby & Skinner, 2015), patient empowerment and activation of “fighting spirit” (Bulsara et al., 2004; Bulsara, Styles, Ward & Bulsara, 2006), willing acceptance of inevitabilities on the path of treatment and survival (Bulsara et al., 2004), as well as patient understanding of their own needs and skills (Holmström & Röing, 2010) all form part of reclaiming personal autonomy and effective adaptation to living with BC as a chronic illness. Other studies have focused on coping and post-traumatic growth (Bussell & Naus, 2010), lifestyle changes (Bitsika et al., 2010), living with chronic risk (Kenen et al., 2003), finding benefit (Urcuyo, Boyers, Carver, & Antoni, 2005), the capacity and ability to rise above a diagnosis of and impending death from cancer (Chiu, 2000), creativity and assertiveness to cope with the challenges of BC (Ziv, 2006), the benefit of applying mindfulness-based stress reduction techniques for overall wellbeing (Merkes, 2010), and, survivor loneliness (Rosedale, 2009). Mindfulness practice calls for awareness of our capacity for patience, acceptance, trust, openness, gentleness, gratitude and loving-kindness (Snyder, Pedrotti, & Lopez, 2011). It is important to note here that a central aspect of self-compassion is mindful awareness (Neff, 2003), and this has implications for the stability of psychological wellness post BC.

Change leads to stress, and BC has been noted as a major life change in cancer related literature (Frierson, Thiel & Andersen, 2006; Heppner et al., 2009; Tallman et al., 2007; Wu, Yang, Thayer, & Andersen, 2014). Breast cancer can herald new possibilities in life, just as it can also be a source of negative psychological change (Burke, Sabiston, & Vallerand, 2012). The outcome from explorations of BC survivorship as a source of richness for life and not as merely the basis of a sense of intense loss, would ideally be greater knowledge of how interventions can minimize internal emotional inconsistency and tension in regard to negative life events.

##### **4.10.1 Post-traumatic growth (PTG).**

Being diagnosed with and treated for cancer has been referred to as a traumatic experience (Tallman et al., 2007) that commonly generates intense emotional and psychological distress (Heppner et al., 2009; Worden, 1989).

However, cancer has also been described as an experience that has the potential to challenge a survivor's fundamental assumptions about life, generate greater interest in self expression and to promote personal growth (Tallman et al.). The potential for an individual to rebuild their life in a positive direction after stressful experiences is the central tenet behind the concept of post-traumatic growth (PTG) (Calhoun & Tedeschi, 2014). The essence of PTG involves positive responses in five key areas of life (Tedeschi & Calhoun, 1995). PTG is observable behaviourally through emergence in an individual of new attitudes, new behaviours, and a refreshed sense of self and one's capacities to overcome adversity. Cognitive evidence of PTG may appear when an individual is able to find benefit in the adversity faced (Huang & Gan, 2018).

When core beliefs about life are severely challenged, as in a diagnosis of BC, PTG can bring about a review or revision of previously held beliefs. A diagnosis of breast cancer brings with it an opportunity for growth – a catalyst for positive forward movement in the way a survivor relates with themselves and the world. While a BCS may be resilient enough to 'bounce back' following treatment, PTG may be something that takes more time and deeper reflection on relationships with self and others as well as spiritual beliefs. This means that in post-treatment therapy or counselling, PTG would be ideally introduced with sensitivity and appropriateness and an understanding of the uniquely lived experience of the individual survivor. To introduce the idea of positive growth too rapidly may be a message interpreted by a survivor as meaning their pain and suffering is being minimised or is invisible.

While most women accept that immediate medical treatment must be undertaken to reduce risk (Henman, Butow, Brown, Boyle, & Tattersall, 2002), post-treatment, women can change focus to one of taking control and maximising their own health outcomes (Dodds, 1999). A cancer diagnosis brings with it a focus on the negative aspects of the disease and its after-effects. However, contemporary research now informs public thinking that BC can herald a psychosocial transition for a survivor, with the very real potential for benefit-finding from a cancer experience (Avila, Coimbra, Park & Matos, 2017; Cordova et al., 2001; Danhauer et al., 2015; Tomita et al., 2016).

In their investigation of whether the journey into cancer survivorship could lead to “improved relationships, enhanced appreciation of life, increased resilience and self-reliance” (Lechner et al., 2003, p. 491) the findings indicate that stage of the disease, level of life threat, as well as continuing need for invasive medical procedures would have a negative impact on benefit-finding post-BC. Similar findings about factors such as survivor perception (Documet et al., 2012), disease severity, as well as level of actual vs perceived threat, may affect the capacity of an individual to experience personal growth or make meaning from their experience (Weaver, Llabre, Lechner, Penedo, & Antoni, 2008). However, with a significant number of cancer patients reporting “at least some positive changes or aspects of personal growth ... because of their illness” (Weaver et al., 2008, p. 771), the indications suggest that positive life benefits can be experienced as a result of a serious illness such as BC.

Analysis of research on positive psychological functioning (PPF) in women survivors of BC offers an important adjunct to studies that confirm negative psychological consequences as an outcome of BC. A review of 134 studies by Casellas-Grau, Vives, Font, and Ochoa (2016) revealed that the psychosocial environment of the BC survivor must be taken into account, in addition to medical and individual characteristics, so as to gain a complete understanding of positive functioning post-BC. These authors also cited the stage of the oncological process as a factor in understanding the relationship between the passage of time and PTG. There is also an argument, from this study, that “the link between the impact of cancer on one’s life and post-traumatic growth ... is connected to the increased personal reflection that patients may engage in when presented with a life-threatening illness” (Casellas-Grau et al., 2016, p. 163). Taking into account that time is a factor in the development of PPF and PTG post-BC, the study by Casellas-Grau et al (2016) offers valuable insight into differences in psychological outcomes between younger and older BCS. The way forward would be for the elements of PPF to be understood, accurately assessed and applied in the clinical practice of psychological support for survivors. Greater understanding of an emotional ‘roller coaster’ that the BC patient and BC survivor can experience as they move through their cancer experience may help diminish tendencies to weigh up outcomes of the experience through a single - or blurred – negative lens only.

One argument that remains controversial, is the one that purports that a positive evaluation of one's wellbeing would be predictive of longer survival post-BC. Caution has been noted that there are a differentiations to be considered in a number of factors, such as causality and types of subjective wellbeing, and physiological impact of intense states of positivity, before correlating happiness and enjoyment with longer life (Diener & Chan, 2011). Despite the caution, Diener and Chan (2011, p. 33) suggested that thinking of societal subjective wellbeing is "something that is indeed desirable and beneficial". The suggestion from these authors is relevant when considering the 'messages' women in general receive about BC from information packages and from their social interactions.

In a study exploring how, in Taiwan, women with terminal BC were able to psychologically transcend their diagnosis, Chiu (2000) found that participants had developed the capacity to embrace both their life and their death, and, through making meaning of their experience, felt they were able to move beyond rumination on the anticipated outcome of their prognosis. To a somewhat lesser extent than Chiu's finding, a study by Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, Lo and Wain (2007) nevertheless found that over seventy percent of their participants reported at least one positive change in their life following their diagnosis with cancer. Hodgkinson and colleagues also reported that the majority of survivors in their study experienced benefits despite a diagnosis that generates distress, fear and incrementally greater negative affect.

In further studies, self-report scales and a self-completed questionnaire has been used to evaluate the level of PTG and its relationship with sociodemographic, clinical and psychological variables in BCS (Romeo et al., 2017). The findings from the study suggested that the "presence of a significant other" can help BCS to more ably manage the traumatic event and "to find new meaning in life" (p. 318). Importantly for BCS the study also identified that a BCS may tend to view future possibilities negatively if they also experience others as demanding of them. What this study suggested is that depressive symptomology, or negative recollection of the trauma, may be more prevalent in women who have insecure attachment, or a dismissing attachment style. The case put forward by Romeo and colleagues does not, however, correlate with findings by Schmidt et al (2012) whose study argued

that PTG was unrelated to insecure attachment styles. What this indicates is the complex nature of resolving psychological distress as well as there being a desire to understand a time and space continuum for the development of PTG.

The capacity for PTG following diagnosis and/or treatment for BC has important implications for BC and for health professionals who support survivors' post-treatment emotional wellbeing. Significant amounts of research has charted the growth of PTG and its outcomes for BCS (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Danhauer et al., 2013; Groarke, Curtis, Groarke, Hogan, Gibbons, & Kerin, 2017; Mols et al., 2006). In relation to BC, evidence of PTG has been found through quantitative measures of how women experienced or created positive changes as a result of their experience. Some of those changes pertained to deepening relationships, an expanded sense of self, and closer association with meaning in life (Avila et al., 2017). An accurate picture of PTG means coupling quantitative data with the narratives of women's lived experience. To do so can provide a powerful and complete image of PTG and its place in adjustment to BC.

Not all women BCS will experience PTG; some will never question their beliefs or challenge their prevailing worldview in the aftermath of BC. Nor should health professionals expect BCS to have a capacity to open to PTG. It is possible that some women may experience PTG without the aid of any particular intervention (Danhauer et al., 2015). Some existential questions that a survivor is faced with may not be satisfactorily 'answered'. A futile search for answers to life's bigger questions may end up initiating another layer of emotional distress.

The variability in the impact of a cancer diagnosis on a particular woman's life, her level of social support, as well as a survivors subjective response to BC must be considered part of a multidimensional approach to considering who and how PTG develops. Furthermore, while PTG can result in reduction in levels and severity of depression (Cann, Calhoun, Tedeschi, & Solomon, 2010; Morrill et al., 2008; ), actual life improvements through PTG need be differentiated from misleading self-enhancing and self-protective statements (Tomita et al., 2016).

While research has been done on the correlates of PTG (Cordova et al., 2001) it is not always clear what helps and what hinders. Early research has pointed to optimism as a factor in positive psychological adjustment for survivors (Curbow, Somerfield, Baker, Wingard, & Legro, 1993). However, some current writers in the field of breast cancer have been more cautious about the risks to wellbeing from maintenance of an external veneer of optimism and positivity. BCS engage in a variety of coping strategies, and it is possible that what could be regarded by a survivor as positive change could possibly be a confusion with their uniquely personal effective coping strategies.

#### **4.11 Psychosocial interventions**

Psychosocial interventions post-BC are ones shaped by the interaction between psychological and social factors. Treating physical aspects of BC without consideration for the psychological and social impact of diagnosis and treatment is an incomplete response to the needs of survivorship. Interventions that offer women survivors of BC access to psychological support that can integrate different aspects of themselves into a coherent inner dialogue / narrative through, for example, the use of mindfulness and art, that could be expected to produce a sense of personal resonance through the artefacts created and having time to develop a re-visioned self. From a social constructionist perspective it is acknowledged that people and their perceptions are not static, nor do they exist in isolation.

Women with BC have been reported to demonstrate the largest proportions of positive psychological adjustment and physical health through a time span of 4 months to 4 years post diagnosis (Stanton, 2012). Despite an optimistic outlook for positive psychological outcomes post-treatment, there are some BCS who find themselves left without effective methods for addressing their experience. To summarise, while significant numbers of BCS can expect relatively stable and positive functioning in recovery over time, other survivors experience compromised psychological functioning (LeRoy, Shields, Chen, Brown, & Fagundes, 2018).

There is significant evidence to support the inclusion of psychosocial interventions to complement biomedical measures as a means of improving the quality of life for women who have had BC (Stanton, 2012). A number of different

psychological and theoretical models have been the basis for development of potentially appropriate psychosocial interventions in cancer care. In particular, interventions that concentrate on reduction of psychological distress after treatment completion, as well as minimisation of persistent stress for female BCS, have been the source of recent investigations in a range of research studies (Ahmed, Marchand, Williams, Coscarelli, & Ganz, 2016).

Therapeutic strategies and approaches that have been included as part of the process of recovery from cancer include camera therapy (Dennett, 2009), supportive-expressive group therapy (O'Brien, Harris, King, & O'Brien, 2008), a couple-based intervention (Baucom et al., 2009), cognitive-existential group psychotherapy (Kissane et al., 2003), mindful exercise (Tacon & McComb, 2009) dance/ movement therapy (Dibbel-Hope, 2000), and writing (Thompson, 2006). In addition, Art Therapy presents art making as a therapeutic process that challenges models of therapy that are pathology or problem focused (Springham, 2016).

Difficulty or inability to express emotional distress has been cited as a potential negative influence in achieving positive health outcomes for a post-treatment cancer patient (Forti & Cashwell, 2012). In the report of their findings, Hegel et al (2006) highlight women newly diagnosed with BC may feel inhibited about discussing or seeking support for their emotional distress. The findings from that study indicated that assessment for emotional distress and psychiatric disorders is critical to evaluate impairment to emotional functioning. This would ensure interventions offered were appropriate for the individual need of the BC survivor. The key ingredient would be help for acceptance of negative emotions and suffering and development of the ability to create distance between thoughts and feelings and the person themselves (Köhle et al., 2017) Findings from a web-based intervention for partners of cancer patients indicate that participants experienced the intervention as helpful for accepting negative emotions, for practice of self-kindness and for clarification of values based on difficult recent experiences (Köhle et al., 2017). Therefore, the importance of integrating psychosocial care within the regime of routine oncology care cannot be overemphasized.

The benefits of a mindfulness intervention for distressed women with BC was

tested by Monti and colleagues (2013). After assessing levels of psychosocial stress and quality of life, 191 women were randomly assigned to two groups: one group to receive psycho-education about stress and quality of life for BCS and the other to take part in a mindfulness based art therapy (MBAT) intervention. Both groups of women were offered an 8-week program of identical time and duration. Immediately following the completion of both programs results showed similar positive gains in terms of improved levels of both stress and quality of life measures. Follow-up at 6 months, however, indicated gains made in terms of self-regulation were more sustained and secure in the MBAT group than for women who received the educational intervention (Monti et al., 2013). In their report on this study the authors highlighted the pairing of art therapy and mindfulness as particularly beneficial. The mindfulness component of the MBAT sessions aimed to support greater self-awareness and relaxation. Combined with an art-therapy component this “offered a non-verbal mode of processing and expressing the stressors that are being observed and re-conceptualized during mindfulness practice” (Monti et al., 2013, p.2573).

Participants in the MBAT intervention had an average age of 57 years, were primarily Caucasian, and for the most part presented with Stage I breast cancer. Approximately one third of participants reported high psychosocial stress on entry into the study. The youngest participant was 31 years of age and the eldest 87 years of age. Although the study confirmed that MBAT is a “feasible intervention” (Monti et al., 2013, p.2574), the broad range of ages may have resulted in outcomes that may not necessarily be accurate for specific age groups. Younger BCS have been identified as being at risk of higher levels of psychosocial distress than older BCS (Takahashi, 2014) and this means that testing of the intervention with specific age groups would provide a clearer picture of the difference between MBAT and usual breast cancer survivor group sessions. In addition, minority groups who may face multiple psychosocial stressors and disadvantage were not represented in the study by Monti and colleagues. Therefore, a study that addressed the needs of participants from racial or cultural minorities may clarify further the usefulness of MBAT with a broader range of BCS.

Defined as a psychotherapeutic intervention, Existential Therapy has at its core the concepts of “self-determinism, freedom of choice, personal responsibility, respect



for the individual, and the need for each individuals to find his or her own unique meaning of existence” (Eliason, Samide, Williams & Lepore, 2010, p. 88). Existential theory has considered universal questions for human existence that revolved around “the search for meaning, self and other” (Eliason et al., 2010, p. 89). The theoretical rationale adopts a philosophical line of enquiry about interpersonal relationships and the subjectivity of existence (Corey, 2015; McLeod, 2013). This approach to intervention was explored in the late 1990’s as a potential model of therapy for women with early stage BC (Kissane et al., 1997). Using a group therapy approach grounded in Existential Therapy principles to support BCS the findings indicated that Cognitive-Existentialist Therapy could offer a transformative experience (Kissane et al., 1997).

In the Kissane et al study seven groups of women (48 women in total) participated in twenty sessions of group Cognitive-Existential Therapy. Facilitated by two therapists, each session lasted for 90 minutes. Drawing on cognitive therapy techniques that emphasised the value of therapeutically-oriented homework, the applicability and efficacy of the model was tested in relation to six goals that together could offer “improved quality of life from participation in group therapy” (Kissane et al., 1997, p.32). In this study transformative experiences for participants related to identifiable, positive reconstruction of their self-relationship, their relationships with significant others, and with the outer environments with which the survivor interacted.

One outcome from the programs indicated that participating in the group provided a support for women to adapt more confidently to an uncertain and challenging personal future. One cautionary note identified in the Kissane (1997) study was that Cognitive-Existentialist Therapy would likely to be more appropriate for women in the early stages of BC and less useful with women who had metastatic BC (Kissane et al., 1997). In addition, therapists who met weekly with participants in this study had, in addition to a stated interest in psycho-oncology, a range of training backgrounds: psychiatry, psychology, nursing and social work. Each of the therapists was expected to establish and maintain group rules and to interact directly with participants. Although trained in the application of a detailed manualised process for the series of workshops, the potential for variance in active interaction with

participants remains. Participants were also given optimistic messages about “the benefits experienced by previous groups”. Being given such a message may have skewed results in a more optimistic direction than if participants had not been primed to the benefits of taking part.

The 1997 research of Kissane and colleagues was followed up in 2004 (Kissane et al., 2004). Using Supportive-Expressive-Group Therapy (SEGT) in a randomised-controlled trial with 227 Australian women with metastatic BC, Kissane and colleagues (2004) questioned whether SEGT held promise for enhanced survival post-BC. In more recent studies SEGT has been confirmed as a technique to foster openness and emotional expression and has been found to improve mood, relieve traumatic stress and improve quality of life. Additionally, the results of the study in 2004 concluded that “psychological care received from SEGT creates the environment in which greater compliance with anti-cancer therapy occurs” (Kissane, et al., 2004, p. 766). In this study therapist-facilitators of the group processes were required to be trained and experienced in group therapy, however, the authors have pointed out that in addition to skill in group facilitation, the therapist-facilitators were required to have knowledge of the cancer journey. To alleviate any gaps in facilitation Kissane and his colleagues used two therapists, one of whom had skill in group therapy facilitation and the other with understanding of oncology. The outcome of the group workshops could then be expected to result in facilitation of empowerment within group participants. Some limitations in SEGT groups remain: potential negative responses to a particular therapist-facilitator, transference issues (particularly if a therapist is not a survivor of BC), and challenges in translating workshops conducted within a research program into everyday clinical settings.

In a further study, Supportive Expressive Group Therapy (SEGT) as a psychosocial intervention for primary BC was also examined in 2002 (Fobair et al., 2002). Twenty women diagnosed with early-stage BC took part in a 12-week group intervention. Results of the study indicated that “a 12-week group intervention can help lesbian breast cancer patients to adjust to their diagnoses” (p. 433). What Fobair and her colleagues found was that an SEGT program resulted in reduction in traumatic stress, improved mood, lowered levels of self pre-occupation, as well as an increase in the capacity to experience contentment in the present moment (Fobair et

al., 2002). What these findings suggested was that the psychosocial support and psychological care available within an SEGT group “creates the environment in which greater compliance with anti-cancer therapy occurs” (p.766). Therefore inclusion of a psychosocial intervention such as SEGT alongside standard medical care could be anticipated to enhance quality of conformity with treatment regimes. While the study by Fobair and others included working with a group with culturally-defined parameters, if tested with Australian aboriginal women BCS, for example, an SEGT program may present varied results that speak to the specific challenges faced by this group of women.

Research that compared two psychosocial interventions - mindfulness-based cancer recovery (MBCR) and supportive expressive group therapy (SET) found that MBCR was “superior to SET for improving psychological wellbeing” (Carlson et al., 2016, p. 750). The outcomes from participation in MBCR groups pointed to beneficial results for participants. However, as in other research studies, there was a high attrition rate from groups that may have skewed results to a positive direction since complete data was obtained only from those who completed the programs.

Participation in support groups has long been encouraged as a beneficial way for women who have had BC to share experiences and activate their own resourcefulness as a way to attend to unique challenges they meet in survivorship (Boutin, 2007). Participation both in face-to-face and online contexts (for example: email, online BC forums, real-time SMS messaging) has been researched and found to lead to positive results. Findings from research into a variety of approaches to support emotional wellbeing after BC treatment have been found to offer “improved cognitive function, body image, future perspective and fatigue” (Björneklett et al., 2012), positive adaptation (Fobair et al., 2002), decrease in mood disturbance (Classen, et al., 2001) and positive changes in depressed mood (Schellekens et al., 2017) .

In another psychosocial intervention program Reeve et al. (2010) investigated life narratives of people with a diagnosis of terminal cancer. The authors of the study focused on two aspects of life narratives post-diagnosis. Referred to as “fracture” and “flow” (p. 179) these terms referred to life narratives that would reflect a person’s

capacity to integrate their illness into a “continuous life narrative” (flow), as opposed to a narrative that contained reports of the illness causing periods of profound disruption (fracture) (p. 179). The implication of the findings from this study was that post-cancer treatment interventions would be more effective and useful when designed to enhance a person’s “emotional capital” and re-connect the individual with their creative capacities (Reeve et al., 2010, p. 192 ). Participants in this study had a terminal diagnosis that set them apart from groups who had taken part in other studies such as SEGT and MBAT programs. A terminal diagnosis has been said to significantly compromise emotional wellbeing in a person receiving that news. The impending loss of a potential future could mean that time becomes critical. This means that a collapsed life span expectation could generate an interest in previously unexamined and intense experiences (Willig, 2015), as well as heightened interest in deeper exploration of one’s life narrative and the emotional high and low points of that narrative. Conversely, the optimistic survival rates of persons with BC may tend to support a trend in survivors toward an expectation of a return to life as it used to be.

Thirteen trials that involved 606 patients with BC were the subject of a systematic review and meta-analysis that investigated whether creative arts therapies could positively affect the experience of anxiety and depression in BC patients. In those trials arts therapies group that explored the effects of creative arts therapies on psychological outcomes in patients with BC used art, music, dance and movement. The findings led the researchers to conclude that arts therapies were appropriate, sensitive and flexible enough for the BC patient. That study identified a positive effect on reduction in anxiety, although no effect was discerned in relation to depression and quality of life measures (Boehm, Cramer, Staroszynski, & Ostermann, 2014).

An investigation designed to introduce women to expressive methods as a safe and positive way to express anger involved a three-day expressive therapies workshop (Rasmussen, 2014). The design of the research was based on the premise that many women find it difficult to acknowledge and express anger. Using Jack’s (1987) Silencing the Self Scale (STSS) Rasmussen (2014) chose to focus on exploration of a hypothesized tendency in women to withhold or silence thoughts

and feelings that would likely bring shame, condemnation or negative judgment from self or another. The research involved preliminary interviews, review of artwork and journals produced by workshop participants, as well as post-workshop in-depth interviews. The findings from the study by Rasmussen indicated substantial beneficial changes for participants across a range of themes identified from the initial interviews. Those themes included participant perceptions that regarded anger as a dangerous emotion, as well as acknowledgment of inhibition on expression of ‘real’ feelings.

Furthermore, Rasmussen (2014) found the use of expressive activities an effective intervention for self-acceptance of anger. That study also had a relevant and concomitant finding of the therapeutic value of group process in accessing and working with negative reactivity. Rasmussen’s research highlighted the effectiveness of expressive creative interventions in fostering safe emotional expression as well as creating greater emotional literacy and enhancing the value of increased self-acceptance.

In therapeutic work with trauma, art has been shown to produce a reduction in acute stress symptoms through non-threatening access to a non-verbal core of traumatic memory (Talwar, 2007). Talwar used drawing to combine cognitive/reflective domains with the affective/expressive domain because to do so appeared to aid client access to a non-verbal realm of imagery (Reilly & Cohen, 2008). Art therapy has been used in a variety of ways, in a wide array of contexts, such as cumulative trauma, with positive outcomes in research findings (George, & Pedersen, 2017; Morrissey, 2013; Naff, 2014). For example, creative arts processes have been used successfully in debriefing professional hospice workers (Westrhenena & Fritz, 2013). Arts-based processes have been found to produce therapeutic effects in the facilitation of communication, promote self-care, and improve wellbeing.

Maintenance of treatment adherence has been found to be negatively influenced by depressive symptoms in women with BC (Fann et al., 2008; Souza et al., 2014) with the risk of poorer adaptation and “poorer survival among more depressed cancer patients” (Manning & Bettencourt, 2011). Therefore research that

has identified interventions that place emphasis on the value of emotional regulation and emotional wellbeing can contribute positively to dissipation of depressive symptoms (Magai, Consedine, Neugut, & Hershman, 2007). This means that an intervention such as Supportive Expressive Group Therapy (SEGT), with its emphasis on “open and honest expressions of thought and emotions” (Fobair et al., 2002, p. 430) and fostering the “connection between the physical self and the psychological self” (Boutin, 2007, p. 268) could offer optimism for significant reduction in disease- and treatment-related psychological inability and morbidity.

Psychosocial interventions developed to alleviate distress in BCS have been argued as tools to improve psychological adjustment after cancer (Mens, Helgeson, Lembersky, Baum, & Scheier, 2016). Two key forms of psychosocial intervention are peer support groups or psycho-educative programs. Both of these processes have been found to offer positive short-term effects. However, the presence of long-term beneficial effects could not be established in the study by Mens and colleagues (2016). At 6 month follow-up, and after the interventions ceased, these authors found no evidence of ongoing benefit for BCS from the interventions.

Generalisability of results from psychosocial interventions to cross-cultural settings requires further scrutiny. In addition, the setting for psychosocial interventions requires further investigation. For example, some interventions have been conducted face-to-face in group contexts, whereas others have been conducted via technology such as the internet. Participants for studies into experiences of BC survival may likely be women who have a desire to offer caring support to others diagnosed with the disease. This means that the experiences of women who refuse treatment, who prefer not to participate in support groups, or are restricted from participation by demands such as work, family, geographic distance, or illness, may not be represented in findings presented. This means presentation of psychosocial interventions may not, in reality, be able to be accessed by a proportion of women with BC.

On the other hand, research into individual patient empowerment provides evidence that for a person diagnosed with cancer acceptance of one’s illness and maintaining hope were “crucial to their sense of empowerment” (Bulsara et al., 2004,

p. 251). Actions taken by a majority of participants in this present study mirrored the findings by Bulsara et al (2004) that shifting gears to adopt a “fighting spirit” (p. 253) was of critical importance and something persons with chronic illness could actively contribute toward survival. Further research is needed that can identify whether any particular psychosocial intervention is of use to strengthen an internally experienced and sustainable fighting spirit, or provide short-term benefit through feeling the support of and connection with other BCS. Therefore, the topic of what psychosocial support interventions have already been explored with BCS is important to examine in greater detail.

#### **4.12 Creative arts for personal enquiry**

Using expressive and creative arts in therapy has become increasingly popular in the field of health care (Boehm et al., 2014). With the acknowledged increase in BCS numbers there is a parallel increase in importance and urgency in helping survivors learn and develop skills that bring stress reduction, emotional soothing, as well as authorise an authentic self to find a place and voice within the lived world. Creative arts activity-based methods for personal inquiry and reflection may be “liberating and provide an openness of expression not readily available in the primarily verbal ... methods” (Moreno, 2005, p. 35).

Creative and expressive arts as a form of support for anxiety, depression and quality of life in BC patients is an approach to wellbeing the effect of which can be somewhat underestimated and not well understood (Forzoni et al., 2010). The intentions behind creative and expressive arts-based support is to offer ways of bringing order out of chaos, encourage the healing potential of a creative process and inspire personal and social change (Levine & Levine, 2011; Thompson, 2014).

An experience of creative-arts-based tools involves activities that can promote useful, effective, and creative ways of exploring pre-existing patterns of feelings, thoughts, and behaviours (Vianna, Mendes, & Bucci, 2013). The underlying intention behind creative arts as a strategy for emotional wellbeing and support is to offer a focused time for quieting the mind. An arts-based process allows a person to become immersed in the process of creation, and from that process be able to reflect

on what has been useful and what is no longer appropriate in the current way of being (Haltiwanger, Rojo, & Funk, 2011).

The outcome of personal enquiry offers a process that can help reshape identity and refresh self-creations. The process would involve use of various arts such as movement, drawing, painting, music, and expressive writing as tools to help a person reconnect with and participate in safe personal disclosure (Pearson & Wilson, 2001, 2009). The underlying principle in the practice of creative and expressive arts is the use of some form of creative process – often symbolic – as a method for externalising internal states. This means there is something the person can do or create and to which they can then, as the creator of the finished artwork, relate (Malchiodi, 1999; McNiff, 2004; Pearson & Wilson, 2009).

Creating art as part of a healing process, has been said to provide access to a broader range of the capacity for learning, communication, and resolution of distressing life experiences (Malchiodi, 1999). Cancer survivors have used art to express fears, tensions and illness, or as a way to celebrate having overcome emotional challenges with their health (McNiff, 2004). For example, Reeve et al. (2010) investigated people living in Liverpool (UK) with a diagnosis of terminal cancer and contended that post-treatment psycho-social interventions had the potential to be more effective and useful when designed to re-connect a survivor with their creative capacities. Use of a broad range of media such as expressive writing, creating an art image, or using miniature objects to create an image of a worldview, may at first seem unconventional. However, it means a survivor has at their disposal myriad ways to move beyond the limits of literalism, and embody the varied contents of their psyche. A new vision of themselves can then be shaped into affirmations of life (McNiff, 2009, p. 46).

Creative arts approaches for sustainable relief from depression has also been used in a formal study of therapeutic work with a woman described as “disconnected from herself, isolated from others, and detached from body sensation and emotion” (Coote, 2015, p. 180). The client presentation was such that the therapist regarded the client as lacking in self-compassion and self-nurturance. In long-term client work described by Coote (2015), creative processes such as art, movement, poetry, images



and drama became part of the approach to rebuilding connection with body and mind. The therapist's report of the work stated that through increasing connection with her body the client "was able to improve her ability to tolerate, make space for and attend to her emotional experience (p. 187). The enhanced integration in emotional, somatic and cognitive processing offered the client reconnection with a creative self. Importantly, the use of creative processes in therapy resulted in a more 'embodied' relationship with self. The intervention appeared to allow the client access to a way of living in which she was able to entertain trust in herself as well as practice self-reassurance and self-nurturance (Coote, 2015).

The inclusion of creative arts with BC survivors as a tool to further develop self-kindness and an enhanced self-relationship provides a non-threatening means for communicating sensitively through a method that can be altered in any given moment to match a person's need and feelings (Pearson & Wilson, 2009). Counselling interventions that combine and integrate the construct of self-compassion, practice of mindfulness, and the techniques of ET appear to offer potential to create interventions that support 1) positive change, 2) constructively re-ordering life, and 3) living with a sense of enhanced emotional stability 'in the moment'.

A central facet of personal enquiry using creative arts activities posits that involvement in activity-based techniques provides an individual with a visual "consequence of their own actions" (Thompson & Neimeyer, 2014, p.15). Creation of a "visual conceptualisation of their emotions" (Rasmussen, 2014, p. 20) helps a person creatively process thoughts and feelings in a visible form. Therefore emotions can be explored and discussed within a context that aids psychological development (Rasmussen, 2014). Use of imagery has been shown to be a highly effective support for emotional wellbeing (Hass-Cohen, Clyde Findlay, Carr, & Vanderlan, 2014; McNiff, 2004; Rogers, Tudor, Tudor, & Keemar, 2012). One motivation for using creative arts activities is the opportunity to foster greater self-acceptance through engagement with creative expression that provides a direct 'view' of an aesthetic product of the individual's own making (McNiff, 2009).

#### **4.13 Compassion and self-compassion**

Given that self-compassion is a central aspect of the thesis being reported in this document, a brief discussion relevant to the concepts of compassion and self-compassion has been included in the literature review. Self-compassion is discussed at length in Chapters 8 and 9 in terms of the relevance of the construct for counselling and counsellors.

The concept of compassion is well known but can also be misunderstood. As a desired human virtue the term ‘compassion’ may become confused with a notion of being charitable, or showing mercy and kindness. Compassion could be defined as a capacity ‘to be with in suffering’. Defined as “the feeling that arises in witnessing another’s suffering”, and as something that motivates an innate desire to help (Goetz, Keltner, & Simon-Thomas, 2010, p.351), a compassionate attitude has been referred to as “focused on caring, concern, tenderness, and an orientation toward supporting, helping, and understanding other[s]” (p. 352), particularly when we are faced with another person whom we sense is suffering or in need (Goetz et al., 2010; Post, 2002). Examples of this human tendency abound when viewed through the lens of natural disasters. Communities caught in devastating circumstances demonstrate their capacity to come together in a spirit of compassion and benevolence focused on the greater good.

Compassion provides an ideal starting place for exploring whether SC could hold significance for people diagnosed with BC. Contemplative traditions refer to loving-kindness as the strong desire for happiness for others (Desmond, 2016). Religious traditions such as Christianity, Hinduism and Buddhism each speak of compassion as the wish to relieve others' suffering. Buddhism in particular emphasizes the idea of compassion and loving-kindness and distinguishes between these two (Desmond, 2016). Loving kindness, in the Buddhist tradition, is regarded as “the wish of happiness for others” while compassion is regarded as a primer for taking action because it relates directly to “the wish to relieve others' suffering” (Lutz, Brefczynski-Lewis, Johnstone, & Davidson, 2008, p. 1).

Identified in research literature as the delicate task of being able to suffer with another, compassion involves the capacity and willingness to witness another’s pain

and adversity, and yet be willing and able to take action. That action involves offering support in a non-judgmental, non-threatening way (Goetz et al., 2010); Young-Eisendrath, 2008). Kagan (2014, p. 60) defined compassion as “the innate human capacity to understand another’s plight and to feel empathy for the person’s existential plight”. Similarly, Singer and Klimecki (2014) echoed the definition proposed by Kagan, regarding compassion as “a feeling of concern for another person’s suffering which is accompanied by the motivation to help” (p. R785). Definitions such as this focus attention on the potential of heightened awareness of another’s suffering to increase the experience of positive emotions such as gratitude and understanding (Rancour, 2008). Another way of reflecting on compassion is to consider it as a spontaneous emotion that arises from the individual caregiver’s spiritual reservoirs (Volpintesta, 2011).

Writing about the challenges of compassionate caregiving and the “precious necessity of compassion” Halifax (2011, p. 150) posited that “Empathy, positive regard for others, kindness, and insight form a basis for ... compassion.” However, use of those terms - ‘compassion’ and ‘self-compassion’ - runs the risk of moving into common and casual usage in daily dialogue (Collins, 2011). The risk then, is that casual usage of the terms ‘muddies the waters’ and the result is failure, individually, communally, and nationally, to be cognisant of the requirement to be with suffering in the context of intra- and inter-personal relationships.

Rather than taking the stance that receiving and extending compassion would be an all-inclusive, effective soothing balm for all human suffering, what needs to be acknowledged is that compassion has also been referred to as being a controversial concept not universally accepted as a useful self-guiding principle (Goetz et al., 2010). Fear of receiving compassion from others has been linked to vulnerability factors such as habits of self-criticism and feelings of depression (Joeng & Turner, 2015). Reluctance to discuss distressing experiences, or seek emotional support from others has been found to positively predict increased negative affect (Dupasquier, Kelly, Moscovitch, & Vidovic, 2018). Concealment of negative feelings or negative experiences means an individual may end up surrendering an opportunity to receive valuable social support. Furthermore, fear of receiving compassion from others may

mean that “psychological interventions designed to reframe distressing personal experiences” may not bring a desired positive therapeutic result (p. 509).

Deliberation of beneficial therapeutic effects of SC focused activities for assisting self-concealing clients requires consideration of the complex influences the concept has on an individual’s psychological and physiological wellbeing. Discussion relative to research into SC is therefore crucial to teasing out the disparate elements of how and why SC may buffer the relationship between distress and lack of self-kindness.

#### **4.13.1 Self-kindness and self-compassion.**

Associated closely with the theory and practice of mindfulness (Tang, Hölzel, & Posner, 2015), SC as formulated by Neff (2003), has been the core ingredient in studies researching SC and self-construal, reaction to self-related unpleasant events, relationship maintenance, smoking reduction, coping with academic failure, and alexithymia in women with BC.

Self compassion as conceptualised by Neff (2003), and Gilbert (2009) has drawn on traditions from Buddhist concepts and practices as well as the construct of social psychology (Karris & Caldwell, 2015). The capacity to be self-compassionate has been identified as useful to promote personal wellbeing (Kelly et al., 2009; Neely, Schallert, Mohammed, Roberts, & Chen, 2009) and has been identified as beneficial for both intra- and inter-personal relating (Neff & Vonk, 2009). It has been associated with reduction in anxiety and rumination, increased social relatedness and enhanced life satisfaction (Neff, Kirkpatrick, & Rude, 2007). Anecdotally, being self-compassionate has also been claimed as an effective antidote to characteristics of what has been called a cancer-prone personality.

Of interest for this exploration of SC and its relationship to living well post-BC is the finding that “compared to age-matched healthy women, BCS had favourable health outcomes, but greater role functioning concerns” (Ashing-Giwa et al., 2004, p. 409). The result of the findings by Ashing-Giwa and colleagues reflects the optimistic outcome for many women for complete physiological recovery from BC. The challenge for full recovery from BC is retrieval of a sense of ownership of body

and mind. Resumption of feeling in charge of your own life once more has been defined by van der Kolk (2015, p. 203) as “feeling free to know what you know and to feel what you feel without becoming overwhelmed, enraged, ashamed, or collapsed”. Self-compassionate relating offers a new focus for emotional recovery from BC. In their interpretation of self-compassion Neff (2003) and Neff, Kirkpatrick and Rude (2007) reiterated that letting go of habits of self-judgment and self-criticism offered positive adaptation to many life events from the past, especially those that leave a person with disruptive physical and emotional reactions.

#### **4.13.2 Fear of self-compassion**

An important aspect of any review of the literature on self-compassion is research that has brought attention to fear of self-compassion. Fear of self-compassion has been cited as having potential to exacerbate post-traumatic suffering (Miron, Sherrill & Orcutt, 2015). One way to alleviate additional emotional suffering and improve psychological wellbeing can be through encouragement of distress disclosure (Dupasquier et al., 2018). However, personal disclosure of distress is not every individual’s preference. For instance, a person high in psychological inflexibility, and who has developed a habit of control or concealment in relation to experiences that contain negative or difficult feelings, capacity for self-compassion may be subject to variability in mood or context (Dupasquier et al.,). Early attachment experiences, such as lack of parental warmth, and fear of activating memories of an emotionally painful childhood have been cited as influential in decreasing a person’s capacity to allow themselves to receive compassion from others (Gilbert et al., 2011; Joeng & Turner, 2015; Miron et al., 2015). This means that maintaining a façade of being strong, and any tendency for avoidance of feeling vulnerable can be mistaken as the way to avoid feeling weak, or being thought of as weak in intra and interpersonal relating (Joeng & Turner, 2015).

Fear of SC has been found to exist in a person who has a predominant obsession with something they are passionate about. It has been hypothesised that the person driven by a passion may fear being kind to themselves because that might mean they would fail to achieve the goal set for themselves (Schellenberg, Bailis & Mosewich, 2016). To fail may mean a heavy burden of self-shame. In self-relating, where there may be a negative view of oneself, there is likely to be a prohibition on

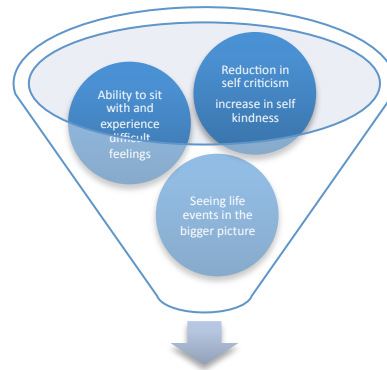
allowing compassion or kindness from others. That negative self-perception would therefore likely mean higher vulnerability to depression (Joeng & Turner, 2015).

What this means is that self-criticism can be positively associated with fear of self-compassion. Since SC has been identified as able to attenuate corrosive self-criticism, encouragement of practicing self-compassion would seem to be a positive direction for individuals who fear SC.

#### **4.13.3 Being mindful: A path to self-compassion.**

In a study that investigated the relationships between mindfulness, self-kindness, alexithymia and quality of life in stages 0 to III BC survivors, Forti (2011) found that “mindfulness was a significant predictor of quality of life but self-kindness and alexithymia were not significant mediators” (p. 88). Of particular relevance in her study, was the notion that “not surprisingly, mindfulness ... was positively related to self-kindness in breast cancer survivors, a positive construct.” Forti (2011, p. 93). Providing a “possible explanation for the positive relationship between mindfulness and self-kindness in breast cancer survivors” Forti (2011, pp. 93 – 94) went on to argue that women who had higher levels of mindfulness found it easier to be gentle and kind to themselves during difficult emotional and physical transitions.

SC is conceptualised as a way to conceptualise a healthy attitude towards one’s self that does not involve evaluation of self worth (Neff, 2003). SC is also said to involve being discerning and gentle with one’s self in the face of perceived inadequacies and failure. Reyes (2012) speaks to suffering as the antecedent to self-compassion. This author has reported that lack of self-compassion results in diminishment in the capacity for self-care, impaired relatedness, a reduced sense of autonomy, and decreased self-worth from feelings of self-hatred and shame (Reyes, 2012, p. 82). Acceptance that suffering, failure and inadequacy are a normal part of the human condition is a key aspect of the conceptualisation of SC (Berry, Kowalski, & Fleming, 2007; Neff, 2009). Drawing on research presented by Neff and others, a simple representation of the core concepts of self-compassion is presented in Diagram 5.



Ingredients in self-compassionate relating with self and others

**Diagram 5: *Essential ingredients for self-compassionate relating with self and others***

Recent studies across a range of contexts have included topics such as self-compassion, affect and health-promoting behaviours (Homan, & Sirois, 2017; Sirois, Kitner & Hirsch, 2015), the role of SC in procrastination and stress (Sirois, 2013), rumination, SC and mood (Odou & Brinker, 2013), relationship maintenance (Baker & McNulty, 2011), symptom severity and quality of life in mixed anxiety and depression (Van Dam, Sheppard, Forsyth, & Earleywine, 2011), self-regulation and smoking reduction (Kelly, Zuroff, Foa, & Gilbert, 2010), attachment, empathy and subjective well-being among college students and community adults (Wei, Liao, Ku, & Shaffer, 2009), PTSD symptom severity (Thompson & Waltz, 2008), and positive psychological functioning and personality traits (Neff, Rude, & Kirkpatrick, 2007). Overall, findings from these studies indicated a positive association between SC and emotional balance. Although the concept of SC has generated significant research into its application for a range of psychological and physiological issues, there remains a need for sustained research into the relationship between self-compassionate relating, self-compassionate interpersonal communication and risk factors and protective factors of BC.

#### **4.14 Self-compassion: Transformation and the self relationship**

Research into psychosocial adaptation to living long-term as a survivor of BC has been focused on the corrosive effect diagnosis, treatment and adaptation to BCS has on mental wellbeing and the physical and emotional suffering that ensues (Reyes, 2012). Understanding oneself and finding meaning and purpose in life experiences, having the capacity for self-care and gentle tolerance of personal experience of

difficult emotions, in addition to being able to extend kindness and gentleness towards oneself, all intersect to form Neff's (2003) construct of SC (Forti & Cashwell, 2012; Yang, Zhang, & Kou, 2016). SC is referred to as the practice of extending towards oneself the same care, concern and kindness afforded to others - especially when we make mistakes, and non-judgmental acceptance of oneself as human (Forti & Cashwell, 2012; Gerber, Tolmacz, & Doron, 2015; Sirois, Kitner, & Hirsch, 2015; Yang et al., 2016). To practice SC therefore requires acceptance, to some degree, that living a human existence may feel 'flawed'. To be self-compassionate stands in contrast to the fundamental processes for development of high self-esteem that positively associated self-esteem with adaptive outcomes to life events (Neff, 2011). Part of Neff's distinction between SC and self-esteem is that a person with high self-esteem may be resistant to enacting change within themselves. Self-esteem has been defined as "an evaluation of our worthiness as individuals, a judgment that we are good, valuable people" (Neff, 2011), and has been defined as a process of evaluation of ourselves, a judgment that we are good, valuable people" (Neff, 2011).

To consider whether SC could enhance the lived experience of women survivors of BC, the complexities inherent in factors that affect post-treatment emotional wellbeing need to be demystified. These factors include anxiety and depression (Andreu et al., 2012; Burgess et al., 2005; Miller & Massie, 2006; Montazeri et al., 2001), shock, self-blame and self-criticism (Bennett et al., 2005; Dafter et al., 2006; Else-Quest et al., 2009; Friedman et al., 2010), shame (Bell, 2014; Hill et al., 2011), stress (Nekolaichuk et al., 2011; Sperry, 2010), the process of returning to 'normal', post-treatment body image (Przedziecki et al., 2013; Zimmerman et al., 2010), personal psychological agency, sexuality (Fobair et al., 2006), as well as the way in which cancer diagnosis and treatment impacts on relating (Dodds, 1999; Sperry, 2010). In addition to the after-effects of BC, another related aspect considered in research was the relevance and importance of finding ways to encourage deeper understanding of an emotional and physical self, and the ways a BC survivor communicates with herself and significant others (Rosenblatt, 2006).



Training an individual to develop compassionate thinking has been suggested as a way to assist emotional regulation, resist a tendency for self-criticism, and promote personal experiences of contentment (Gilbert & Procter, 2006). Terry and Leary (2011) reported that the link “between self-compassion, self-regulation and health is likely to be mutually beneficial for two reasons” – self-blame and self-forgiveness (p. 359). Their investigation focused on the part self-blame and self-forgiveness may play in self-regulation and health-related behaviours.

Gilbert (2009) also argued that self-compassionate communication could stimulate affective responses that would complement a sense of encouragement and validation from a supportive other. What stands out is that “framing medical problems and their treatment in ways that foster self-compassion may enhance people’s ability to manage their health-related behaviour and deal with medical problems” (Terry & Leary, 2011, p. 352).

Conversely, Terry and Leary (2011) draw a distinction between negative affect and *harmful* negative affect, noting that particularly for BC, negative affect can be the medium for beneficial outcomes. The benefit referred to by these authors is that the experience of negative affect could provide a non-negotiable catalyst for a woman to more closely monitor her breast ‘health’, seek medical advice, or be proactive about early screening for BC (Terry & Leary, 2011). It should be noted that the most common method used in research studies to assess the quality of self-compassion in participants has been the Self-Compassion Scale (SCS) in its Short Form variant (SCS-SF) (Muris & Petrocchi, 2017). These authors conducted a meta-analysis of studies into self-compassion that used the SCS-SF and concluded that potential exists for an overestimation of the capacity of self-compassion to protect against psychopathology. To be specific, it has been argued that while therapeutic interventions with a self-compassion focus do improve positive affect, “they do not appear to decrease negative affect more than other interventions” (Muris & Petrocchi, 2017, p. 381).

In contrast to conclusions reached about assessment of SC and psychological wellbeing, a strong argument remains for becoming self-compassionate as a way to positively assist development of healthy self-perception and support subjective

wellbeing in the aftermath of a global personal crisis of BC (Neff & McGehee, 2010). Researching reaction to unpleasant events, Leary and colleagues (2007) highlighted the implications and benefit to psychological wellbeing of treating one's self in a kinder manner. Working with five groups of undergraduate students who received credit for participation, the Leary et al study investigated people's reactions to everyday events (Leary et al., 2007). From their investigation the authors concluded that emotional responses to experiences of "failure, rejection, embarrassment and other negative events" could be more evenly regulated through a self-compassionate attitude (Leary et al., 2007, p. 901).

Reduction in negative reactivity was linked in the study by Leary and colleagues (2007) to a capacity for SC "in the face of real, remembered, and imagined events and with patterns of thoughts that generally facilitate people's ability to cope with events" (Leary et al., p. 901). A significant finding from this study was that in instances of being able to be self-compassionate there was more often a willingness to "accept responsibility for their role in negative events" (p. 901). At the same time a person with a high level of SC was found to experience less rumination about unpleasant self-evaluations, or to "experience negative affect when confronted with their mistakes" (Leary et al., p. 901).

Self-compassion has been found to reduce episodes of emotional distress, enhance coping skills, optimism, and improve a sense of life satisfaction (Smeets, Neff, Alberts, & Peters, 2014). SC has been found to be confidently associated with positive changes in mental wellbeing (Neff, Kirkpatrick & Rude, 2007). In an investigation into positive psychological functioning in male and female undergraduate students a positive association was found between SC and self-reported measures of happiness, optimism and positive affect (Neff, Rude, & Kirkpatrick, 2007).

Factors relevant to the relationship a woman has with herself need to be intricately explored to ensure that any reported decrease in episodes of depression and anxiety are not interpreted in such a way as to lead to underestimation or obfuscation of what happens psychologically for women post-BC. Less visible, but nevertheless critical is the need to understand existential concerns and offer

appropriate support. Issues such as persistent concerns about the future, fears of disease recurrence, existential questions, increased levels of self-criticism, loss of hope, existence within a liminal space between who they were and who they are becoming, and the demand to maintain optimism, remain strongly associated with BC.

Self-compassion does not appear to be a concept that can be applied universally. In a study of the influence of SC in couples' dating behaviour, and a follow up study of SC in the relationships of newlyweds, Baker and McNulty (2011) identified that for men, a positive intrapersonal orientation to seek repair of ruptures in their intimate relationship was aided by an increase in SC. Conversely, relationships for men with a low level of attentiveness to their relational interactions were not only not helped by the concept of SC, but becoming aware of self-compassion was found to be detrimental to relationship satisfaction (Baker & McNulty, 2011). These authors concluded that in relationship, men who were self-compassionate were less likely to attend to disruptions within the relationship.

Reports from female participants in one study provided evidence that although SC was regarded as beneficial in personal relationship, females were "more likely to engage in [relationship] maintenance behaviours than men" (Baker & McNulty, 2011, p. 869). Relationship maintenance behaviours in women was reported by those authors to be independent of their level of SC. What the study was able to highlight was that self-compassionate women experienced "no declines in their satisfaction over the first five years of their marriage" (p. 869). Outcomes from the study by Baker and McNulty (2011) reflect a need to consider the specific psychological make-up of an individual and their capacity for SC. The reasoning is that if women automatically engage in relationship maintenance behaviours they may do so from an uncompassionate attitude toward themselves. This means a therapist would need to assess the sensitivity of an individual to overcompensating for others mistakes, their level of relationship distress, as well as their motivation to caringly address mistakes made within their relationship with themselves and others.

For women living with physical and emotional consequences of the after-effects of BC the anticipated personal outcomes from exploration and integration of

the practice of SC would be a stronger sense of self-efficacy fostered through self-understanding. SC would be expected to lead to a survivor having a greater sense of connection with their ongoing and changing needs throughout survivorship. The development of a more accepting, less critical, self-relationship would be anticipated to positively facilitate an enhanced ability to discern one's uniquely individual emotional, physical and spiritual needs.

#### **4.15 The body and self-compassion: Self-care and coming to terms with body changes**

Positive, or at very least, beneficial, life outcomes are not a universal experience among women post-BC (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009). Traumatic or emotionally wounding experiences are regarded as those that negatively influence healthy functioning of the human body. Recovery from BC is a 'two way street' that involves both mind and body, and both mind and body have been shown to interact in the process of emotional healing. What is important is the hypothesis that internal and unresolved emotional processes end up being disguised, but ultimately expressed, in the language of the body (Pert, 1997). Somatic psychology has also theorised about correspondence between physical and emotional dysfunction (Broom, 1997).

Research indicates that women with BC are particularly vulnerable to body image disturbances that can lead to long-term distress (Falk Dahl, Reinertsen, Nesvold, Fosså, & Dahl, 2010; Przewdziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-bilinski, 2013). However, BC patients who had undergone surgical treatment were the centre of a study by Collins, Liu, Schootman, Aft, Yan, Dean, Eilers, and Jeffe (2011). These authors pointed out that their original study highlighted that increased body image problems post-mastectomy were experienced at the six months stage when a woman may be struggling to cope with changes to her physical body and to the way her body functions. The recommendation from that study pointed to the benefits of involving women in decisions about surgical treatment for BC. In general, advances in recent years in oncological care mean a woman is more actively included as part of the team that decides on her options for treatment. Conversely, not all contemporary options for breast surgery are, however, available or appropriate

for all women who need to undergo a mastectomy or medical treatment for BC (Sherman, Woon, French, & Elder, 2017).

The image a person holds in their mind of what their body looks like and the attitude a person has toward their body has been said to be an important feature of self-relating (Berry et al., 2007) expression of emotions, identity and personal attractiveness (Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016). The attitudinal aspect of body image refers to how people feel about their bodies and is a combination of both physical appearance and physical functionality (Reboussin et al., 2000). In a study conducted in the 1990's with both younger and older people, it was found that, in general, women experienced greater levels of dissatisfaction with their bodies than their male counterparts (Tiggemann, 1992). Although body image issues have been reported as reducing over the lifespan, nevertheless recovery and restoration of a non-cancer identity for BCS can be compromised by a demeaned sense of value of her body to herself and to others.

A BC survivor is likely to experience observable body changes such as hair loss, changes in weight, discolouration in her skin and nails (Przedziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-bilinski, 2013). These changes will happen rapidly and negatively alter a woman's self-appraisal of her femininity and sexual attractiveness. In turn, less tolerance of changes to body image and personal attractiveness can lead to self-dissatisfaction. A study involving 279 Australian women BCS who had undergone surgical treatment explored the association between body image, self-compassion and psychological distress (Przedziecki et al., 2013). Statistical analysis of the results of measures used in the study established that body image disturbance reported by the women was consistent with previous research on the topic (Favez et al., 2016). One relevant study by has identified that women who were able to be compassionate to themselves were found to experience lower levels of distress from body image disturbances (Przedziecki et al., 2013). The indications from this study are that attending only to external body image may not be sufficient to support women BCS who either report distress, or who may have internalised distress, as a result of a changed body.

Self-compassion has been identified as a moderating factor in psychological distress that results from post-surgery psychological distress about body image (Sherman et al., 2017). In the study conducted by Sherman, eighty Australian women participants, 75 of whom had been diagnosed with BC, and five of whom had chosen to have breast surgery as a preventive procedure, completed measures such as the Body Image Scale, DASS-21, Impact of Event Scale, the Self-Compassion Scale – Short Form, and the Appearance Schemas Inventory – Revised. In conjunction with demographic and medical information these measures were analysed to gauge body image disturbance and psychological distress. The findings confirmed the association between greater self-compassion and lower negative self-evaluation, as well as pointing to the association between low self-compassion, high levels of investment in personal appearance, and heightened emotional distress from body image disturbance. An important feature of including self-compassion in support for BCS would be development of an appreciation of their body as unique (Berry, 2007).

For the BC survivor, the body that once was healthy becomes, post-BC unfamiliar and unreliable. Yet an undeniable paradox remains that even after the cancer is removed, the body that once housed (and may still house) the physical disease simultaneously houses the psychological self. This situation gives rise to reflection on how to facilitate reconciliation between these seemingly oppositional influences. As the body is gradually released from its burden of un-wellness, the psychological self must also keep pace with physical recovery.

#### **4.16 The contribution of counselling to emotional wellbeing and mental health**

The desire for wellbeing is a natural pursuit of humans (Rybak, 2013). Becoming mindful of how relationships with self and with others are created and enacted can be an important step in building positive mental health (Rybak & Decker-Fitts, 2009; Rybak, 2013). The accepted and unstated premise of counselling is that nurturance of positive thoughts and emotions are regarded as optimal for mental health (Forti, 2011, p. 90). The heart of counselling concerns itself with a personally-focused orientation toward human growth and wellbeing (Cochran & Cochran, 2015; Corey & Corey, 2014; Ivey, Ivey, & Zalaquett, 2016; McLeod, 2013).

Counselling has been identified as having a trusting, secure therapeutic alliance in which a client is respected, and the personal power they already have is recognised and responded to (McLeod, 2013). The alliance is one collaboratively created between therapist and client, and has been recognised as instrumental in facilitation of positive outcomes in therapy (Duncan, Miller, Wampold, & Hubble, 2010). What this means is that a sense of finding and locating a new vision of self can be created and fostered by the actions and intentions of two persons - client and counsellor. The success of those actions and intentions is directly influenced by the strength of the working relationship between the individuals involved (Duncan et al., 2010; McLeod, 2013).

Accurate identification of the disparate elements in a client's counsellor presentation requires attentiveness on the part of the clinician as well as knowledge and understanding of how people change (Duncan et al., 2010). Therapeutic approaches require proof of being supported, not just by theory, but through evidence that corroborates findings from research and practice, and bridges any potential gap between the two (Tal-Margalit, 2012). In this regard, confidence can be drawn from evidence that supports the effectiveness of mindfulness-oriented counselling with a range of presenting issues that include mild to moderate depressive symptomology (Fledderus, Bohlmeijer, Pieterse, & Schreurs, 2012). For the BC survivor it appears as though emotionally-focused counselling could offer help find the balance between the self they would love to be and the 'survivor self' they can accept and love.

Complex psychological effects related to altered body image, symptom management, communication about emotions, self-expression, and attitude to quality of life for women who have had BC, and for their families, requires understanding of the connection between body, mind and emotions (Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010; Dodds, 1999; Han, Grothuesmann, Neises, Hill, & Hillemanns, 2010; Salovey, Stroud, Woolery, & Epel, 2002).

To include SC as a positive adjunct in a counselling process in the response to BC-induced distress, attention would focus on how a woman may have already employed 'mentalising' tools to help a survivor of BC interpret, resist, or make sense and meaning of the experiences. Mentalising has been defined as awareness of and

being able to perceive one's own and others' thoughts and feelings. It is the process through which a person can understand and make sense of their experiences. Mentalising is also a capacity that brings understanding that other people have differing views (Bateman & Fonagy, 2013; Brüne & Schaub, 2012). While the skills of mentalising are usually regarded as a positive tool for managing emotional distress (Klimecki, Leiberg, Ricard, & Singer, 2014), what seems a logical outcome for a person who may have become over-identified with helping others is that the same skill of being able to focus on someone else's suffering may have potential to become a distracting defence mechanism.

Counselling appears to be a useful means to support a client's capacity for mentalising when they are under stress. A therapeutic method used to support individuals with borderline personality disorder (BPD), or antisocial personality disorder (APD) (Bateman & Fonagy, 2013), mentalisation, within a therapeutic relationship offers a temporary, but secure, (therapeutic) attachment experience, is a key element in effective therapy to help a client regulate distress (Springham, Thorne, & Brooker, 2014). A distinctive theoretical feature of mentalising is that the person counselled would be supported to develop the capacity to make inferences about their own and others thoughts and feelings. What can complicate the practice of mentalisation is that conclusions reached about one's thoughts and feelings or others' thoughts and feelings - may not always be accurate. In this regard, mentalising may be a 'skill' that seems to aid a person either not dwell on an illness experience, or alternatively, to manage symptoms and cope with existential concerns by suppressing any inner emotional chaos (van der Kolk, 2014). The risk of erroneous interpretation of mental processes can be reduced with the support of a trained counsellor.

Counselling is discussed in this section of the thesis to provide a framework for understanding helpful benefits of bringing order out of the personal chaos that characterises the BC experience. Further discussion of the relevance of SC for counselling as well as the implications for counsellors of SC are discussed in Chapters 8 and 9 of this thesis. Survival of BC and engagement in work with a professional counsellor initiates a process through which the person can reconstruct a traumatised self. The activity of counselling could be said to involve a self-catalysed



process of integrating conscious awareness into daily living. In consideration of the psychological repair needed after BC, the term self-catalysed has been selected because it would be the BC survivor who could bring conscious awareness and pro-activity to personal development beyond where it was pre-BC. This idea would be in line with a key element of a counselling process. Finding a new horizon of meaning within herself and about herself could emerge from the unmistakable turning point that BC presents.

The capacity to look beyond the immediate crisis prompted by BC and ascribe positive opportunity to the situation could be regarded as beneficial for healthy long-term adaptation. One argument is that when the normal order of life is disrupted, far from being unsettling, that same disruption could be viewed as something that forces a new sense of order out of chaos; a re-activation of individual resourcefulness and creative responding (Sturdy, Schwarz, & Spicer, 2006). While the authors of that study focused their research on the field of organisational psychology. Nevertheless, the primary idea of finding order out of chaos could be useful to assess application of that principle of order after chaos to BC survivorship. The initial step would require a BCS to be able to access, or be supported to develop access to, intrapersonal mechanisms that allow, or genuinely engender, creative and resourceful responses to life events.

#### **4.17 Chapter summary**

As an illness, cancer follows a trajectory different to other illnesses often not conforming to society's expected patterns of illness and recovery (Sattman-Frese, 2009). A well person can plan for the future, can have hopes and dreams. A chronic or life-threatening illness impedes that process. For women with BC, a future that could include death means their imagination can direct their attention, thoughts and behaviours to loss of hope and a sense of despair (Mitchell et al., 2008).

To develop a greater understanding of the emotional legacy of the disease and counselling approaches that could support development of effective responses to the psycho-social needs of women living long-term with BC, this review considered the ways in which women with BC experience self-criticism and self-blame, self-worth, shame, and self-acceptance. From the literature reviewed, there is evidence that,

overall, women desire a reconnection with their previously-established non-cancer identity. With its concentration on the individual's capacity for enhancing and supporting integration of enduring, positive changes in response to emotional challenges, this review explored whether a self-compassionate relationship that embraces balanced and compassionate attentiveness to the self and the body, could support a greater sense of sustainable emotional wellbeing in women living with BC.

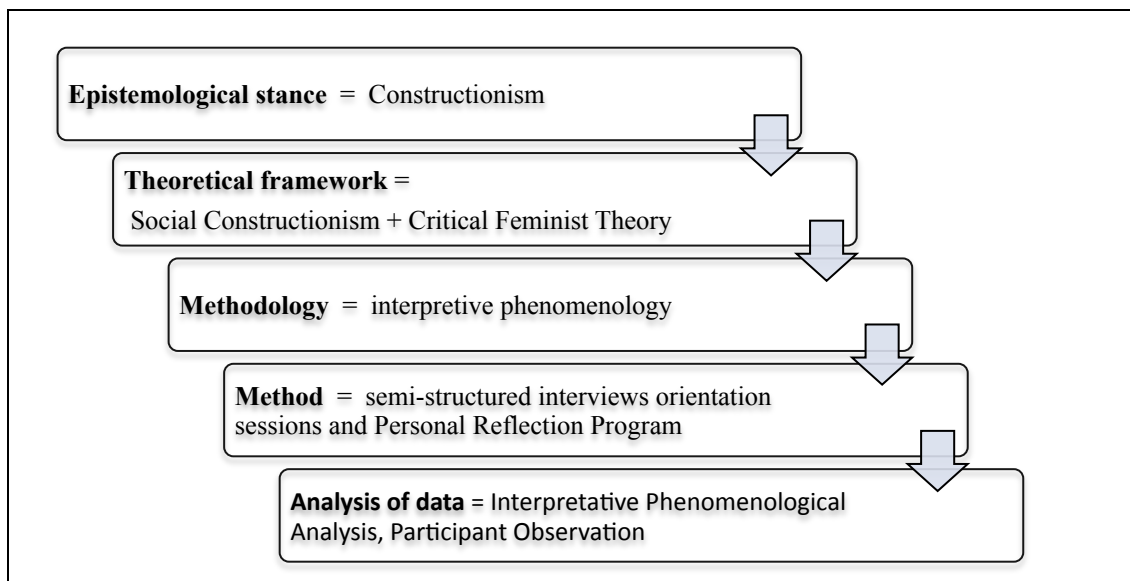
This chapter has reviewed literature relevant to an exploration of a range of psychosocial and psychological factors located within the experience of BC. The transformative journey a BC survivor navigates as they transition from patient to survivor involves integration of a distressing and challenging experience into the bigger picture of their life-world. The complexities of communication about BC with self, others and health care professionals such as counsellors, highlights the challenges of unique emotional reactions that can bring a temporary loss of direction in life. The review of relevant literature review addressed the existential concerns of the BC survivor as they reintegrate into the world, through exploration of literature relevant to the contribution to distress of stress, as well as depression and anxiety in BC survivorship, relationships with self and others, and the post-treatment body and self-compassion. Psychosocial interventions that have been offered to BC survivors were reviewed in addition to a review of literature on Expressive-Arts Therapies. Compassion and self-compassion were discussed briefly along with the role of counselling and the notion of BC bringing the opportunity for a 'new beginning' in life.

## Chapter Five

### Methodology and Research Methods

#### 5.1 Overview

Rigour in research is maintained through provision of detailed methodology that builds on a robust framework for a research project. The purpose of this chapter is to provide detailed descriptions of the process of first posing a research question, to recruitment of participants, data gathering, and analysis of data collected. At the same time, credibility and trustworthiness of this research study were considered paramount. This chapter will discuss the epistemological stance, theoretical perspective, methodology and methods employed to explore the question of how women survivors of BC (BCS) experience SC. The rationale for choosing a qualitative methodology will be discussed. Depicted in Diagram 6 are the chosen frameworks and the process of interaction between the four methodological elements of this project.



**Diagram 6:** *Elements of the research process*

Research is informed by basic beliefs, observations and/or premises we have about the world. This set of beliefs represents a worldview that provides information about the nature of the world, our place in that world, as well as information about how we interact and create our personal niche within our social environment (Hesse-Biber & Leavy, 2013). For the design of this study it was important to consider the nature of the topic being explored, the nature of personal narratives contributed by participants, and the vulnerability of the population being interviewed. An important adjunct to these considerations was my own motives, presuppositions, and personal history.

The methodological choices arrived at mirrored research in the human 'sciences' that has reasoned for a qualitative epistemology rather than a quantitative method as an appropriate methodology when setting out to study individual interpretations and meanings in participant's lived experiences (Bradshaw, Atkinson & Doody, 2017; Ezzy, 2002; Fossey et al., 2002; Hesse-Biber & Leavy, 2013; Moerer-Urdahl & Cresswell, 2004; Sousa, 2008).

A relevant factor to consider was an epistemological stance that would acknowledge experience as replete with contradiction, richness, and complexity. Additionally, in research that specifically involves exploration of gendered experience the recommendation is to use qualitative methodology (Hesse-Biber & Leavy, 2013). This project had as one of its objectives locating in academic literature, and the discourses of women themselves, the effects and subtlety that social constructions of BC and negative after-effects of BC would have on the erosion of personal empowerment as survivors of BC age.

When researching sensitive topics within the discipline of counselling, tension between the roles of counsellor and of researcher must be accepted and addressed. The boundaries can become blurred, particularly when participant distress is evident in the interview process (Mudaly & Goddard, 2006). As a professional counsellor the nature of my relationship with participants had to be considered carefully. In this study the chosen methodology needed to reflect the important question of 'how I wanted to be with and respond' to participants when they spoke about distressing life experiences. To avoid potential bias it was therefore

appropriate for me to step aside from my profession as a counsellor and confine myself to the role of researcher. This stance was taken so that participant narratives were neither interrupted nor influenced by a shift to counsellor mode. For example, in a research project that involved interviewing abused children Mudaly and Goddard (2006, p. 75) found the shift from skilled professional to ‘naïve’ observer a necessary although “uncomfortable” stance.

Another decision made prior to embarking on the project involved consideration of which methodological framework was best suited for me as the researcher and to the research questions (Moerer-Urdahl & Cresswell, 2004). The key was to choose methodology that would provide the most useful frame of reference for participant narratives to be honoured and to reveal useful data. Since research methodology creates a direct link between the choice of method and the use of it (Caelli, Ray, & Mill, 2003) a combination of professional interest, topic, participant gender, relationship with a woman with BC, and professional and personal factors led me to nominate qualitative enquiry through interpretative phenomenological analysis (IPA) for all interview data. Participant observation was used as the most appropriate method for reviewing information from the three Opening to Self-compassion (OtSC) sessions as well as for the Personal Reflection Program. Overall, the clear focus that phenomenological enquiry could bring to the essential experience of women survivors was particularly useful for this qualitatively-driven study (Fleming, Gaidys, & Robb, 2003; Lopez & Willis, 2004).

## **5.2 Research question**

The perceptions, concerns, meanings and unique lived-through experience of seventeen (17) Western Australian women survivors of BC was investigated through interpretative phenomenological exploration. The temporal, social, interpersonal and intrapersonal aspects of the ongoing self-relationship post-BC were prime matters of interest. The primary research question asked in this study was:

*What is the experience, in women survivors of breast-cancer, of self-compassion in relating with self and with significant others.*

### **5.3 Purpose of the study**

The purpose of this study was to investigate in detail:

- 1) the extent to which women's experience of living post-BC affected their feelings and attitudes about themselves and their body
- 2) whether the concept of self-compassion had relevancy for women survivors of BC
- 3) what particular aspects of the construct of self-compassion might women survivors of BC need to nurture in order to enhance self-care, self-acceptance, and self-kindness?

### **5.4 Significance of the study**

The significance of this study lies in the fact that understanding what women need in terms of appropriate emotional support post-breast cancer treatment, and what factors influence their post-cancer relationship with themselves and others may lead to more efficient, effective holistic survivorship care. While acknowledging the need for women to monitor their health and to understand the changes their breasts go through as they age, helping women actively reduce any post-treatment emotional burden may eventually prove useful in reduction of fear-driven presentations to medical support. Research has identified self-acceptance and self-compassion as able to engender a more peaceful and hopeful attitude (Birnie, Speca, & Carlson, 2010; Dodds, 1999; Neff, 2003; Neff, 2009; Neff, Hsieh, & K. Dejitterat, 2005) in people with cancer. This means there is the distinct potential for women with BC to relax into an enhanced quality of life that would support a capacity to deal more securely with the uncertainties of the future.

The ability to tailor psychological support that encourages women to reconnect with personal resourcefulness for successful individual adjustment to living post-treatment for BC is anticipated to have positive implications for effective, empathic health care and for appropriately informed counselling strategies. Results from this study will help inform counsellors, counsellor educators and other mental health professionals who specialize in the psycho-social concerns of oncology populations.

A benefit, therefore, would be to increase the awareness of women with BC that so-called ‘negative’ emotions are a natural part of the reactions to cancer and provide a means of understanding their experience without judging development of or vulnerability to cancer as a failure on their part. Awareness of self-compassion would be expected to help reduce rumination and restore feelings of connectedness with self. To be able to lessen fear and distress in the transition from BC patient to survivor may offer women who suffer from post-BC depression and anxiety hope of more experiences of peaceful, positive self-acceptance of themselves ‘as they are’ (Neff, 2015).

Tailoring psychological support that encourages women to reconnect with personal resourcefulness for successful individual adjustment to living post-treatment for BC is anticipated to have positive implications such as a kind, connected, clear-sighted way of relating with themselves (Neff, 2015). Through convey to women the continued support available from effective, empathic health care and compassion-informed counselling strategies. Results from this study will help inform counsellors, counsellor educators and other mental health professionals who specialize in the psychosocial concerns of oncology populations.

### **5.5 Strategy and design**

This study was developed with the view to observe individual realities as they emerged from the unique perspective of participants. The frame of reference was that the ‘actualities’ (details, perceptions, facts) of the lived experience of participants were critical (Butler, 2016; Morrow, 2007; Smith & Osborn, 2008; Tan, Wilson, & Olver, 2009). This means that while the results of this study may not be able to be generalised universally to all women with BC, nevertheless, the outcome is expected to have implications for psychological support for those with BC who share similar social and cultural influences to participants in this study.

### **5.6 Epistemological stance**

The epistemological issue in research addresses how we come to know the world. Given that research is about knowledge and generation of new knowledge, the approach taken in this study was an holistic one. The aim was to try to understand different parts of the issue by first looking at the whole ‘picture’. Taking this stance

meant I commenced from the standpoint of my personal assumptions about the way the social world can influence health behaviours and personal identity. I also began this study with my assumptions about the perceived social reality of participants. Therefore, the larger picture of their experiences incorporated both the positive outcomes of survival as well as the possibility of persistent, increased levels of depression and/or anxiety, as well as a personal malady of insistent self-criticism for some breast cancer survivors. Treating reports of the lived experience of the individual as an active process of interpretation rather than passive collection of concrete information indicated that phenomenology as a method for research merged comfortably with social constructionist epistemology (Karnilowicz, Ali, & Phillimore, 2014; Morrow, 2007).

Rather than reporting abstract representations of the participants, the importance of presenting findings that gave an accurate reflection of the phenomena being studied was central to the search for data (Butler, 2016). The process of conducting interviews, plus observation and monitoring of the 8 women in the group OtSC sessions and Personal Reflection Program (PRP) enabled development of an informed inventory of possible themes. The progressive stages of the research process encouraged participants to bring more ‘voice’ to their experiences as well as time to deeply explore meaning within their experience. In addition, the experience of face-to-face contact with participants gave me the opportunity to more closely consider and reflect on how the range of personal variables in each woman came together in the real world of this group of BC survivors.

Therefore, in this study the combination of social constructionism and a feminist standpoint provided an epistemological foundation from which to explore how each participant experienced their self-relationship living with the after-effects of BC. The potentially exploitative nature of qualitative research interviews with vulnerable populations was central in my thoughts. Gathering data from a feminist perspective in which the safety of participants is seen as a critical factor in the process of gathering knowledge (Gatrell, 2009). Understanding of whether women BCS do or do not experience self-compassion, and how they practice self-compassion, requires developing conceptions of both knowledge and reality (Ramazanoglu & Holland, 2002).



Exploration into each woman's particular experience considered whether each narrative differed from or was similar to that of other participants. From a feminist perspective the knowledge gleaned was considered as not-total (Ramazanoglu & Holland, 2002) in that the findings were not regarded as 'true' for all BCS. Treating the data in this way allowed a more nuanced understanding of each of the women who participated in all three phases of the process of information gathering. Taking a feminist perspective meant beginning from the argument that women's experience of BC and survivorship had, traditionally, meant that in the past, the emotional struggles of women with BC may have been rendered silent. The women in this study were active and experiencing participants, particularly through their involvement in the OtSC sessions and the PRP sessions.

The experience of significant others and of counsellors who supported women with BC revealed insightful and compelling narratives. Their personal 'explanatory model', and the meaning each person had made of their experience, revealed itself in the characteristics, nature and essence of their stories. A constructivist frame provided the means of being able to look specifically at how participants had constructed meaning, and the lens through which they viewed the world after their encounter with a life-threatening illness (Morrow, 2007).

### **5.7 A social constructionist perspective**

One of the central components of the methodology adopted for this study was to privilege the knowledge of ordinary everyday persons and the way in which they interacted within their social world. Constructivist theory has posited that human beings construct knowledge and meaning from life events and experiences. Social constructionism situates knowledge of the self in a linguistic, narrative and interpersonal realm (Guterman & Rudes, 2008). Constructivist thought suggests people take action based not on 'things' but rather on the 'meanings' things have for them (Gergen, 1985). The main argument is that cultural and historical perspectives are not necessarily inherent in a phenomenon but arise as a by-product of the social context in which the phenomenon exists (Guterman & Rudes, 2008; Walker & Charles, 2015). For the study reported here this means that the meaning participants made of their BC, revealed in conversations about their social, emotional and

cognitive constructions, considered the interactive elements within the dynamics of the event.

An extension of constructivism, social constructionism presents a postmodern epistemological formulation that firmly places knowledge within the context of human conversational transactions (Guterman & Rudes, 2008; Järvinen & Miller, 2015). While acknowledging the experiential, interactional, language-based foundations of constructionism, what cannot be denied are the constructed nature of some realities, and the reality that some social interests are served by particular constructions (Hesse-Biber & Leavy, 2013).

The language of illness has now become socially constructed at an experiential level (Conrad & Barker, 2010). This can affect how the person diagnosed understands their illness, constructs meaning of their experience, and as a survivor, then lives with the psychological and physiological consequences (Galgut, 2007). Contrary to a stance of objective detachment from the participant narratives, it was important in this study for the research lens to concentrate on the idea that the lived experience of participants and the meaning they made of that experience was the central focus.

Since the points of view I sought most to understand were those of the participants, active engagement with and observation of the combination of verbal and non-verbal responses offered was required. Standard ‘talking cure’ methods for listening were not the only ones employed in the process of the interviews. Without a focus on ‘doing’ listening through making mental note of congruence and incongruence in statements made, being alert to feeling statements, observation of verbal versus non-verbal communication, and listening as a prelude to responding, the quest was to subordinate the ‘will-to-help’ below the ‘will-to-hear’ (Wilberg, 2004). This meant learning to listen in the way that has been referred to as a ‘pregnant silence’. This type of listening meant perceptive observation for signals that the participant had space and time to make ‘inner contact’ with her own realities (Wilberg, 2004).

Therefore, the relevance of a social constructionist frame for counselling research meant that what transpired between the researcher and participant was largely constructed through ongoing linguistic and energetic interchange. The process of focusing on the dialogic and interpersonal exchange meant social constructionism offered a useful epistemological framework for this counselling-focused research. In summary this means that language and social processes are regarded as impactful on the ability to know an objective reality in as close to its completeness as is possible.

Social constructionism has been referred to as a product that is in a continual state of change that makes it subject to reconstruction (Guterman & Rudes, 2008). This approach involves the construction of shared meaning-making happens between a client and counsellor (Russo, 2005). This means that phenomenological research addresses the meaning a person makes of their lived experience through connection to a world that, in turn, “is translated in a social and cultural co-constructed network” (Sousa, 2008, p. 144). Humans are constantly monitoring the environments in which they live this can mean that emotional responses to life events become themselves guided by social constructions (Averill, 2012; Järvinen & Miller, 2015).

The critical task in this study was to explore the nature of reality for BC survivors as well as face the challenge of taking into account multiple perspectives in an attempt to discover what more could be known about each participant’s experience of BC (Cresswell, 2007). Those multiple perspectives included the cognitive, linguistic, affective, and physical self of all three groups of participants. For this research project qualitative methodology provided the most appropriate and suitable platform for a sensitive and thoughtful exploration of the inherent complex processes (Morrow, 2007; Tong, Sainsbury, & Craig, 2007).

Criticism of social constructionism as a tool for understanding counselling processes refers to the challenge that a constructivist perspective does not directly focus on individual liberty or personal agency (Guterman & Rudes, 2008). The concern that constructionist analysis dispenses with any notion of there being one ‘objective truth’ or fact, is another criticism that has been levelled at a constructionist approach (Jacobs & Manzi, 2000, p. 37). However, Sousa (2008, 2013) has

highlighted that phenomenology is ideal for studying human experience because it makes use of context; something that other models may not employ. Therefore the method seeks to explore and understand how people interpret and make meaning of their life world to allow the researcher a deeper understanding of the life of the participant and the potential to uncover hidden meanings in narratives provided (Matua & Van Der Wal, 2015).

Qualitative research positions the researcher as a subjective and necessary part of the research process. This is in contrast to a quantitative approach that attempts to eliminate or neutralise any influence from a researcher. Qualitative research is a collaborative process between researched and researcher (McLeod, 2011). The life world of participants is structured in relation to the particular meaning and relevance they attributed to the events of their life. Meanings and relevance can be inherited from parents, teachers, or friends (Embree, 2009). Therefore, adoption of a qualitative frame of reference offered an important response to the genuine necessity for a non-abstract way of appreciating and understanding consciousness as expressed in participants' narratives.

Research into survivorship experiences of survivors of BC means there was a need to choose a methodology that could both improve the understanding of professional helpers about the challenges of living through the experience of confrontation with one's mortality, and additionally, could provide a way to disentangle some of the powerful and lingering socially constructed rhetoric about cancer survivorship. Furthermore, since this project revolved around a selfishness versus self-kindness dichotomy for women, inclusion of a feminist perspective guided the research. Feminist methodology offered a frame of reference that was a constant reminder of maintaining deep respect for participants and their narratives. Using a feminist lens fostered honesty and openness, along with awareness of, and sensitivity to, the value of listening to and being able to bear hearing the realities of life in the long shadow of breast cancer.

## **5.8 Feminist methodology**

The uncovering of meaning is the basis of phenomenology. Doing so in an environment that privileges women's experiences is one basis of feminist

epistemology. Critical Feminist Theory offers encouragement for exploring women's lived experience and uncovering the potential for invisibility of women's intuitive knowing in regards to what they perceive they need in relating with themselves and their lived environments. In research, adopting a feminist-oriented methodological approach presents a challenge to our existing understanding of gendered social realities (Ramazanoglu & Holland, 2002). These authors maintained that feminist methodology can uncover authoritative knowledge that is able to highlight ways in which women's experiences may be discounted, trivialised or misunderstood.

A feminist framework explores the origins of socially accepted knowledge and power within a female context. Feminist epistemology acknowledges a collaborative interaction between researcher and participants. Through emphasising the denial or obfuscation of women's voices and the ways women's experience has been employed by a dominant culture to reinforce notions of gendered norms, feminist enquiry seeks to challenge claims to knowledge from those who occupy privileged positions (Hesse-Biber & Leavy, 2013).

Although BC is not unique to one gender, women are, primarily, the ones treated for this disease, and consequently the ones who make up the vast majority of survivors (Bennett et al., 2013; Frazzetto et al., 2012; Hanchate et al., 2010). BC is an illness that has become socially constructed as 'women's business'. Reports from women who have had BC as well as from experts who research the effects of the disease (Galgut, 2007), confirm the painful, uncertain and enduring process women encounter in their quest for survival and restoration of their wellness.

Understanding the ways a particular method of investigation can influence, and how methods chosen 'interact' with research participants is of importance when researching from a feminist standpoint (Ezzy, 2002). The heart of feminist theory has highlighted the need to question prevailing constructions of what is truth as well as accepted assumptions about gender norms and how social institutions perpetuate inequalities for women, particularly gendered interpretation of women's emotional distress (Fullagar & O'Brien, 2014). Taking this into account meant feminist theory was able to offer a position from which to understand the implication of how

unexpressed psychological residue compressed by, or ‘capturing’ the BC experience, might negatively affect psychological and psychosocial recovery.

Medicine in our society has operated within a ‘cultural metaphor’ that has influenced and guided language, attitudes, assumptions, and actions around healing practices in Western medicine (Petersen et al., 2001). This notion of a cultural metaphor is particularly important to consider in exploring women and self-compassion. Although no longer the status quo, a history of BC indicates that women with breast cancer have traditionally received treatment from male surgeons and scientists whose expert knowledge afforded them power over treatment regimes for female patients Olson (2002) This prevailing dynamic means a feminist standpoint was required for this study so that women’s experiences were placed inalienably “at the center of the research process” (Hesse-Biber & Leavy, 2013, p. 56). The women in the study were regarded as the expert ‘knowers’.

Diverse feminist perspectives currently exist and in effect there is no one rigid standpoint for feminist research (Eun-Ok, 2013). Traditionally, feminist epistemology has sought to ensure those who have been oppressed and objectified are able to tell their own story (Levy, 2012). The focus in feminist research is that the research would be in the interests of women (Eun-Ok, 2013). Therefore, as a researcher this means listening so as to hear the unsaid. The methods used in this study meant that women were afforded opportunities and encouragement to express themselves in a safe context using non-threatening activities. As a person who has not had breast cancer I became aware that the final thesis meant I would be ‘speaking’ for the women participants. This view is in line with feminist research that requires a researcher to consider their own attitudes, beliefs, values and bias (Eun-Ok, 2013). For me, the responsibility of speaking on behalf of these women was held ‘close to the heart’. My family experience of BC called into consideration whether my family history would compromise my position as researcher of the topic of BC. On reflection it was not the issue of BC that was the primary consideration, but the topic of how self-compassionate women are to themselves, especially when they have undergone a life-changing experience.

Contemporary feminist research seeks to include both women and men rather than conducting research that includes only women. One of the interests of my study was to discover if women BC held the same, or different perspectives on self-compassion to males whose partner was either a survivor or had died from BC.

To safeguard and privilege the voices of BCS taking part in this study, to value the meanings they ascribed to their experience, and gain an accurate understanding of their experience, a safe psychological forum in which women could discuss the impact on their lives, their perspectives on self-compassion, and their perceptions of what emotional and social support might help women diagnosed in the future was created in the Personal Reflection Program discussed later in this chapter.

## **5.9 Knowledge generation**

There is always more than one way of knowing; knowledge is available from a range of sources (Ramazanoglu & Holland, 2002) including available research literature. In this study critical knowledge came from the women who have had BC, and from the significant others in their lives. A third source offered both knowledge and practice evidence. This was available from practitioners - therapists whose work placed them in the high touch field of professional contact with people with cancer. Each of these sources had its own unique construction of meaning and ways in to establish what was a perceived reality. However, when combined, these sources presented an appropriate method to understand how some women's lives had been shaped by their experiences.

In addition to the three sources of knowledge from which data were gathered formally, there were three women whom I came to know, in a social context, who provided a background source of 'reference' for me. The women were each survivors of BC, were not known to me prior to the study, did not want to participate in the study, but made contact with me because they wanted to help. The three women became a source with whom I could 'check' ideas, discuss my thinking, and learn more about how women live with BC. These were sources of anecdotal information and as such no direct material from those conversations is included here.

## **5.10 Theoretical framework**

Both qualitative and quantitative approaches have been used to investigate BC and the influence its sequelae has for the quality of life of a survivor. A definition of qualitative research informs a researcher that qualitative methodology is a broad umbrella term for research. It is a method that describes and explains persons' experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification (Fossey et al., 2002, p. 317).

Characterised by its in-depth subjective nature, a qualitative approach lends itself well to better understanding the needs and concerns of receivers of qualified support (Greenhalgh & Taylor, 1997). Qualitative research in health care provides a means of locating a clear understanding of how 'end-users' experience emotional and psychological support provided. The aim is to understand perceptions, perspectives, meaning and the uniqueness of the subjective life experience of an individual; to understand the encounter between the carer/system of caring, and the cared for. This then provides a reliable base from which to create, test and implement appropriate interventions.

Qualitative methodology has, at its origin, a broad range of disciplines such as anthropology, psychology, and sociology (Fossey et al., 2002; Morrow, 2007). It is particularly suited to research that is closely related to professional counselling practice because of its capacity to answer 'how' and 'what' questions rather than 'why' questions (Morrow, 2007). Its aim is to focus attention on the perspective of each participant in the study (Fossey et al.). In a qualitative enquiry the researcher's clear intent is to be reflexive and thereby develop a deeper knowing, and understanding, and have insight into how to make sense of the meanings or uniquely personal interpretations people have about their lived experiences (Cresswell, 2007; Ezzy, 2002; Morrow, 2007).

To know and understand as best as possible, the contexts in which survivors of BC live and how those settings influence and organise their experience, places the survivor at the centre of that knowledge and understanding. To understand their experience means to accept that "Humans are embedded in their world to such an extent that subjective experiences are inextricably linked with social, cultural, and



political contexts” (Giorgi, 2010; Lopez & Willis, 2004, p. 729). The outcome of this approach was to ultimately treat the data from interviews and information gathered in the Opening to Self-Compassion sessions and PRP, not as a concrete reality, or an objective truth to be isolated from the verbatim reports, but rather, as a type of ‘unfinished’ but unified work in progress.

The central component, however, is to highlight the knowledge, experience, and meaning-making of people in their everyday lives. One aspect of the epistemological frame of this study rested on the notion that an extensive array of meanings are developed as we experience the world; meanings that then form the basis of engagement with our social and emotional environments (Morrow, 2007). To carefully listen to women with BC, and thoughtfully explore the real meaning of words used is a participant need that can easily be overlooked (Galgut, 2007). In order to gain answers of value a researcher accepts the responsibility to carefully and reflexively consider which methods of enquiry and analysis to adopt (Shinebourne, 2011; Englander, 2016). The risk, otherwise, is that the needs of the research project, or the researcher, could be prioritised.

As a research approach for the counselling profession, phenomenology has the potential to generate knowledge that can be directly applied to practice in the field (Pringle, Drummond, McLafferty, & Hendry, 2011). Phenomenology calls into question what has been taken for granted. This means that in order to critique a particular idea or commonly held view the task is to first disengage from any presuppositions. Phenomenology is not a research tool with which to follow an empirical epistemology that would base the search for credible knowledge on causality (Sousa, 2008, 2013).

As a method of qualitative enquiry, phenomenology has “many different strands” (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013, p. 18) that seeks to examine and evaluate data about a person’s uniquely lived experience without any attempt to present that data as an absolute actuality. Because phenomenology privileges the person’s experience and their perception of the world, it is more about an inevitable truth than generalizability. In this study the search required me to care enough to reach out for a deeper understanding of women’s meaning of their

experience and so exploration of the meaning of an issue for women meant encountering experiences that, perhaps, an ‘outsider’ may never be able to fully comprehend or capture.

An emphasis in a phenomenological perspective is to listen to and learn from the other’s voice (Orange, 2011). Possibilities for new meanings to emerge requires that a researcher is able to set aside, as much as possible, any prevailing understandings of the phenomena and be present to our immediate experience of the phenomena. The power of phenomenological investigation for this study was that it provided a lens through which to hear, see and understand, in a new way, the depth, diversity and richness of women’s experiences (Finlay, 2009, p. 13). The aim was to examine and interpret the phenomenological experience of women’s feelings, attitudes, experiences and concerns in connection with their self and other relating in breast cancer survivorship (Cronin-Davis, Butle, Mayers, 2009). Therefore it became possible to understand what it is that is actually happening for BCS rather than giving descriptions of what had happened to them.

### **5.11 Phenomenology**

Based in philosophical traditions, phenomenology is rich in both its history and approach (Cresswell & Plano Clark, 2007). Phenomenology delivers detailed exploration of the essence of the lived experience (Priest, 2004); the experience of people in their particular context. This form of enquiry provides an effort to identify, understand, describe and maintain the subjective experiences of ... respondents. The preference for phenomenology as the basis for investigation for this study was to encourage participants to talk about their experiences and promote open discussion about the topic being explored. Methodology that encourages giving voice to a person’s concerns and their unique experience is well suited to exploration of the concept of being self-compassionate.

Listening to the voices of participants meant being ‘with’ them and following their conversation, and “letting participants speak for themselves” (Mudaly & Goddard, 2006, p. 67). What was said was listened to and respected; their self-interpretation of BC and their survival was central to the discussion. At the same time the researcher’s expertise as an experienced counsellor was useful, in an

ethically respectful way, to offer probing questions that might uncover rich multi-layered data.

The interpretative process then involved adoption of a person-centred approach that would allow me to take a step back from the position of ‘expert’ or ‘psychological knower’, and look at the inter-relatedness of various aspects of participants’ human experience (Wilberg, 2004). While research and therapy are undeniably distinct from each other, interpersonal capabilities of a therapist would be useful in a qualitative interview and consequential interpretative process.

### **5.12 Interpretative phenomenological analysis**

Interpretative phenomenological analysis (IPA) offered significantly more than what has been referred to as an ‘insider perspective’ (Smith, Larkin & Flowers, 2009). Women who survived BC were the experts in the lived experience of what happened, how they felt, what they wanted, and what was needed for them to nurture a healthy self-relationship post-treatment. The women were the specialists in the everydayness of life after BC.

IPA specifically focuses on the depth and richness of individual lived-through situations (Sousa, 2008, 2013) and provides a phenomenological account of subjective experience through exploration of the context, structure and essence of that experience (Aisbett, 2006). This means that IPA affords a researcher unique advantages over more traditional forms of analysis. Using an interview process means that the researcher uses a simple tool of questioning to gain access to information that can lead to greater understanding of a particular phenomena (Aisbett, 2006). When language and personal interaction forms the nature of the relationship between participant and researcher the result is they are present to and with each other (Tan, Wilson & Olver, 2009).

The epistemology of Heideggerian philosophy with its view of human beings as embedded and immersed in their world of objects and relationships, language and culture, projects and concerns (Paley, 2014; Smith et al., 2009) is particularly relevant to this study. Because this study sought to gain a detailed and in-depth view of the multi-faceted phenomenon of how women BCS experience self-compassion, it

was important to adopt a research approach that would achieve a broad understanding of women's lived experience and at the same time be able to delve into the realms of complex emotional processes. The interpretative counselling researcher seeks not to exclude bias but to become more aware of their own bias, and in so doing derive a clearer, more true account of the phenomenon as experienced by each participant.

My responsibility as a researcher and counsellor was to present sufficient detail of how I went about the task of designing this research. That responsibility extended to being able to present in this chapter relevant information so readers could reach their own conclusion about methodological rigour and the credibility of my interpretative process. This chapter discussed the fundamental epistemology of the study, methodological framework, research method, sampling, recruitment of participants and process of data analysis.

### **5.13 Historical factors for a phenomenological perspective**

Phenomenology is categorised into two key method pathways, each going about the process in a different way. Two main philosophical traditions in phenomenology offer separate pathways for exploration: one descriptive and the other interpretive (Lopez & Willis, 2004). For this study, the accepted, essential difference between the two options was that one approach would seek to find out 'what' was the experience a BC survivor had of a the phenomenon being explored, whereas another phenomenological approach would explore 'how' a person experiences a particular phenomenon.

### **5.14 Bracketing**

Bracketing can be defined as excluding a habitual way of perceiving something. It involves active management of pre-understandings in an attempt to allow a phenomenon to reveal itself in novel ways (Finlay, 2009). The process of bracketing calls for identification of a researcher's own assumptions, biases and presuppositions so that their influence could be negated or at least minimised. This works to ensure that a 'phenomena' spoke for itself and data would therefore remain uncontaminated (Moustakas, 1994). This means analysis would need to be conducted in a way that reported the actual experiences of individuals rather than presenting

abstract theoretical concepts.

Working from the perspective that a researcher's presumptions about the phenomenon being investigated will be present prior to embarking on the investigative journey, the task in interpretative phenomenological enquiry is to set aside pre-existing ideas and hypothesising. The effect of bracketing enables deconstruction of perceived reality and information about a participant's authentic self is able to be discovered (Ashworth, 1999). In addition, bracketing was regarded as a way to allow unanticipated insights, themes and findings to emerge (Landridge & Hagger-Johnson, 2009). For research this means all preconceptions can be reformed and reconstituted through a process of re-interpretation by keeping a central focus on what the participant has to say.

In contrast, Caelli, Ray and Mill (2003) claimed the notion that a researcher value neutral can be questioned. These authors further claimed the existence of neutrality can in fact be overturned (Caelli et al., 2003). Another precept these authors placed under question was of the capacity of a researcher to set aside or bracket their presuppositions (Caelli et al., 2003; Finlay, 2008). McConnell-Henry, Chapman and Francis (2009) also argued that the concept of bracketing was not compatible with interpretative phenomenology. Acceptance of these argument means the inability to completely "set aside all conscious and unconscious thoughts, beliefs and influences" (Tuohy, Cooney, Dowling, Murphy & Sixsmith, 2013, p.18) that to bracket completely one's personal or professional perspective would not be possible.

My own pre-assumptions were that the experience of surviving BC would leave a residue of both trauma and growth and that there would be a 'back story' that could negatively or positively influence the meaning a woman would extract from the event. Therefore the challenge to be faced in the study reported here was one of constructing meaning out of another person's construction of what they experienced. In short, to make meaning of the meaning they had constructed around having had BC (Wertz, 2005). Prior acknowledgment of my own biases and influences in relation to psychological recovery from breast cancer and self-compassionate communication supported openness to the meanings imbued into participant's experiences.

### **5.15 An Heideggerian perspective**

The work of Martin Heidegger (1889 – 1976) emphasised the idea that while each individual is unique, they do not exist separately from the world in which they exist (Paley, 2014). Heidegger argued that an individual's subjective experience is inexorably connected to their outside world, meaning that the everyday lived existence entails interactions or involvement in the world (Paley, 2014). To this end, Heidegger philosophised that human beings are constantly self-interpreting, constantly involved in making meaning of the experiences and events of their lives. Bracketing, according to Heidegger, can be only partially achieved (Smith et al., 2009).

The research position taken for this study was that existing experiences and perceptions can never be separated out and treated as entirely detached from the researcher themselves. In phenomenology the researcher is regarded as having experiences and perspectives valuable to the study, and as such is recognised as an instrument in the process. In addition phenomenology allows for emergent design because “it is inconceivable that enough could be known ahead of time about the many multiple realities to devise the design adequately” and because diverse perspectives and values systems of the researcher and participant “interact in unpredictable ways to influence the outcome” of the study (Lincoln & Guba, 1985, p. 41).

Central to a phenomenological approach is the concept of hermeneutics as a systematic method of interpretation; an approach to enquiry that focused on examining common, everyday experiences for shared meaning and practical wisdom (McLeod, 2011; Paley, 2014). Originally concentrating on interpretation of sacred or religious texts, hermeneutics related more specifically to the ways people make sense of their lives through the meanings inherent in everyday processes. Hermeneutics has been described as going beyond “mere description of core concepts and essences to look for meanings embedded in common life practices” (Lopez & Willis, 2004, p. 728).

The implication for data reported in this thesis is that Heidegger's perspective provided a way to be receptive to human feelings and unveil detailed life narratives

of women who have had BC. In addition this approach can provide a deeper understanding of how to create and provide emotional and psychological support mechanisms for women in their recovery from a confounding and complex disease. In this regard, the argument is that understanding of a phenomenon is best gained by studying that phenomenon in the context of daily life (Larkin, Watts, & Clifton, 2006; Tuomola, Soon, Fisher, & Yap, 2016).

### **5.16 Hermeneutics**

Hermeneutics, the process of interpreting a text seeks to go beyond descriptions of core concepts, instead searching to “make clear, to make sense of an object of study” (McLeod, 2011, p. 23). The aim is to find out what people experience rather than “what they consciously know” (Flood, 2010, p. 9). The researcher engages in a process of inquiry “through moving back and forth between the part and the whole” (McLeod, 2011, p. 28).

Heidegger’s definition of hermeneutics allowed for the notion that interpretation of a participant’s experience is likely to be influenced by the history, culture, bias or empathic response of the researcher (McLeod, 2011). Another way in which Heidegger’s approach to phenomenology differs from Husserlian principles is a central question of how an individual experiences a particular phenomenon rather than what the person’s experience was. Thus, Heidegger’s work epitomized a move from epistemology to ontology (Flood, 2010). McLeod defined ontological hermeneutics as “a way of understanding that view people as existing within multiple horizons of meaning, as striving to make sense of their experience, as constituted by their cultural and historical context, as engaged in dialogue” (2011, p. 30).

An interpretative approach highlights the active role of a researcher as well as the dynamic nature of the research process. Therefore, my own perceptions could be thought of as a complication with my understanding of participants’ lived experience. This then requires interpretative activity by myself as researcher and results in what could be called a ‘double hermeneutic’ (Smith & Osborn, 2008). In other words, while the participant is in the process of making meaning of their world I was simultaneously making sense of the participant’s meaning-making. This process required balancing concern for what things were like for the participant

alongside my questions about whether something else was happening that was not in the participant's awareness.

To help bring to consciousness elements of my own experience that might interfere in a non-productive way with clarity I sought as I read, re-read and reviewed transcripts and audio-recordings, I maintained a series of personal journal notes (see Appendix 8, p. 425) and a series of sand tray images I created as tools for reflection on the process of living in to the task I had set myself (photos of sand trays created are at Appendix 8, p. 430). Peer debriefing with a colleague with extensive experience in counselling as well as experience as a qualitative researcher supported deliberate contemplation of my personal and professional connection to the topic and the demands of writing a doctoral thesis. Transcripts of three of the interviews with women in Group 1 were given to my colleague to code. This was done as a means to cross-check that themes identified in the remaining transcripts were a complete and faithful reflection of what the women had said and how they had related their experience and its meaning. Regular de-briefing discussions were had with my colleague to uncover any potential bias, and monitor and bring awareness to my perceptions, interpretations and the relationship with emergent themes from the stories told to me by participants.

During the process of analysis instinctual gut reactions, ideas from informed intuition, reflections on emerging themes, and links to reviewed literature were recorded in a process journal, and then formed as an image in a sand tray. The creation of sand tray images has been found to be a useful resource for deeper reflection in relation to the participant narratives, as well as opening to the process of non-verbal thinking (Pearson & Wilson, 2001). The significance of recording journal notes was that this resource documented my views, beliefs and relevant background information (Tan et al., 2009; Willig, 2008). The reflexivity afforded by both the series of visual images and journal notes created a heightened awareness of perspectives and beliefs that I brought to the process of exploration (Finlay, 2009). Creation of sand tray images provided a process of temporarily suspending rational thinking. This helped maintain a continual experience of a new or renewed sense of myself as researcher in relationship with both participants and with the stories they willingly donated.



## **5.17 Participants**

Phenomenology means that a researcher can work with a select group or groups of participants who have particular knowledge, and something to say, about the topic being explored (Aisbett, 2006). For this study three different groups of participants were recruited through purposive sampling to provide rich, in-depth data relevant to the relational experiences of women who have had BC (Fossey et al., 2002). Gathering narratives of women's experiences of BC in a number of ways and from a diversity of sources (women with BC, significant others, and counsellors) delivered a way to enhance and extend my understanding of what it is like to live through diagnosis and treatment and provided a way of harvesting more complete and holistic data (Yardley, 2008).

The narratives from three husbands (SO) about their witnessing of their wife's journey, along with the perspectives of three professional counsellors was invaluable in helping expand and enrich the women's narratives with more detail. The aim in seeking information from additional participants was by way of ensuring each woman's story of BC could be seen in the larger context of life. This focus came from the recognition of the importance of emotion and emotional adjustment in illness recovery in addition to the way that emotional states from stressful events can be transferred onto significant others (Segrin et al., 2005; Sharpe & Curran, 2006).

### **5.17.1 Participant Recruitment.**

A purposive sample of participants was recruited by third party email and twenty women responded to the invitation to participate in this study. The email request was sent by the Institute of Health Research, University of Notre Dame Australia, to women who had indicated an interest in taking part in an earlier research project into exercise and counselling for BC recovery. Of the original twenty respondents, seventeen elected to take part in this study.

Significant others and counsellors were recruited by convenience sampling. Three counsellors who took part in the project were all known to the researcher as professional colleagues and were approached in person by the researcher about participation. Three significant others were recruited by convenience sampling. Two of the significant others were husbands of women who were already participating in

the project and offered to take part. The third significant other was known to a colleague of the researcher (but not known to the researcher) and on hearing about the project volunteered to participate. Table 1 outlines participants in each group.

**Group 1:** Seventeen women who have been diagnosed and treated for BC who reside in the Perth metropolitan area in Western Australia with an age range of between 35 and 70 years. Treatment for BC had been completed at least 12 months prior to participation in the study and may have involved treatment such as mastectomy, double mastectomy, radiotherapy, hormonal treatment, and /or adjuvant chemotherapy. Participants may also have undergone breast reconstruction, however, this treatment option was not an essential part of the inclusion criteria; nor did breast reconstruction exclude a person from participation. Exclusion criteria for participants in Category 1 were if a woman were pregnant or became pregnant during the course of the participation process.

**Group 2:** Recruitment of participants who were a ‘significant other’ in the life of a woman with BC, was not limited to spouses or partners. Three men, who had each been, or were, in a long-term married partnership with women who had undergone treatment for BC no less than 12 months prior to commencement of this study, volunteered to take part in this study.

**Group 3:** Three counsellors who work with women living with BC. The counsellor participants need not have counselled any of the participants in Groups 1 or 2.

<b>Group 1 Women living with BC</b>	<b>Group 2 Significant others</b>	<b>Group 3 Counsellors</b>
Women living in the Perth metropolitan area of Western Australia.	Spouse, partner, close family member	Currently in practice as a qualified Counsellor / Therapist
Women who had completed medical treatment for BC at least one year prior to participation in this study.	Currently or had been in a spousal, long-term, or familial relationship, with a woman with BC	Has worked with persons with BC (client population need not be exclusive to women survivors)

**Table 1: Participant groupings**

### **5.17.2 Sampling and sample size.**

For qualitative research that involves IPA a recommended sample size of between 3 and 6 participants is considered sufficient (Smith & Osborn, 2008; Tuomola et al., 2016). A limited sample size has been deemed preferable to a larger study that might seek to generalise findings to a larger proportion of women with BC (Higginbottom, 2004). The uncertain nature of living with a life-threatening illness, particularly fatigue, experienced side-effects of medication, specialist medical appointments, and the possibility of recurrence of BC prompted the decision to interview a larger than required number of participants. Mindful of the various phases of data collection, it was acknowledged that not all seventeen (17) women may be able to participate in all phases. This turned out to be the case. Of the initial group of 17, eight women participated in the OtSC sessions and the PRP. Reasons for the reduction in numbers able to join in all phases of the project has been discussed elsewhere in this chapter.

Of the 17 women interviewed one woman experienced a recurrence of cancer and did not continue with involvement, with eight participants taking part in all steps of the data collection process. Of those eight women, seven completed all phases, while one person was absent from two of the OtSC sessions in addition to one of the 6-hour Personal Reflection Program sessions due to health issues. Work and family commitments, health issues and the scheduling of the phases all mitigated against more extensive involvement.

### **5.17.3 Saturation of themes.**

Saturation is a concept used in qualitative analysis and has been said to refer to the point at which sufficient participants have been recruited to access the data needed (Morse, Lowery, & Steury, 2014, p. 558). The point of saturation is also the point at which new data constantly fails to yield new themes additional to those already identified. Since qualitative research operates on the assumption that the social world is not predictable, and so does not seek to generalise the findings, the sample does not need to be representative of the population as a whole.

Saturation of themes is generally considered to occur after 12 interviews, although basic elements for meta-themes has been found to be present as early as six

interviews (Morse et al., 2014). Saturation of themes in the analysis of interview transcripts was facilitated in this study through seeking diverse sources of data through interviews with significant others and counsellors in addition to group processes.

For this study the sample size of 17 participants if Group 1 provided a ‘buffer’ in case the number of anticipated participants dropped below the desired 12. That reduction in numbers may have happened because of BC-related health complications. However, all 17 women who originally accepted the invitation to participate were interviewed.

The perceptions of significant others in the lives of women with BC, and the perceptions of counsellors working with women with BC was triangulated alongside reports from the women with BC. Consistent with qualitative research the sample size in each category was relatively small, however, the amount of data to be collected was extensive and provided rich and textured data as well as a means to reduce researcher bias (Fossey et al., 2002).

#### **5.17.4 Inclusion criteria.**

In this study, it was anticipated that combining variables such as age, diagnosis, time since completion of treatment, would influence the available number of women able to take part in this study. It was anticipated that theoretical saturation would likely be reached with between six and up to fifteen (15) Group 1 participants. Too large a sample size was considered to be uneconomical in terms of time, energy and finances and would have yielded cumbersome amounts of data beyond the point when saturation was reached.

#### **5.17.5 Phases of participation.**

The women were invited to participate in one semi-structured interview, followed by three Opening to Self-Compassion (OtSC) sessions. Participants were invited to take part in a 12-hour (three four-hour sessions) Personal Reflection Program - an experiential creative arts program focused on self-discovery. These sessions did not involve participants undertaking group or individual therapy. In the interests of maintaining participant protection, the program was facilitated by the

researcher who had extensive training in the clinical application of creative arts in therapy.

The OtSC sessions had a twofold purpose. Firstly these sessions gave the women time to orient themselves to the nature of the topics to be discussed. Secondly, responses to issues raised for discussion in the sessions provided a framework for creating the experiential PRP program. The aim of the PRP was to provide participants time and space to reflect, share, and discuss in greater depth their experience of BC, as well as an opportunity to explore their perceptions and revisit their experience in a small group context.

Significant Others (SO participants) were invited to participate in one semi-structured interview. A third group, counsellors who worked in the field of cancer recovery, were invited to take part in a single semi-structured interview.

### **5.18 Data collection**

The qualitative interview has been referred to as an important tool for gathering extensive data (Cresswell & Plano Clark, 2007). Largely directed by participants, the qualitative interview and following the frame of an interpersonal conversational style (Tong et al., 2007). A semi-structured interview is characterised by the fact that the researcher facilitates and guides the interaction (Smith & Osborn, 2008) but does not control or direct it – a type of up-close and personal approach rather than taking the stance of the ‘knower’ who provides and manages a set agenda and priorities for the interview (Galletta, 2013). Semi-structured interviews offered the capacity to be responsive and flexible (Fossey et al., 2002) and optimise opportunities for receiving subjective, rich and complex responses from the women.

Although the interview format was based on a set of pre-defined ideas and questions developed from my previous experience of providing facilitation for group counselling for women in recovery from BC, this approach still was consistent with a feminist perspective where the women being interviewed were regarded as expert, and ultimately the person who directs the process. Because the interview was semi-structured it allowed individually-focused exploration of each woman’s exclusive

experience of their life including their perceptions, attitudes, values and beliefs (Galletta, 2013).

Transcription of audio-recordings of the interviews was attended to either by myself, or for several of the recorded interviews, a qualified transcription service. Five interviews transcribed by a transcription service in the interests of economy of time, were then carefully reviewed to ensure every word had been captured as accurately as possible. Transcripts of the interviews were returned to participants for verification of accuracy.

### **5.18.1 Instruments and procedures.**

Data was collected from the following source:

- one-on-one semi-structured interviews

Additional strategies included in this study are listed below. No measurable data was gathered in the OtSC and PRP sessions. The primary purpose for inclusion was that through deeper sharing of experiences it was assumed that women would reveal truths that may have been obscured by the need to concentrate on physical survival. In that process of deeper sharing and reflection it was considered the women would be able to express extended ideas of personal meaning and interpretation of their experience and their 'world' of BC. Hearing the lived experience of others was considered to encourage personal reflection. The focus was on the way in which participants gave direct expression to their experience prior to interpretation by the researcher of those experiences. Details of these additional strategies are:

- three one-hour (3 hours) Opening to Self-Compassion (OtSC) sessions, and
- observation by the researcher of group responses and interactions in three 4-hour (12 hours) sessions of a personal reflection program (PRP) during which participants engaged in creative arts activities designed to enhance personal enquiry.

### **5.18.2 Opening to Self-Compassion sessions.**

Group interaction was regarded as the optimal way to stimulate in-depth discussion in part because of a snowball effect that happens when groups come together to discuss a personal and socially pertinent issue. Three one-hour Opening to Self-Compassion sessions were conducted to provide participants in the ‘core group’ time to meet each other and to familiarise themselves to the central topics of this study. This number of sessions (3) was considered necessary to successfully orient the women to in-depth discussion within a participatory group context. The rationale behind this strategy was informed and driven by the sensitive and personal nature of the topic. It was integral to this study for the women to feel able to talk freely about their experience. To allow empathic connectedness it was essential to meet more than once so as to allow the development of connection, trust and openness with other group members and with the researcher/facilitator. Topics suggested for discussion at the OtSC sessions were pre-selected by the facilitator prior to the women meeting. This was done because of their relevance to the study topic. Responses to those topics were used to inform the design of self-discovery-focused creative arts activities that would be offered in the Personal Reflection Program sessions.

The group format for the OtSC sessions also allowed the women an encounter of having their opinions accepted and their experiences mirrored in collaborative, facilitated discussion with other post-BC women. The first group session consisted mostly of the women telling what seemed like a familiar narrative. Those narratives were ones used when they had tried to communicate their feelings and concerns to others.

### **5.18.3 Personal Reflection Program sessions.**

The Personal Reflection Program employed the use of creative arts activities. The idea behind these sessions was to provide an opportunity to further explore and ask for clarification of what participants had said during the interviews and OtSC sessions. In addition, using creative arts was regarded as a way to provide non-threatening alternative ways for participants to more fully articulate their experience of BC using creative, expressive methods. In short, it was a means of providing additional, meaningful information for this study; a means of participants having an opportunity to relate with each other in a non-threatening environment, and to reflect

and discuss at greater depth the unique aspects of the way they felt about themselves both before and after BC. The nature of the experiential activities included exploring metaphor, painting, music, journaling, reflection time. No therapeutic work or counselling was offered for the women. The sessions provided only a different way to express themselves and their experience of BC. An acknowledged beneficial relationship between art and health was the basis for deciding the PRP could be an appropriate intervention that could offer the group of women relaxation from the exacting process of trying to process a new life as a BC survivor. Changes in attitudes, beliefs, values or behaviours as a result of participation in the PRP sessions were not measured. This would have been the case had the methodology for the research been quantitative in nature. What mattered was the personal reports of the women of their understanding and experiences – or lack of - self-kindness.

One underlying principle in the practice of ET is the use of some form of creative process – often symbolic – as a method for externalising internal states by offering something the client can do, or create, and then relate to (Malchiodi, 2005; McNiff, 2004; Pearson & Wilson, 2009). The artifacts such as drawings, expressive writing, and self discovery worksheets produced in the PRP have not been used, nor analysed, as data; drawings or expressive writing produced have, however, been used with permission to amplify comments made within the interviews, OtSC sessions or the PRP.

### **5.19 Participant observation**

Participant observation has been referred to as a way to explore and discover social interactions of a group of people (Shah, 2017). As such, this was the methodology chosen for the second and third phases of participation for this study (OtSC group sessions and PRP group sessions). This method was employed as an appropriate means of gaining insight into the historical/personal perceptions of those woman survivors who participated. Participant observation in this project offered the possibility of “gaining insights into behaviour, beliefs and attitudes that participants might otherwise find difficult to articulate or predict” (Moore, 2010, p. 159). While the group sessions did not form a major part of the data gathering process, they were nonetheless a rich source of new knowledge about participants’ interactions with each other, their interactions in a social setting, and the way in which the women



talked about their experiences with BC. Participant observation of the group process provided much greater understanding of aspects of BC culture that either encouraged or demoralised these women. The observations were gathered in a narrative form as notes kept by the researcher as well as photographs of images created by the women participants. The information gathered from this particular group of BC survivors revealed more about beliefs, attitudes and behaviours than would have been possible to glean from interviews only. The tension between involvement and detachment (Shah, 2017) was managed through the researcher taking the facilitator role without engagement in the experiential processes.

## **5.20 Data analysis**

O’Leary (2010) suggested that a researcher check their interpretations with people considered to be “insiders” (p. 33) as a way to consider alternative and even pluralistic points of view. In this study, it was accepted that participants and the researcher were engaged in a collaborative, interpretative processes as meaning was generated through the stages of interview, group sessions, transcription and analysis (Dallos & Vetere, 2005).

Interpretativism has been defined as a way of tapping into complex subjectivities that otherwise may go unnoticed. Interpretative Phenomenological Analysis has been found to be useful for a type of hybridised version of focus group activity that combines an interview style with a focus group approach (Palmer, Larkin, de Visser & Fadden, 2010). Throughout the various stages of connecting with participants for this study, an interpretative approach to analysis involved reflexivity with the focus not on bracketing myself out of the picture, but on being able to provide an in-depth picture of exactly how the interpretative process of reported experiences was undertaken. Application of an interpretative frame of reference offered a medium for extracting both the complexities and subtleties of meaning.

### **5.20.1 Analysis of semi-structured interviews.**

Use of IPA involved detailed analysis and intense examination of verbatim reports from a small number of participants (Larkin, Eatough, & Osborn, 2011). Interviews were recorded using a digital recorder and/or smart-phone facility. The

researcher listened to each audio recording, paying particular attention to vocal tone, voice energy, laughs, pauses and any other indicators of meaning. To maintain a sense of close contact with each woman's interview, audiotapes were read four times and listened to twice, with a reasonable time lapse allowed between listening sessions granted that my first impressions may need to ease and then further develop. In the first analysis, interpretations were not ascribed to interviewee responses (Tan et al., 2009). The first reading was done simultaneously while I listened to the taped material for a second time. This was a way to orient myself with nuances in the spoken word and connect what I heard with what had become the written word.

As transcripts were read for the second time, relevant words, phrases, passages were highlighted. Using a two-margin approach to coding was used. One margin was used to record key words and phrases with attention paid to frequency of possible emergent themes (Dallos & Vetere, 2005). The second margin was used to record in-the-moment reflections of the researcher (Dallos & Vetere; Willig, 2008).

A third review of the transcripts highlighted similarities and differences in responses. Each transcribed interview was then coded according to themes characteristic of different sections of the transcripts (Willig, 2008). This process helped underscore distinctions between major and minor themes. This review helped ensure no relevant themes had been overlooked.

Transcripts were reviewed a fourth time to explore meanings inherent in statements made by participants (Fossey et al., 2002). Themes identified and catalogued in the third reading were reviewed with a view to exploring the relationships and commonalities evident in the themes from each transcript (Willig, 2008). I was also reading to consider if there was a stand-out core characteristic of optimism and strength post BC. Statements made by the women that seemed to highlight the experience of self-compassion were extracted and connected with identified themes. Super-ordinate themes that had been identified were cross-checked against the table of super-ordinate and subordinate themes categorised and classified in the third review (Willig, 2008). Major themes and sub-themes were compared and contrasted with extant literature. These themes were at all stages connected to

extracts from the transcripts so as to maintain a direct link to participants' experiences (Chapman & Smith, 2002).

### **5.20.2 Opening to Self-Compassion (OtSC) sessions.**

Exploration of data generated within these three 1-hour sessions involved coding participants' open-ended talk into categories or themes. Coding aided summarizing and systematizing the data (Wilkinson, 2008, p. 198). Responses from the sessions helped illuminate participants' dominant discourse. From the interview questions a draft list of core ideas or topics was generated and this approach required the researcher to prioritise, from reading and review of transcripts and relevant literature, categories to be included in the list of topics for possible discussion. Review of written notes made during and after the group sessions was used as a means to identify and consider the impact of subtle forms of expression.

### **5.20.3 Personal Reflection Program (PRP) session discussions**

A period of art-making or artistic activity has been found to provide some relief from stress at a time when an individual is experiencing a personally stressful situation (Curl, 2011). Therefore artistic activity was the tool used to allow the women in this group to engage in deeper personal exploration without the risk of adding to their stress. As a result of requests from participants, however, they were re-assured any artefacts created during these experiential sessions would not be analysed as a means of extracting significant data. They were asked if they would, however, be willing to allow photographs of their work to be included in the final thesis. Assurance was given those images would be accompanied by minimal comment that respected the depth of the reflection and shared personal experiences. As a result it was agreed that comments made in the sessions would be used only as a way to highlight an overall theme or therapeutic experience. The process of the group interactions and participant involvement in those sessions was monitored and observed by the researcher using the concepts of participant observation research. Notes made immediately on completion of sessions served to emphasise or highlight themes that had emerged from the individual interviews, and the OtSC sessions.

### **5.21 Protection of participants**

Approval for the study was received from the Human Research and Ethics Committee of the University of Notre Dame Australia. Particular attention was paid, in the application for ethical clearance, to sensitivity to the potential for emotional vulnerability in participants. Survivor and Significant Other participants were supplied with information about available counselling services in the event of any distress as a result of participation. A discussion was had with each participant to ensure they knew that support was available for them. Once ethical clearance was received, recruitment of participants then began.

Names of participants were known only to the researcher. Participants did use their real name at the time of registering an expression of interest and during the interview. However, these names were deleted from the transcripts and were replaced with a name chosen by the participant. For example, they were asked to choose a name that they would want used when the study was published, and that, for each participant, would make it easy to identify their contribution.

Paper-based materials from this study were filed in a locked cabinet in the office of the researcher. Signed consent forms were filed in a locked cabinet separate to other documents and audiotapes of interviews. Electronic files were stored held on a computer that was password protected. All documents such as transcripts, journal notes, photographs of the paintings and images created by participants using miniature objects, and audiotapes, were kept in a secure office accessed only by myself.

### **5.22 Credibility**

In qualitative research it is critical to ensure that not only are participants' views accurately represented but also that comment has been gathered from a range of sources (Fossey, et al. 2002). As a validating strategy, data was generated from a range of sources and analysed in a way appropriate to qualitative enquiry. Intra-method triangulation was used as a way of exposing differing perspectives and identification of any irregularities in the interpretative process. Triangulation provided both a sense of completeness and confidence in the data as well as reducing the potential for bias (Casey & Murphy, 2009).

Interview schedules (Appendices 1, 2, & 3) were reviewed by two independent researchers with professional qualifications and expertise in counselling. Feedback from both reviewers was used to refine the interview schedules. In addition, the design and structure of the multi-phase approach for this study was reviewed by another researcher with expertise in the field of BC research.

Discoveries made were attributed to the collaborative working relationship between researcher and participant (albeit focused and short-term), and the participant's lived-through experience. Useful engagement with participants was met by spending sufficient time with them during the interview process, OtSC sessions and the PRP. Interviews lasted from 50 to 150 minutes, with the average time around 75 minutes. The 75-minute time frame offered enough time to gather detailed narratives that resulted in rich text.

Two methods of establishing reliability – triangulation and obtaining participant verification of and feedback about transcripts – were used. Participant checking of transcripts gave participants the opportunity to validate my interpretation of their stories. None of the participants provided negative feedback from reviewing their transcript. One woman commented that she felt the study gave her an otherwise missed opportunity to reconsider her self-relationship. Yet another commented that she felt deeply moved when she read her interview – she had forgotten how challenging the process of BC had been for her. Others participants gave positive feedback about involvement in the study.

To provide referential adequacy for this study I read extensively in the area of qualitative research, particularly phenomenology, read texts from both authoritative academic sources and from self-help collections about cancer and BC, and listened to audio-recorded material. My reading and listening concentrated on what was being written and said about the history of treatment regimes and the psychological sequelae of BC, about shame, guilt, and self-acceptance. I became acutely conscious of the emotional experience that coincides with hearing someone has received a diagnosis of cancer and had renewed insight into the phenomenon of living with the legacy of BC.

### 5.23 Chapter summary

The primary benefit of qualitative enquiry is that it has significant application in the field of health research (Aisbett, 2006). More specifically, research into the domain of psycho-social interventions for BCS becomes problematic when consideration is given to the uniqueness of personality, personal cultural history in forming and maintaining relationships, and the nature of a woman's relationship with her body. Taking a phenomenological approach to exploring the individual's experience of self-compassionate relating in women survivors of breast cancer afforded a way to clarify the nature and practice of self-kindness in BCS. Additionally, using Interpretative Phenomenological Analysis meant the potential for evolution of knowledge and understanding of the psychological wellbeing of BCS could be realised through gathering first-hand reports of how a BCS relates with themselves and significant others. IPA meant more accessible understanding of the phenomena of self-relating and provided a more flexible way of reporting findings. Applying a phenomenological lens in this study also provided a way to take notice of non-verbal ways of communicating experience.

Social construction theory helped draw attention to the role of social stigma in the experiences of BC survivors. This is an area of importance for women who survive. Social constructions of BC can impact on a woman's capacity to shape their own response to BC. In summary, social constructionism helps identify that public discourse on BC and survivorship can unwittingly 'locate' any challenges (with pessimism or optimism) within the individual of the woman herself .

During the writing of this thesis four close relatives were diagnosed with cancer; two of whom have survived. This close personal encounter provided me with greater insight into how the phenomenon I was exploring was understood by each participant in this study. Conversations with women not participating in this study, but who had lived through BC occurred by happenstance and without my initiating discussion on the topic. These coincidental and animated conversations with people I had never met and may never meet again took place on bus journeys, at conferences, at social events, and in a myriad of unlikely ways and places. Each conversation informed and extended my relatedness to and engagement with the topic of self-compassion. In some of these conversations the women talked openly and

unashamedly about their experience and how they now related with themselves and others. Others, I observed, talked in quietened tones and while giving a lot of detail about what they had been through, contained the discussion to the two of us and changed the topic if we were ever joined by a third person.

## **Chapter Six**

### **Findings**

#### **6.1 Overview**

In this chapter, findings from three sources are presented in three separate sections.

Section 6.1 presents findings from interviews with 17 participants, as well as summaries of observations from the Opening to Self-Compassion (OtSC) sessions and Personal Reflection Program (PRP) sessions with a group of eight of the original 17 women participants who volunteered to take part in this study.

Section 6.2 highlights findings from interviews with three male significant others (husbands) of women with BC.

Section 6.3 offers findings from interviews with three female counsellors who have worked as professional emotional support for women with BC.

Pseudonyms have been used for direct quotations from all participants.

A record of my observations during the first of the PRP sessions is included at Appendix 6 (p. 412).

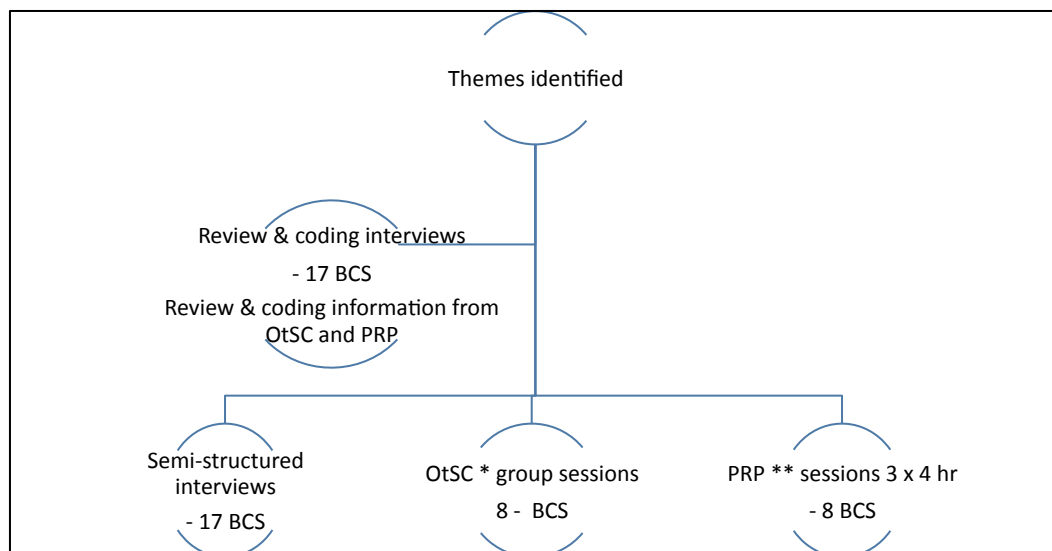
Images of women survivor's responses to expressive therapies activities in the PRP sessions have been presented in Appendix 7 (p. 417).

A section of my personal reflection journal is included at Appendix 8 (p. 425).



## 6.2 Women survivors of BC

Seventeen women chose to participate in this study. Each was interviewed in an individual face-to-face semi-structured interview. Of the 17 participants interviewed, 8 women accepted the invitation to take part in three 1-hour (3 hours in total) OtSC sessions. In addition, those 8 also agreed to participate in three 4-hour Personal Reflection Program (PRP) sessions. Interview narratives from the remaining nine women was reviewed several times and used to ensure saturation of themes had been reached. This process of review of data to establish the point of saturation is discussed in Chapter 5 - Methodology. Diagram 7 represents a 5-step systematic process followed for gathering data from women survivors who participated in this study.



**Diagram 7: A 5-step process of theme identification**

\* = Opening to self-compassion groups \*\* PRP = Personal Reflection Program

At the time they received a diagnosis of BC, each of the women, whose narratives of that experience are presented in this section, were living full and active lives with families, careers, and social networks. Some of the women reported high levels of stress in their work life in the year prior to diagnosis. One woman talked about the demands from her commitment as carer to an aging relative while another woman spoke about the strain of supporting one of her children who was experiencing a profound state of depression. The women could be characterised as middle class socio-economic status. Each of the participants were married, with one

recently separated from her husband. All but one participant had children ranging in age from 15 years to late thirties.

All participants had been treated for BC through surgical treatment lumpectomy, mastectomy or radical mastectomy. In addition, each had undergone radiotherapy and/or chemotherapy. Two of the women had chosen to have breast reconstruction. Treatment to avoid recurrence was being implemented with daily doses of oestrogen-blocking medication with none of the women having passed the critical 5-year survival mark, although one participant was approaching that point. None of the eight women had a previous personal history of cancer, although two disclosed they had a family history of cancer, including BC.

Table 2 presents known demographic information about the women participants who completed all three phases of participation.

Participant	Relationship status	Time since diagnosis	Surgery	Radiation	Chemotherapy
Geneva	M	2	Yes	Yes	Yes
Carole	RS	5	Yes	Yes	Yes
Shirley	M	4	Yes	Yes	Yes
Lara	M	2	Yes	Yes	No
Jenny	M	1	Yes	Yes	Yes
Gemma	M	4	Yes	Yes	Yes
Terri	M	2	Yes	Yes	Yes
Beverley	M	1.5	Yes	Yes	No

M = married RS = recently separated

**Table 2: Demographic data for PRP group participants**

The demographics of these women is represented here because their narrative information was indicative of overall participant demography. Throughout the findings in Section 6.1 comments from some additional participants who had taken part only in the semi-structured interview), have been used to amplify the significance of a theme (e.g. Nicole, Wendy, and Stephanie). Time since diagnosis refers to the time in years that had elapsed between diagnosis and the time of

interview. The column titled surgery refers to mastectomy (single or double), or lumpectomy.

Finding a breast lump immediately raises the possibility that a malignancy might be present. A woman facing a diagnosis of BC may immediately construct an emotionally negative threat from positive identification (Montgomery & McCrone, 2010). The ways in which an individual will define or express tension, anxiety, distress or shock are varied (Hewitt & Holland, 2004). The variability in expression of emotional distress can bring initial confusion to the task, both for the woman diagnosed and for significant others, of being able to recognise exactly what feelings are experienced, what thought processes have been generated, and what action steps have been suggested or decided. Evident in this study was the fact that not all of the women openly expressed heightened levels of anxiety and distress on receiving a diagnosis of BC. However, this did not mean they did not actually register, at some level, any intensification of emotional distress, or had any concerns about survival. Investigation of the major themes identified by the women in this study highlighted a variance in the way they described their response to initial symptom discovery and eventual confirmation of a definitive diagnosis of BC.

From the narratives provided, it was clear that themes overlapped with each other considerably. Identified themes were found to be strongly interconnected. Major themes as identified from disclosures by the eight women participants in the PRP group are listed in Table 3 below. Themes were validated when checked against interview transcripts from the remaining 9 women participants (who chose not to take part in the OtSC or PRP).

	<b>Major themes</b>	<b>Associated themes</b>
<b>1</b>	Response to diagnosis: <i>“I never said why me”</i>	What do we do now?
<b>2</b>	Survival and the meaning of life: <i>“I don’t have a Plan B”</i>	Survival is the only option Fixing the problem
<b>3</b>	Support: Receiving/Not receiving: <i>“People care in different ways”</i>	Allowing themselves to receive; Disappointment at not

		receiving;
4	Cognition and functioning: <i>“The kitchen’s a mess”</i>	Chemo-brain and fatigue
5	Putting myself first: Adjusting the priorities: <i>“I’ve changed a lot I guess”</i>	Change in their self-responsiveness
6	Emotions and personal growth: <i>“I’m a more spiritual person”</i>	Some things are harder than cancer
7	Relationship with my body: <i>“It’s carrying my soul and my heart”</i>	Ignoring the warning signs; I think more about it now
8	Self-worth, self-blame: <i>“We’re over-generous givers”</i>	Being of service to others
9	Unexpected benefit: The gift of cancer: <i>“It’s probably been more positive than negative”</i>	I realise I’m stronger than I thought
10	Self compassion: <i>“Learning to say no”</i>	Beginning to know self; I don’t want to be selfish
11	What women need: <i>“The young ones - they need to know”</i>	Wanting to help

**Table 3: Major themes for women participants**

### 6.3 Findings from women survivors of BC

#### 6.3.1: Response to diagnosis: *“I never said ‘Why me?’”*.

Emotions are resources that help humans to solve many of the challenges faced in daily living. Emotions are also regarded as socially learned responses constructed within each person’s culturally specific situation. This first theme reflected the women’s attitudes to the announcement that BC was now a permanent aspect of their future. BC had forced them out of a comfortable illusion about their body, as well as about wellness and health.

Women who are able to be more optimistic about a possible cancer diagnosis have been found to worry less about the diagnosis than women who have a pessimistic response to a potential diagnosis of BC (McGregor, Bowen, Ankerst, Anderson, Yasui, & McTiernan, 2004). Other research findings highlighted the need to help women successfully navigate the experience of diagnosis and the transition to survivorship (McCann, Illingworth, Wengström, Hubbard & Kearney, 2009).

Diagnosis meant that for each of the women their assumptions about how they expected life to unfold was dismantled. However, as a strategy for coping, a number of participants in this study had engaged in a type of cognitive bypassing to temporarily conceal or suppress initial fears and concerns. Their focus was not on what could be anticipated as a frequent response on finding a breast lump, but on containing and restraining emotions, and preserving an exterior orientation of coping as a way to avoid emotion-laden responses. The women's responses to diagnosis indicated that maintenance of equilibrium in relationships with significant others was an important means by which participants maintained their own equilibrium at a time of inner turmoil.

Shirley's BC had been diagnosed when she was around the age of 66. She had discovered a breast lump while on holiday with her husband. Being a long way from home meant a delay of almost two weeks before Shirley was able to consult her regular General Practitioner. Shirley said the delay did not really mean a worrying time for her. She reported being able to use "*self-talk*" that the lump "*could just be a cyst or an abscess*" to override what she said was her deeper knowing. Shirley did admit, however, to an internalised concern for her husband if the 'cyst or abscess' were something more sinister. She divulged "*I didn't want to spoil the holiday for [him]*". Her next comment highlighted her intuitive knowing that the presence of the lump was most likely to be something other than a cyst. Shirley said "*I knew deep down*" but again, went on to comment that she "*didn't want to spoil it [their holiday] for me*". The power of her capacity to dispel, temporarily, the thought of threat of confirmation of BC became more evident when, in our discussion, Shirley admitted "*I was stunned when I found out*". However, she talked about being able to quickly adopt a rather philosophical approach to diagnosis and commented "*but I never said 'Why me?' ... because other people get it ... you know*".

Shirley's response to diagnosis was one of learned stoicism. She said she was pleased with her capacity to contain her emotions when talking with her doctor, even though "*all I wanted to do was cry, but I thought well, crying's not going to ... all it's going to do is make me wrinkly*". While confessing in the interview that the diagnosis of BC was "*not the result I hoped for*", Shirley responded to her doctor by saying, "*I can't change it*".

Likewise, Lara also spoke about her “*initial shock*”, and similar to Shirley, Lara said that she too “*didn’t have tears and crying and all that sort of thing. It never occurred to me to do that. And, it never occurred to me to say “Why me”*”. Lara explained that at the time of diagnosis she thought of herself as “*a pretty good candidate for it [BC] because of the lifestyle I led*”. This comment related to Lara’s discussion about seriously elevated levels of stress she experienced as a result of workplace bullying. Lara disclosed her firm belief that the intense, prolonged stress had caused, or at least been a significant contributor, to the development of BC.

Lara pointed out that her way of dealing with crises or difficult life events was to get in and do something. Lara was not one to sit and wait for someone else to get things done. She talked about removing and re-laying pavers around her house, doing some work on the roof of her house, and providing emotional support for her daughter whose partner had died in a motor-vehicle accident not too long before Lara was diagnosed. Adversity was no stranger to Lara. Part of her life story was that as a child she had supported her parents to adjust to a very different life in Australia after migration from Eastern Europe, she had experienced a “*breakdown*”, and had struggled with “*fairly major depression in my life*”, and had an ongoing challenge in the form of a blood disorder that required constant monitoring. BC simply presented another field on which Lara’s resilience would be tested through struggle. Lara commented that “*I think the first couple of months – maybe 3 months or so, I was on adrenalin. I felt the best I felt in a very long time*”. Lara’s reaction was “*wow ... its as though I had something bigger to do than going to work each day*”. She was positively motivated by the fact that “*I had something else to do and ... I had a fight on my hands*”.

On the other hand, Jenny referred to her experience of diagnosis as “*fairly traumatic*”. The primary thought for her was “*I can’t cope without breasts*”. Jenny recalled that while she felt she would be able to manage chemotherapy and radiation, the thought of a mastectomy or double mastectomy generated significant distress. For her, the surgical procedure itself did not generate fear, but the prospect of having her breast removed generated an intensely negative reaction. “*I just can’t [cope]*” because “*I’m only 54, I’m in an active sexual relationship, and I just can’t...*”. Prior to her surgery Jenny’s thoughts were that the outcome of BC would mean her sexual

functioning would be seriously impaired, and sexual expression between her and her husband would no longer bring the pleasure they had enjoyed.

In contrast, Geneva sounded quite accepting of her diagnosis when she spoke of her experience of finding a lump and then progressing toward the process of a confirming diagnosis. From her close emotional proximity to two other female family members (not biologically related) diagnosed with BC eight months previously, Geneva had a feeling of immediate certainty that the lump she could feel was likely to be a BC. Her experience as a nurse, and her personal experience in previous months meant she knew the signs.

*Once I felt the lump I figured out that that's probably what it was, because I'd had two sisters-in-law, one on either side, diagnosed in the ... eight months previous to that. So I kind of ... you know... you knew what to look for ... and ... what to expect.*

Geneva felt surrounded by the occurrence of BC and recounted “*there was about eight people within the space of a year that I knew, including us who'd been diagnosed ...*”. Perhaps as a sign of uncertainty about discussing something so personal with a stranger, Geneva used humour to follow up on her statement to me about knowing so many women diagnosed in such a short space of time. A gentle laugh led into her comment “*so it takes the specialness away when something like that happens*”.

Two other participants had also made comment in their interviews about having a sense of personal validation, as well as feelings of now being special having been generated by their diagnosis of BC. They seemed genuinely perplexed that the attention from friends and family had waned not long after treatment had ended. One of the women, Penny, had commented that she was disappointed because she felt her sister had received much more supportive attention during her time with BC. Penny's sister had died from the disease some months prior to her own diagnosis. The difference when speaking with Geneva was that she made her comment with a wink, a broad smile and a solid laugh. It seemed as though Geneva's non-verbals indicated her comment was not one to be taken as fact. Penny's comment was an accurate disclosure of her experience.

Terri commented that she had a feeling of relief and gratitude when first advised by a medical specialist that “*we think it’s just a benign lymph node. Don’t worry about it*”. But the lump under her arm was “*in a funny place*” and Terri recalled that her doctor re-assured her “*it will be OK*”. Because of the unusual position of the lump Terri said she thought “*maybe it was a metastatic melanoma, or maybe it was some other horrible thing, because it just wasn’t typical*”. She talked about actually feeling relieved to eventually learn that the lump was a “*primary breast cancer*” Terri went on to comment that the next steps were that “*I had surgery ... they took out three lymph nodes ... they were all negative, and I was sewn up and on we went*”. Terri’s attitude to life was one of expressive optimism. She had a belief system that she felt gave her ‘strength’ and courage to face adverse life experiences. It seems that Terri’s relief was that she regarded BC as something much less threatening than other possible diagnoses. BC was something Terri felt able to overcome. Terri’s perspective was that a diagnosis of BC meant survival was more likely than not.

By the age of 44, Gemma had not ever had a mammogram, but was aware that the time to do so was probably drawing closer. After feeling a lump Gemma had thought to herself “*that’s not normal, I wonder what that is*”. An immediate visit with her doctor meant she was referred for an urgent fine needle biopsy and mammogram. Gemma’s career was in the health-care field and this meant she had some knowledge and awareness of what did not look ‘right’ on the screen her mammographer was viewing. Gemma said although her health knowledge was limited, she was “*looking at the screen ... and there’s a big black thing there ... and I’m thinking that just doesn’t look normal to me ... it just didn’t look right. And you just know it’s not good*”. Identification of her BC came as a result of an MRI because the manual exam, mammogram and ultrasound did not provide conclusive evidence of BC. But Gemma’s cancer was in the form of “*diffuse cancerous cells all through my right breast*”.

Similar to other participants Gemma made comment on her ability to absorb the shock inherent in news of her BC. She recalled that her GP was slightly taken aback by her capacity to so calmly endure hearing bad news. “*My GP actually said to me when she first gave the diagnosis ... ‘I can’t believe you’re so stoic’*”. Gemma



seemed pleased with herself when she commented that *“I had had a tear, but I didn’t fall apart in a mess”*. Later in our interview Gemma admitted there was a point, prior to being called in to her doctor’s office to receive the results of the tests, where she *“got really alarmed”*. The reception staff had mistakenly handed the pathology report to Gemma in the expectation that she would take them with her into the doctor’s office. Her first step was of course to read the report herself. Reading comments such as *“necrotic cellular ... blah blah blah”* Gemma said her instantaneous thoughts were *“I’ve got breast cancer”*. She said *“I went into the GP knowing I had breast cancer”*.

Talk about BC activated, for Carole, memories of the past as well as recollection of the challenges she now faced since treatment had ended. One of the most significant memories was the fact that Carole’s mother had BC although she did not die from the disease. Regardless of family history, Carole recalled that *“the doctors said ... ‘it’s not related’”*. She also remembered being told by her doctor *‘there’s nothing to worry about’*. This advice was given just a couple of months prior to being diagnosed with BC. Similarly to Geneva, Carole exhibited a somewhat philosophical response to the fact that she had eventually received the same diagnosis as her mother.

At the time of interview with Carole it was exactly five years since treatment had finished. My observation was that discussion about her experience of BC, and her relationship with herself and others, seemed less emotionally charged than for some of the women who had completed treatment more recently. However, a lumpectomy, radiation and chemotherapy had taken its toll on Carole. She felt it had taken her 5 years to recover from treatment and that her journey with BC had been intense and challenging. Carole felt there was a lack of understanding in others of the broad-ranging after-effects of BC. Her perception was that *“Its just not like a cold, which many people think it is. You know ... you have a cold ... six weeks later you get over it, but it’s not like that at all. And yeah ... you just live with it”*.

The ‘knowing’ with which another participant, Beverley, approached her diagnosis was similar to the response spoken about by both Gemma and Shirley. Beverley remembered *“that very first time, when I was waiting to hear what the*

*diagnosis was, I knew. I had the feeling that yes it was ... what it was going to be ... from all the indications*". Comments she made to a cousin who was her support person on the day, highlighted the depth of Beverley's understanding. Beverley recalled speaking with her cousin in the following terms as they waited to see the doctor. *"Everything is going to change. Everything is going to change now ... nothing will be the same (said with emphasis). It's all going to be different now"*. Beverley felt that her 'knowing' was *"like a bit of a ... you know ... premonition. And it was very true"*. Indicating that once the diagnosis had been made she began to reflect on what this would mean for her life, Beverley went on to say that her deep knowing that *"everything is going to change now"* was true *"because once you've been told that you have a malignancy ... well then ... your mortality comes into perspective and you realise ... that ... what it's all about"*.

### **6.3.2 Survival and the meaning of life: *"I don't have a Plan B"*.**

For the women in this study, diagnosis provoked a state of mental ambiguity between the will to survive, and either an acknowledged, or stifled but present, fear of death. On the one hand, the women felt optimistic and encouraged by reminders that a very high percentage of those diagnosed survive. On the other hand, the shift from 'patient' to survivor meant these women entered an indistinct phase of uncertainty about what their future would be or what health issues they might encounter as they lived with any unanticipated legacy of BC treatment. While the women in this study most likely knew the spectre of a poor prognosis hung over them, a decision each of them made was to concentrate on physical survival and beating cancer. Despite this, many of the women spoke during their interview about the fact that, even if they did not acknowledge it openly at the time, diagnosis had confronted them with their own mortality. Most participants also reported that they made a decision to set those thoughts to one side and actively work to ensure they were amongst those who survived. The implication of these reports was that taking action to 'rid' their body – and their life – of BC was more of an immediate imperative than consideration of the emotional impact on them. Loss of control was a significant issue for the women. Seeing life in a bigger picture of physical survival became a major focus. To some extent thinking about their emotional crisis was deliberately delayed through taking 'action steps' that could likely ensure survival.

There were shared commonalities in the women's stories of their BC experience. One of the experiences commented on by at half of the women was that despite being ill they considered themselves adept at being able to put to one side any inclination to collapse into fear. The women's comments emphasised their capacity to reconceptualise their relationship with life now that BC was definitely in their orbit. The re-conceptualisation process would involve physical, mental and social challenges such as diet, exercise and reviewing their worklife.

Beverley was aware from initial diagnosis that "*I did have to think about dying ... about my mortality*". However, she went on to say that "*I didn't think about it too deeply because I didn't have a lot of spirituality*". Without a belief system that subscribed to the idea of there being an 'afterlife', Beverley felt that death was death. The end of life was an event for which she had no frame of reference or no way to conceptualise. However, as treatment for BC progressed Beverley began to draw emotional strength and connection from BC support groups. Participation in support groups brought a subsequent change in her worldview. She said this was because "*then my spirituality grew. And so then I thought a lot about dying and what it was all about ... the meaning of life ... and everything*".

Lara talked about her resistance to seeking out in-depth information about BC that might generate a negative view of her chances of survival:

*I didn't want to read up. I was thinking about going on the internet to read about all sorts of things, but I thought "no", I don't want to see words like 'terminal' and 'death' and all of those things that were very off-putting. So I thought no, I won't even go there.*

Lara revealed that after returning home from hospital she "*was on an absolute adrenalin high*". She added to this statement by saying "*it never even occurred to me that death was a possibility ... until my son said something that suddenly burst the bubble*". Another instance that had put Lara very much in touch with the gravity of her situation was a comment from her employer. The comment was paraphrased by Lara as "*doesn't she get it ... either it gets you or you get it*". This statement activated in her a sudden awareness of her mortality and the fact that there were no guarantees about length of life left. Lara explained that it was only at

that point in time she thought of herself as having a limited future, but contemplation of a negative outcome was short-lived. Lara said that she thought about death only “*sort of ... for a very short time*”. She went on to say that her thought processes changed from that time onwards:

*Then I thought ... it's not going to happen to me. I'm going to do everything I can to do all the right things to get me well. I started to do meditation, I went to courses, I went and did the exercises ... I went and did basically ... they tell you to do it ... and I'm still doing it.*

Rather than dwell on the spectre of death, Gemma approached her situation in a slightly different way to both Beverley and Lara. Gemma's response was one of pragmatism:

*I can just remember thinking OK it's breast cancer and the first thing is ... what do I do now ... not fall apart ... it's like ... what do we do about it?"*

Gemma acknowledged that “*another thing I've learned about myself is I do 'get' things*”. She was able to ‘get’ that, for her, she wanted to be pro-active in her response to the diagnosis. Gemma focused her energy and concentrated on what practical steps were to be faced. She commented that her immediate response was to devote her thoughts to “*what do we do about this*”. Hinting at the absence of emotion in her more rational response, Gemma said “*... and I don't feel ... perhaps that surprises me, but its sort of logical all at the same time ...well to me it's logical ... its just, like, do something about it*”. Gemma continued her recollection by giving a clearer description of the way she responds to challenge:

*I'm not one to sit and go 'oooooh' and worry ... well, I do worry about stuff, but I'm more likely to try and act in some way. I'll take action. OK, this needs to be done ... just get it done.*

Similarly, Shirley was not one to dwell on the fact that her BC could be terminal. When her doctor clarified that “*it's not good news*” Shirley confessed that she responded to his serious delivery of the news with a laugh followed by a directive to her doctor. She said, “*yes, but what are we going to do about it?*”. Her reply to him caused the doctor to pause and check “*do you understand it is cancer?*”. In that discussion with her doctor Shirley maintained her focus on the task ahead -

survival. She asked her doctor “*so what are we going to do about it now?*” Talking about survival, Shirley described herself as a person who “*didn’t have a ‘plan b’* “. For her there were no optional outcomes. She explained there was only ‘plan a’ which was a code-word Shirley used rather than the word ‘survival’. Shirley emphasised that her only response to the doctor was to focus on problem-solving and finding a useful direction. Her mantra was “*what are we going to do about it now ... that’s what I need to know, I need to know what I can do*”. Shirley made this last statement with a strong emphasis on the word ‘I’. Her primary interest was to move toward a solution rather than look back at wonder why. She wanted to avoid feeling helpless in the face of a powerful ‘foe’.

Shirley pointed out that while she could acknowledge the possibility of cancer recurrence she always felt confident and optimistic about survival. She highlighted the personal empowerment she had gained from confronting her own fears about death. Shirley regarded the prospect of recurrence as something she felt able to confront both physically and emotionally. To highlight her hopes about being resilient in the face of recurrence, she said, “*it [recurrence of BC] doesn’t concern me ... I know that I can deal with it ... because I’ve dealt with it before*”. These comments indicated that Shirley now felt she was more mentally informed, and emotionally and physically prepared should cancer be found in her body at some future time.

Faced with a diagnosis of a life-threatening illness Terri highlighted the change in her relationship with her husband and at the same time a deeper sense of life having meaning for her. The certainty of BC and the threat it brought had an immediate impact on her relationship, and what her marriage meant to her. In speaking about her marriage, Terri commented that BC “*brought us a lot closer together in that for the first time he had to face that I might not be there*”. Life had taken on a new self and husband-centred meaning. BC had generated a new sense of value for the ‘other’ in her life. BC had also generated a changed perception of what life was about. Terri started to think about the fact that she had not been able to have children, the importance of family in her life, and about her love of her career.

Geneva explained that her life was very full and busy at the time she received the diagnosis and was progressing through the eight-month treatment regime. When talking about her BC experience Geneva situated it in a bigger picture perspective. Her capacity to adopt a reasoned approach to her illness was highlighted with Geneva's comment that although the "*most challenging [part] was the chemo ... because I did feel quite sick during it*", she added that she was aware of another woman who "*had a more severe form of chemo ... and, mine was ... easier than hers*". The capacity to look outside of herself and analyse her predicament in comparison to the situation of other women with BC gave Geneva a sense that the life event she faced was somehow less demanding.

The decision to have a breast reconstruction at the same time as her mastectomy meant the three months until surgery moved slowly for Jenny with a number of decisions to be faced before the scheduled date for the operation. Her faith in God had offered Jenny a sense of stability in life both before BC and through the time waiting for and undergoing surgery. However, she stated that when it was suggested to her to "*pray away*" her BC, she had enough understanding to reject the notion. In the hours post-surgery Jenny said she "*was still in the stupor of the anaesthetic*", but had a clear memory of an intense feeling of confidence so much so that she made the comment to her husband that even though she had a "*full auxiliary clearance and ... got to have full chemotherapy and radiation*" she felt confident that "*I'm going to be alright*". Jenny found her experience in the immediate time post-surgery to be affirming of the value of life. Physical recovery was steady and positive. But several months later, after experiencing a period of elation and high energy, Jenny succumbed to a deep depression in which living lost all sense of purpose and meaning.

Not all of the women participants were as resigned to having had BC and not all were able to say they held no fear of the future. Judy stated clearly that she was challenged by the thought that "*I can die from this*". After a pause, she went on to mention that "*... that's something I still have in my mind*". Judy's way of coping with the fear was to avoid using the word 'cancer' and to engage in an internalised, silent, dialogue with her body. Judy explained this in the following words:

*“I don’t like the word cancer ... I call it hiccup or it ... and I have said to it “I have locked the door and I am holding that damn door and you are not going to get through there ... so stay away”.”.*

Judy’s determination to stay positive and to only talk in positive terms of her recovery were acknowledged as useful, she said, by one of her doctor’s. The acknowledgment of her efforts was validating for Judy.

### **6.3.3 Support: “People care in different ways”.**

Breast cancer is a disease encountered by the whole family even though only one person is diagnosed. Others within the family experience their own form of suffering. Propelled into the unfamiliar environment of a healthcare system and cancer treatment, families have little time to emotionally, financially and psychologically adjust to a changed life. For the women in this study, family and social support became a balancing act as significant others were challenged to develop the willingness and capacity to notice what the woman survivor was thinking, feeling, needed, or even feared.

For some women in this study a sense of deep connection was made with people who had not previously been in the category of close friend. Similarly, some family members were able to make a solid commitment to being the support person throughout the treatment phase. Other women wanted family not to fuss over them or try to anticipate their needs and felt relieved when the relationships in the household maintained the appearance of normality. Yet other women chose activities such as yoga and exercise as a self-support mechanism.

Differences in commentary about the support and caring received from family, friends and relevant others indicated that support can be a complicated issue. Some participants were reluctant to accept compassion and care from others to support them during an anxious time. For those women they preferred family members to integrate the diagnosis of BC as just another life experience and take it in their stride. One of the most telling comments was from Shirley who was pleased that her family treated her ‘as normal’. Yet other participants indicated some disappointment that an expected level of intense support was perceived by the

woman as not forthcoming. Several women spoke directly that advice-giving was not welcomed. There were comments also about not wanting people to give unsolicited positive comments about survival. The indications are, therefore, that how care is communicated to BCS is a complex rather than straight-forward process.

Participant comments showed one of the problems was that both a woman diagnosed and family members could encounter feelings of burden and distress from different sources and at different times on the journey through BC. This could make a coordinated helpful response to living with BC challenging. Through review of participant statements a question arose about whether significant others may at times be the ones to exhibit fear and concern that may not yet have been acknowledged by the BCS herself.

The theme of gratitude for the support they received from family and friends. In particular, Lara found that an unanticipated consequence of her diagnosis was that it connected her with friends in positive and surprising ways. She revealed that on the day she was discharged from hospital a friend phoned to ask to visit Lara that afternoon, saying she and another long time friend of Lara's would "*only stay a few minutes*". Lara spoke with delight and laughter when she recounted that "*they arrived at 3pm [and] we didn't finish up until after midnight ... it was the most incredible night of laughing and tears and it was the best medicine I could've had*". Talking about the value of having friends connect with her, Lara also mentioned an awareness that "*[some] people complain that a lot of their friends can't deal with it and they've lost friends because of their diagnosis ... I've had the exact opposite, people have been so friendly, so helpful, and I think I'm blessed*".

In contrast to the support from female friends, Lara highlighted her experience of feelings of empathy as well as uncertainty in relation to whether she could trust that her husband "*knew how to handle things*". In this comment Lara was referring to an uncertainty about whether emotional and physical support would be available when she needed it. Commenting that "*he wasn't 100% sure what to do or say or how to react*". Lara said she found the way he responded as "*hard*" for her. His response was to encourage Lara to return to her normal life as soon as possible. "*... he wanted to keep things on an even keel as if nothing had happened*". In the



comments about the lack of emotional support from her husband, Lara emphasised her sadness and sense of alone-ness. For her, there was an absence of being able to have a safe place where her thoughts, feeling, and fears, could be heard and acknowledged.

Shirley talked about how she “*had a lot of support from the family*”. She remarked that “*they just treated me normally*”. To clarify this comment further she said, “*although they looked after me, they didn’t make excuses for me*”. Shirley expressed how comfortable she felt with the fact that, for her family, having BC was a situation which she felt they treated as something not to fuss about. “*Mum’s mum, you know, she’ll be OK, we’ll all get on with life*”. Having made this comment Shirley, whose interview took place in her back garden, also pointed out that it was “*not that they were ignoring ... I mean they were all upset ... but they weren’t ... um ... overpowering, except “B” [names husband in a lowered voice so as not to be overheard]*”.

It was important to Shirley that BC not intrude significantly on her sense of normality. In relation to receiving support, she felt much more comfortable that “*family and friends let me live my life*”. An experience Shirley spoke about at length was the ability of her family to continue to regard her as a well person rather than seeing her as ill. She found it easier when they did not relate with her as a person needing assistance or careful attention:

*Even though they kept an eye on me they didn’t... they let me be me... they let me cope the ways I wanted to cope. And I ... sometimes we’d have a laugh or they ... you know ... would have a go at me ... or something ... and I’d think, yes, I am ... I’m still mum, they still love me regardless of what happened. You know... so....*

Inside herself Shirley was aware of a tension between a desire to keep life as normal as possible “*because I .... If I’d stop and think about it I’d crash because ... I don’t think I’m a very strong person*”, and a simultaneous positive realisation “*but I guess I am*”. Shirley’s realisation that she was psychologically stronger than she thought “*made me realise that you don’t have to go round and think poor me*”. Shirley qualified that comment by adding “*And I know that people cope in different*

ways". Shirley also acknowledged that *"I didn't realise how sick I felt until I got better. But having said that, and I know this sounds strange ... I had a lot of fun with it"*. One of the ways in which Shirley felt she had *"fun"* with the BC diagnosis was when she *"bought a red wig and that was the fun bit"*. Wearing her red wig, she said, *"made me feel good ...it made me feel that yes, you are alive...yes, you're going to make it"*. Maintaining a sense of humour throughout helped Shirley to keep to the path she had set for herself when first diagnosed. Humour was integral to her care and support of herself.

Terri commented about feeling grateful for considerable emotional support she experienced given by her sister. Her sister had taken on the task of accompanying Terri to chemotherapy sessions and Terri repeated a comment made by her sister when they began their journey to the hospital for the first session. Her sister had said *"I'll give up my life for the next 6 months for you"*. This commitment held significant meaning for Terri who had always been the one to offer support and comfort to others. She commented, *"... how about that ... you can't replace a sister like that can you!"*. The support Terri felt helped her accept that she was valued and loved by people close to her. Support for Terri came in a variety of ways, not just emotional sustenance.

Terri's experience of support from unexpected sources brought positive memories for her. People, *"that you never expected"*, she said, *"came out of the woodwork to help"*. Kindnesses from *"a little angel that dropped on my doorstep"* who delivered bowls of home-made soup each time Terri had chemotherapy, and who attended to planting strawberries in her vegetable garden, were significant reminders of emotional nourishment from others. Terri also spoke about her surprise at the lack of support from people she thought *"might've been the most close to you"*. She mused during the interview about whether *"they couldn't handle it and so they kept their distance"*.

As Gemma spoke about the support she received her emotions welled up. After a long pause she said, *"it's hard to speak ... um ... family and friends, just the support that you get ... that stumps me"*. In discussion about feeling supported, Gemma commented that some women she knew preferred to *"keep it [BC] totally*

*quiet ... who didn't tell ... really, anyone*". Talking of her own experience she said, *"how on earth can you hide that you've lost your hair"*. She went on to say that *"I would regard myself as open, but not feeling like I had to go to the top of a mountain and yell it out"*. Gemma was very aware of her willingness to speak freely about events in her life. She expressed her willingness to talk about her BC, and rather than internalise emotions, she said, *"I do probably tend to want to vent or say it out loud rather than sit on it"*. Gemma's sense of personal dignity and independence was firm and her comments about support indicated that sympathy was not what she wanted. Empathy and awareness were more valuable to her. As Gemma said, *"I didn't want anybody wanting to be overly sappy and overly commiserating and overly whatever... it's just going ... even someone saying ... or showing that they are thinking of you is enough ... to say, you know ... and for people to perhaps be aware"*.

Carole recounted that her adult children and *"several friends ... that were very good"* provided a safety net of support. Her ex-husband from whom she had recently separated, featured in her memory of what supported her, saying he was *"very good at the time"*. Carole compared what was helpful with what had not been so helpful. She talked about the general lack of understanding of others about the after-effects of treatment. Referring to advice-giving from one friend, Carole recalled:

*I think she thought once I'd finished [treatment] I'd be over it. And she was the one telling me to break up with my husband. She said "Break up with your husband. You don't wanna get breast cancer again". And she said "And I don't wanna get breast cancer 'cause I'm worrying about you"*.

Although delivered in a well-meaning way, advice-giving was something Carole regarded as out of step with where she was physically or what she needed emotionally.

Not all women enjoyed community support. Wendy commented:

*I found it very disappointing the amount of care I got from other people, but that was me expecting it to happen ... you know like thinking there was this great support system in a way for me. But there actually wasn't because I*

*found after having cancer it didn't make .... You know some people go "oh you know ... when I had cancer these amazing things happened, family all around me ..." I thought, actually it's not what I thought it would be" ... it was actually harder.*

Beverley found an internal source of support in the development of her spirituality. In addition, her self-support was strengthened by welcome external support from a friend who recognised that Beverley's mind "*was racing away, and that was all the scenarios of dying*". Her friend was perceptive enough to realise that Beverley had moved to a position of "*imagining that all the cancer was spreading all throughout my body*". The suggestion to Beverley from her friend was to visualise:

*the tumour to be tied up in a little parcel or a box or whatever I wanted. And then get a ribbon or a piece of string, of whatever colour, or what I wanted ... and then tie a ribbon around it and say that is where it was all going to stay.*

Being able to create an internalised image in which she could imagine physical containment of the disease was considerably supportive for reducing her rumination. Using this imagery helped Beverley reduce a tendency to catastrophise her situation. She said, "*and whenever I was thinking about the tumour .... I had to think about that. That was another really good thing .. um... because then I wasn't thinking about it going into my lymph nodes and going around my body*". Overall, Beverley felt that she was able to move to a place of acceptance supported by attending counselling for a year. In addition to counselling:

*I started the meditating, and then the reading some of the ... you know ... some of the authors and books and things, and had a little bit of a look at the Buddhist side of things and everything .... I thought that was a pretty good idea ... so that's become more meaningful ... and that's the basis of living and acceptance.*

Geneva felt supported by work colleagues who arranged for a meal to be delivered each week during her treatment. She said she hadn't expected that type of support but said, "*it was really lovely*". She pointed out that she was also able to practice self-support, and mentioned that "*I guess I did ... a lot of sleeping ... a lot of*

*lying down*". Geneva said that having cancer had given her an opportunity to be more vigilant about self care. She commented "*I'd virtually been given permission to do that, so I did it*".

Veronica had a similar experience to Geneva and in recounting to me the kindness that meals supplied by mothers of her daughter's school friends meant "*the world*" to her, Veronica became teary. She talked about the support she had received:

*I think the support from my family, my kids ... and my 9 year old at the time, she like made up this little ... in my bedroom ... she made me like a princess there, put flowers, made the bed up, she like ... real caring, to look after mum ... and the school, the food, ... they made meals every time I had chemo, its those things. The school ... they were incredible ... they would come around with meals for a week, every ... after every chemo session. My husband ... he was really great with the kids .... My little one was only one, at the time ... that was pretty tough.*

At first Jenny found herself channelling her energy into a number of projects:

*I was ... from 5 in the morning till 11 at night ... I was up cleaning my house, I sorted stuff and made stuff, making turbans for people, I made baby quilts and alphabet blocks and was in such a high manic state, and every day I lived to 100% full.*

However, the higher energetic state she experienced was not sustainable. Jenny explained that her need for support from others happened some months later when she "*hit rock bottom*". It was a time when:

*the second chemo hit me, like a tonne of bricks ... At the time I had been doing belly dancing ... the Red Hatters ... I had to give up the belly dancing, and I kept up the Red Hatters, and by the end of the year I was just lying on the couch basically.*

BC forces a re-evaluation of life; it changes everything. Daily functioning is altered, along with relationships, overall life satisfaction, and the ability to attend to work tasks. Geneva had been able to accept that she needed rest and to allow support to be

given. On the other hand, Jenny maintained a busy schedule driven by wanting to be of help to others.

#### **6.3.4 Cognition and functioning: “*The kitchen is a mess*”.**

An expected finding in this study was that women reported symptoms of cognitive impairment in the form of temporary memory loss, inability to concentrate, and feeling like their mind no longer worked as rapidly or as astutely as they experienced pre-BC. They talked about feeling in some ‘altered state of consciousness’ which required and sometimes demanded surrendering the idea that they could maintain relational equilibrium and the household status quo.

The problems associated with ‘chemo-brain’ and post-treatment fatigue was raised as an important issue in survivorship. Communication with oneself and with others was experienced as compromised by, according to a number of participants, the interference from drugs that on the one hand were life-saving, and on the other hand left the women feeling that their cognition was impaired. Their previously well-trained professional brain was in conflict with the ‘fog’ they talked about. That ‘fog’ introduced a confusing disparity between how they remembered being able to work productively, their desire to continue to work as a way to maintain a semblance of control, and the cancer-related interruption to intellectual functioning.

One of the key issues presented was challenges in functioning once they had returned to work. In addition, there was the tendency to be hard on themselves for not achieving or completing tasks with their usual level of efficiency. Four of the eight women in the OtSC and PRP ‘core group’ had not found it possible to resume their usual employment. For some they no longer felt physically capable, for another it was a case of wanting to take the opportunity to change career direction, and for another it was a situation in which she felt directly excluded from her previous workplace. This brings to the fore the problems not just of maintenance of everyday functioning, but of a potential identity crisis, and the transformative process that cancer generates. As well, there is the added financial burden BC can bring for couples and families with changes in income levels.

Jenny talked about the challenging effect chemotherapy had on her cognition “[it] had a huge effect on my brain, where I felt I wasn’t getting to my life, my reality”. She expressed surprise that no-one had mentioned to her that cognition might be negatively affected, even if temporarily. Her experience was that “it was really scary and I went to my oncologist and said why didn’t anybody tell me I could lose contact with reality”. A significant increase in her experience of body pain during chemotherapy left Jenny feeling even more divorced from daily life and unsure of what was happening to her. Her interpretation of that time was that “I wasn’t sure what was real or what wasn’t real”. Jenny talked about her experience of a combination of “the pain and my chemo-brain ... I’d have moments of sheer lucidness in which I knew at least that I still existed, and then I’d drop into this fuzz brain ... It was just so unreal”. Jenny felt that post-treatment she “had no control over [her] brain”. She explained what happened next and said she became very focussed not on herself, but instead “focussed on other people”. For the first twelve months after treatment Jenny said she existed in a mental state in which she experienced a sense of having a storehouse of drive and energy. This was a state where “I would do things just because I could ... and would ... I felt like I could do anything”.

Jenny added that:

*I did things that I felt I could not, not do ... so I was in this state that I could do anything ... which was a very kind of amazing thing ... I wasn’t worried, I hardly had a headache, things I suffered from before my diagnosis ... I was in this kind of state ...*

The problem for Jenny was that her elevated mood did not continue. Just over a year after treatment had finished she became clinically depressed and suicidal. Her attempts to return to work had been marred by intense feelings of being left behind or left out of the workplace she was keen to re-enter. Her usual energetic state was replaced by fatigue, lethargy, and unrelenting depression.

Carole and Terri both commented on the alteration in a sharpness of mind they had previously enjoyed and relied on. In speaking about the effect of chemotherapy, Carole indicated that she believed the chemical treatment that had

helped save her life had also denied her the capacity to think clearly. She pointed out that at the present time, five years after treatment was complete, she still struggled with impairment to her cognition. As an example Carole explained that even with the passage of time since treatment she regarded herself as still “*very slow at process thinking*”.

During treatment Terri reduced her working hours, and worked “*for one week every three weeks*”. It was her workplace supervisor who brought attention to what he regarded as a reduced capacity to concentrate. Terri’s supervisor offered what she described as well-intentioned, but honest, feedback, saying “*you’re just like a tornado ... you start this and you start that...*”. Terri herself admitted that during her treatment phase “*... nothing got finished*”. The implication from Terry’s comments was that her energy was high but concentration and awareness were low. She also highlighted that her cognitive abilities were still not functioning at full capacity two years later. Although accepting of these changes, Terri illustrated the point she was making when she said:

*And I’m having to really work at that, because that is hanging over ... I’ll be halfway through the dishes and I’ll think ... don’t think I want to do them anymore. But I’ve got to finish them. Or I’ll get halfway through cleaning up and I’ll think ... oh I can’t be bothered ... I’ll go and do something else ... which I don’t remember was part of my psyche before.*

Terri returned the conversation to the hope she held of a return to her previous mental acuteness to help her complete daily tasks. She explained her desire for restoration to her mental alertness as “*being able to picture the job finished and be excited to work towards it rather than think, oh, I’m sick of doing this thing, I wanna do something else*”. A “*trail of destruction*” is how Terri described the awareness she had of so many things she wanted to do but which she had very little interest to complete. By way of example, Terri commented that “*the kitchen is in an absolute mess, which is just not like me*”.

The lack of being able to celebrate even small achievements from completing a task was wearing on Terri. Terri’s self-worth was strongly linked to her ability to ‘do’. Her evaluation of self suffered when not able to draw positive comfort from



what she had achieved. She said the “*hardest thing*” for her was feeling as though she was “*doing something*”, but repeatedly making comparisons between what she had or had not achieved, and “*people on the telly ...you know the women ... and I read that thing in Australian magazines this woman’s doing this, and that woman is director of that company, and this one is the head of Shell, and I’m going... what am I doing ... and I think that constantly*”.

The aspect of life that helped Terri deal with a constant flow of inner criticism was “*I know that in God it doesn’t matter what I do, but who I am that matters*”. Terri was realistic. Her faith in her God helped put things into perspective, but she added to the statement by saying, “*But knowing that, in your head, and experiencing that in your life ... you’ve still got to work through that. And I don’t think that is going to happen overnight*”.

Nicole’s cognition had not been negatively affected by treatment. However, she reminded me that she had experienced cognitive overload when trying to listen to her oncologist as he explained to her there was a strong likelihood that her BC would return at some future time. At the time of hearing those words Nicole’s cognition deserted her and fear filled her mind.

*as a patient you stop listening when you get to a certain point ... because your mind goes off on a tangent because they might say something .... And you go uh huh ... And then miss what they say next ... so it is important to have someone with you.*

During the treatment regime Shirley experienced ongoing negative feedback from a work supervisor in relation to the way she was carrying out her work tasks as well as comments about the amount of time needed away from work to attend treatment sessions. Shirley said, “*you do forget things*”. She also commented that “*you say things back to front ... you do have a little ... chemo brain ... and they say it can last for years*”. After being chided by her supervisor whom Shirley said had commented “*I’m sick of you making mistakes*”, a self-caring decision was made and the outcome was that Shirley resigned.

Post-treatment Shirley felt she still had energy to contribute and chose to become involved in a volunteer organisation for business women. Eventually Shirley found that what she could offer was valued by others in the organisation, and this led to a situation where she accepted a position on the executive committee of the organisation. Continuing this conversation with me, in a rather surprised voice, Shirley proudly admitted that now, “*yes, I’m, President Elect. A couple of years ago I would’ve said no. I might not have even joined the club*”. Shirley offered this example as a way of indicating that while she had experienced ‘brain fog’ she was not overwhelmed by this after-effect, and on the contrary, was able to contribute significantly to a community organisation.

### **6.3.5 Putting myself first: Adjusting priorities: “I’ve changed a lot”.**

The women survivors in this study wanted to live. In their quest to survive they surrendered much that they had held precious - breasts, hair, wellness, and body image. In addition, their personal independence was temporarily suspended. Women BCS had transitioned from considering themselves healthy to confirmation of a state of liminality in which a previous taken-for-grantedness of health was now denied. Lack of awareness of the extent of personal change as a result of BC can mean a disconnect from others as the repercussions of personal change take shape in daily living. The women talked about noticing changes in the relationship with themselves and others. The implication of personal growth and change as a BC survivor would seem to be that adjustment may be needed within their relationships with significant others so as those relationships can accommodate new ways of being, or revised priorities, values and beliefs. The problem may be that a pre-BC relationship may not be able to accommodate a woman’s changed self and changed perspectives on life.

Comments from the women in this study led to an observation that they had never questioned an internalised expectation to be of service to others, to sacrifice much to care for others, and to put others needs before their own. Paradoxically, the women also were strong in their belief that women’s contributions often went unrecognised.

In this study survivors found they temporarily became reliant on others for support and care at a time of encountering an illness that threatened to overwhelm

them physically and emotionally. At the time of participation, however, their narratives indicated life priorities were being adjusted to make room for self-care. Those self-care priorities, for some, took the form of losing weight and then going shopping for new clothes. For others self-care meant wearing whatever pleased them on the day, or taking time from their self-employed work to play with grandchildren when they arrived unannounced.

The women believed that after the disruption and adversity presented by BC, the process of reintegration into life was helped by their willingness to resume life in a positive way. Some of the women achieved this by retiring from their workplace and spending social time with people rather than working hard to be the carer of others. Other women found themselves able to set clearer boundaries in relation to their acceptance of the role of making sure everything was attended to for family.

Wendy was the parent of a child with special needs whom she said was “*very, very difficult to look after*”. Wendy’s view was that there was no one who would look after her son the way she would, and so prior to being diagnosed with BC she had decided to surrender her career to be a stay-at-home mother to give her son the care he needed. Prior to having BC Wendy said she would “*be the one doing, doing, doing ...*”. Wendy went silent for quite a while and eventually she commented “*but then, when it came to me ...*”. In this comment Wendy was emphasising that her needs had to be put to one side so that her son felt nurtured and his practical needs met. Because care of her son would require a life-long commitment from Wendy she was aware that not much change could be made to prioritise her needs.

Professional work in a scientific field had provided Terri with a sense of identity and she “*would’ve stayed there forever, because I really had huge value*”. She regarded herself as a “*mother*” to other employees in her workplace. She said, “*it was me who kept it as a family*”. Finding herself now in a position of grieving the loss of her place in the organisation as well as the loss of her sense of value to others, Terri talked openly and honestly about how she had used her work as “*an excuse*” to avoid being available for social chit-chat with people. Prior to her BC, work had been “*all encompassing*”, whereas post-BC Terri felt, “*I’m much more available to people who want to have a chat ... which I never used to be*”. Rather than deriving

personal value from what she did for others, Terri began to allow herself to receive care and to find value in quiet, still, moments of social encounter with people in her immediate neighbourhood.

After completing treatment, Geneva felt she needed ‘time out’ to contemplate the future direction she wanted her life to take. Despite financial pressures Geneva made a decision that BC had delivered the ideal opportunity to put her need for ‘time out’ first. She felt that BC had allowed her to stop leading life in a way that she never questioned. Having BC had given Geneva space and time to consider a range of options in terms of future employment. Extended leave of absence from her work in the healthcare sector meant time to re-evaluate life. Geneva explained that:

*I’ve changed a lot I guess in that I’ve just stopped. I haven’t been back to work yet and I haven’t ... mainly because I’ve taken this as an opportunity to re-assess my whole life.*

Giving time and attention to consider what she needed, and what would best suit her, was a state that was personally uncomfortable for Geneva. The absence of a clear direction or some personal guidance about ‘what next’ left her feeling as though “*I’m still stuck in the middle ... but... And I’m not quite sure where I’m going*”. In taking her own needs into account, Geneva had come to the decision that the most useful way forward was to stay with the internal disquiet, and wait until she felt clarity about whether to return to her usual work, or to pursue a different career direction.

An example of beginning to put herself first was given by Veronica who talked about washing the dishes at a family gathering. She regarded her changed response to dirty dishes in the kitchen sink as a signal that in the post-BC time she had become more aware of traditional gender roles within her extended family. Her story told of discomfort she felt seeing her (recently bereaved) brother taking on what was normally considered “*always the girls*” task.

*it came [time] to do the dishes, and it’s always the girls, my other brother’s wife, myself, and ‘X’ ... always get up to do the dishes ... but that evening my brother got up and he’s doing the dishes ... I couldn’t believe it ... then I thought ... what do I do ... do I go and chill out or do I go and do it*

*... let him do it ... so I let him do it for a little while ... and eventually I took over, but ... it was like ... really strange*

Gemma had, post-treatment, decided to change her work situation for something more amenable to her wellbeing. For her, consideration of her own needs was related to being mindful of the fact that BC could result in her death. Facing the issue of mortality alerted Gemma to reconsider whether she prioritised her own needs over the perceived needs of others:

*I think the other thing that I took out [from the BC experience] which is probably a bit more personal ... is just the fact of ... well, you know this logically, but you don't know it emotionally, or something ... you don't know what's around the corner .... Never take for granted that you're ok ... and perhaps taking charge of your body a bit more and realising that maybe I actually do need to put myself first*

A life-long habit of ignoring herself meant it was not difficult for Gemma to place others' priorities before her own, and therefore not take look to her own needs. Creating limits around what to prioritise did not come naturally. Aware that placing a restriction on her availability to others' needs was "*not the first thing I think about ... put the boundaries there*", Gemma pointed out that "*setting boundaries is a huge big issue for me and I think it'll be an ongoing thing*". Coming back into the present moment in the interview, she explained that "*and I need to listen to myself saying this now, because I think I'm falling back into the thing of ... do everything else first before you get to yourself*".

Lara had negotiated leave from her government position for just over a year while undergoing treatment. Aware of "*fairly major depression*" she had experienced over her lifetime, and revealed she had suffered a "*breakdown*", Lara realised she felt mentally unprepared to return to work when the time came. Lara felt the desire to take better care of herself warranted additional time away from a stressful work environment in which she felt "*bullied*". She was able to allow self-awareness to take precedence when deciding a direction to follow. In describing the time since diagnosis, Lara talked in the following terms "*the first year was basically not doing much of anything. Then the second year was starting to do things for myself*". In that

second year Lara resigned from a position she had held for many years, and began to involve herself in community activities that were more personally satisfying than her paid employment had been. As a ‘treat’ for herself, Lara said she had begun a daily ‘practice’ of walking by the river and observing pelicans. This was quiet time for her, time to think for herself, and to be by herself.

Stephanie decided that putting herself first meant to no longer worry about whether people in the social world judged her. Stephanie’s post-BC self was someone who felt comfortable to “*go out and wear the most hideous ... my pyjamas, my slippers, whatever ... and I’ve never once thought ‘oh, she’s looking at me’ ...*”.

In terms of putting herself first, a different experience was had by Jenny. Treatment had been completed and Jenny was on extended sick leave from her employment. In our discussion Jenny recalled that she had always found it difficult to prioritise her own needs and this remained the case once the intensive phase of her treatment for BC had ended. Combined with “*my chemo-brain*” Jenny said she felt incapable of returning from extended sick leave and taking up the challenges of her pre-BC work. There were financial imperatives in her life that made it a priority for her to return to work. However, in one way, Jenny was able to put herself first when she acknowledged her inability to pick up where she had left off. Acceptance of the fact that she would not return to work that had given great meaning to her life meant Jenny felt confused and disturbed. She was confused about whether the decision not to return to work was actually hers, or whether her employer had manipulated the opportunity so as to leave no ‘vacancy’ to which Jenny could return. Jenny described that confused state as one that made her feel as though she “*couldn’t believe this was my real life*”.

### **6.3.6: Emotions and personal growth: “*I’m a more spiritual person now*”.**

Adjusting emotionally to the presence of adversity in the form of BC offered the women in this study an opportunity for both new vulnerabilities and new strengths to emerge. Some attempted to reduce negative feeling states and remained focused on more positive thoughts. However, avoidance of negative feelings did not offer a guarantee of a positive outcome. Participants talked about the process of assimilation of the experience of BC into their personal narrative. One way they

seemed to bring a new sense of meaning to BC was to use positive words in their references to BC. The results were, for some, life-changing, but for others fear and anxiety resisted any encouraging rhetoric that did not fit with internal reality.

Spiritual beliefs were experienced as positive, as well as a significant emotional support in their focus on survival, by two participants in the core group. Spiritual beliefs would be regarded as a support when a woman begins the isolating journey of dealing alone with BC. This may mean that women who pre-BC do not cannot draw on cultural resources that religion and spiritual beliefs afford, could struggle and ultimately experience more existential distress as they transition to survivorship.

Terri said she felt as though during the time since diagnosis and treatment she had found it almost impossible to fully process the emotional or psychological adjustment. She admitted that her first priority had been the need to concentrate on physical wellbeing. Emotions for Terri were generally experienced as uncomfortable. However, the spiritual and personal strength drawn from her Christian faith system was what Terri found was a mainstay during difficult times. Participation in this study was a way Terri considered useful in helping to explore any emotional residue. However, she admitted:

*dealing with all of that [feelings] ... I have struggled with it ... um, I think I probably bury it rather than deal with it ... but I am thinking you can't carry on like this, you do have to deal with it.*

Carole had formed the opinion that “*emotionally ... I don't think people understand how much it wreaks havoc with your system*”. Describing herself as someone who “*usually*” could “*control my emotions*”, Carole's BC coincided with the breakdown of her marriage and it was this combination that she felt contributed to a change from being a person who would “*not say anything, possibly take it in internally*” to someone who “*used to cry very easily*”. Carole admitted that prior to diagnosis her marriage was not flourishing and since having BC she found herself contemplating “*if that contributed to it [BC]*”. In the bigger picture Carole felt that she was now emotionally stronger than the person she had been prior to BC. Although Carole reported that she felt she had found more “*confidence*” in herself

since having BC, she also pointed out that her sense of self-esteem felt “*worse*”. She hastened to add that “*I don’t know whether its because of my marriage break-up ... and whether that’s come into it as well*”.

Beverley felt that emotionally she was “*really quite good*”. This personal evaluation was given from the perspective that she had dealt with significant challenges in her personal life which Beverley referred to as having been more “*emotionally upsetting*” than having BC. However, she talked about her realisation that for her lumpectomy was no longer “*like they’re taking out a mole or something*”. She went on to clarify her comment by saying, “*it’s a little lump yes, but with the surrounding tissue it’s not ... there’s a lot in it*”. She had found that regular reassurances from the breast surgeon that her breast was “*settling down nicely*” were helpful in giving Beverley a clearer sense that she was making progress in her recovery. This was important for her emotionally because she had not realised that physically “*the repercussions went on for so long*”.

Jenny’s emotional adaptation to BC took a distinctly different pathway to the majority of other participants in this study. Initially Jenny found herself experiencing a state that could be described as invincible. During that phase she maintained a tireless routine of creating clothing and quilts for her family, as well as being vigorously supportive of other women with BC through activities such as making bandanas and turbans, and organising a fund-raising event. Despite these efforts, Jenny expressed a deeper feeling that “*people misunderstand me, or are jealous of me*”. She described herself as “*one of the most talented people that I know*” who was a “*give-it-all person*” with a “*full-on approach*” that others may have felt threatened by.

Jenny attributed her ‘give-it-all’ attitude to her response to trauma experienced with the murder of her father some nineteen years prior to her diagnosis of BC. His murder meant that although she had suffered a “*breakdown ... after my Dad got killed*”, she also said that now “*I live every day to the fullest*”. Jenny had not always acknowledged herself as clever or talented despite being creative and musically gifted. She provided a more open description of herself as someone who had previously “*always felt second best because I HAD to get married*”. Jenny



explained that throughout her life feelings of self-doubt and low self-worth generated a drive in her to prove she was not second best. When still a young mother one way Jenny said she had attempted to subdue emotional discomfort of not being good enough was to push herself and achieve outstanding success in all areas of her University degree.

Jenny admitted that in the most recent time her sense of self had “*taken a battering over the last six weeks trying to get back into [work]*”. In that statement Jenny was referring to her attempt to return to her pre-BC employment. Her comment confirmed that she was aware her emotional state was not sufficiently stable to make re-entry into a work situation appropriate or advisable. One cause of her distress was that Jenny felt her “*touch with death*” had gone largely unnoticed by others. This had left her with the feeling that “*nobody actually cares*”. She felt alone in her despair at what had happened to her life.

Shirley had a different outlook and talked about feeling “*lucky*” because of her perception that her experience was not as physically or emotionally demanding as that of other women with BC. Her work with BC support groups had provided insight into the struggles of others. Shirley had then offset her experience by comparing it with that of other women with BC. Shirley felt that other women who may have had a sick child, an aging relative, or experienced a range of other environmental demands were not as lucky as she. Shirley said that, emotionally, she felt “*good*” although she admitted to getting “*cranky*” when tired. She now felt able to “*just take it slowly*” and reiterated that emotionally she considered herself in a good place and in the bigger picture considered herself more fortunate than others when she thought about her experience of BC.

Lara was pleasantly surprised by a feeling of being able to access her emotions more easily since having BC. Always able to feel empathic “*with other people’s feelings*” Lara talked about the grief she experienced throughout life through being open to other people’s emotional experiences. “*Now*”, she said, “*it’s come back to me big time*”. With this statement Lara was referring to her understanding that prior to BC she “*didn’t get the teary side of it*”, but used to feel a tinge of enviousness about others ability to express their emotions. She said that she

would think “*aaahhh, look at those people crying*”. Since having BC Lara’s experience of emotions had changed from a focus on what other people were feeling to being in tune and curious about what she was feeling. The shift in Lara happened, she said:

*Because of the hormone changes. I’ve become more feminine. I suppose I’ve got more of those hormones or some flooding. But I’ve become a lot more emotional, I cry a lot easier and there’s more empathy [for myself].*

Carole was pleased she had grown personally to the point that now “*if I don’t like it ... I better tell*”. Her commentary in the interview revealed a marriage in which she said she “*was probably not happy*” but had stayed with longer than she wanted. Judy talked about the fact that she:

*was always anxious when my husband came home ... what sort of mood would he be in .. I never knew how high to jump, and when I jumped it wasn’t high enough ... or it was too high.*

Having separated from her husband Carole said she realised she now had “*a higher meaning in life which I didn’t have before*”. She added that “*deep down I’m much calmer than before I had cancer. I just say “ok, take a deep breath, and it’s ok”.*” Carole commented that through having had BC she had grown personally to the point where she can say “*no*” without feeling as though she needs to make an excuse for refusing an invitation to socialise. Despite her awareness of the threat to her health inherent in BC, Judy said that she was now able to feel excitement in each day. That excitement she said “*it’s like when you remember ... when you were a kid ... on your birthday ...*”.

Gemma was able to talk about now being able to feel the “*big sadness*” in her family; a sadness that had persisted for several generations. She also spoke of her belief in the danger inherent in not being able to let go of hurts and worries, particularly those hurts that happen in relation to the behaviour of loved ones “*because that can eat you up inside and make you more bitter and twisted*”. The description of herself was of someone who had always attempted to keep their emotions in check. Years before being diagnosed Gemma said she had felt clear that if ever she had BC her decision would be to “*just cut them off*”. However, she

confessed that “*its harder ... you're not quite as flippant as that when it actually happens*”. But Gemma had found that her chosen belief system helped provide a “*sort of guiding thing*” that she felt was needed in order to navigate life without becoming overwhelmed by it. It was important, she said, to have “*some sort of guiding thing, in your head ... to help you to step back, to give you something else to focus on and also to centre yourself back in yourself*”. She referred to herself as someone not likely to “*fall apart*” but to consider things in logical and practical terms and be more interested in what needs to be done rather than what needs to be felt.

A brief comment by Nicole was very poignant. In her understanding of emotions and opportunities for personal growth Nicole felt that “*women are overly critical of other women*”. She was of the opinion that the very people who can show care for another woman were often not the ones to give that care. To highlight her point Nicole had also commented that she often felt more safe and trusting of workers in supermarkets and shopping malls than with people who should care.

Nicole said that optimism had declined significantly because of the fear of recurrence hinted at by a treatment specialist. She described her worsened state in the following way:

*I think I'm worse now than what I was during the process, I think during the process ... my husband tells me, I was quite strong and because it is a process and you know what you have to do ... you're spending your energy doing it and not thinking about it so much .... in November I had to go back and see the radiation oncologist and he said to me ... how are you coping with your Arimadex ... and I said, 'oh you know, it stops side effects and goes well'. He replied 'you know you can always stop it and save it til your cancer comes back and use it then' ... and I'm like, I beg your pardon? And he says 'you're in the top 5% group for this cancer returning' ... I go, 'no' ... I'm thinking am I hearing things ... and he said 'you should be looking after your body'.*

### **6.3.7 Relationship with my body: “It’s carrying my soul and my heart”.**

Treatment for BC takes place in as rapid a time as medical resources can offer. However, survival and living with a changed body is a lifelong process. For the women in this study the time post-treatment brought with it a stark reality of what it was like to live with embodied reminders of BC. Some of those embodied reminders became obvious when they first looked at the scarring from surgery, when they encountered chemotherapy-induced alopecia, a fatigue that refused to accept denial, as well as unpleasant burns and blisters as a result of radiation therapy.

The women wanted to appear to their social world and family environment as though life was back to normal – the often-spoken-about ‘new normal’. While wearing a prosthetic breast was the choice of some participants, others said they were not perturbed by the lack of one or both breasts. Clothing was chosen to enhance the body as a whole rather than focus visual emphasis on the breast area.

Questions about the relationship with their body elicited a range of responses. In particular, when invited to comment, the majority of women in partnered relationships preferred not to comment about restoration of intimacy and sexuality. Perhaps the women felt they were of an age where engagement in an active sex life was either not of particular interest in the bigger picture, or the topic was considered too personal to discuss with me. On the other hand, the topic of sex and sexuality was openly discussed by two of the participants.

One example of openness about sexual intimacy was when a participant talked of her decision to have breast reconstruction because, she said, her double mastectomy would likely mean the end of an active sex life. Another felt frustrated and concerned for her husband because her experience was the surgery meant their experience of foreplay and sexual intimacy was significantly limited. Using the terminology of a baseball game, she commented that:

*you’re actually asking your husband to go direct to second[base], or if you want to look at it as third base ... to basically go direct to third, and you have to bypass it because it's not there... that sensory part of you, is not there... so being in the mood is something that doesn't exist...*

For a year post-BC treatment Jenny was proactive in improving her relationship with her body. Jenny mentioned that she was now eating better, exercising more, and said “*I am more aware how my body is feeling and I honour my body more*”. To explain this, Jenny said she had moved from a position where she “*didn’t like it[her body]*” and “*used to berate my body*” to a gentler position where she felt able to be kind to herself and say “*what a good body you have*”.

Prior to BC Jenny had struggled to manage her weight. She described her relationship with her body as “*a roller coaster ride of weight gain and loss all of my adult life*”. Since BC Jenny had come to recognise the ways her body reacted to particular drug therapy. She was especially aware that using chemical means to encourage sleep had a detrimental effect on her cognition. Cognisant of the variation in responsiveness to psychopharmacology, Jenny said:

*so now I think ... good body ... so I think I look at it in a different way ... it’s carrying my soul and my heart ... it is incredibly responsive to chemicals, and so I kind of say to myself now, I’d better look after this body.*

Even though reconstructive surgery had left “*big scars*” Jenny said “*I think I’ll be much happier with my body*”. During the interview she said her overall outlook was that “*there have been some positive changes with my body*”. However, Jenny’s positive outlook at the time of her interview was not able to be maintained. The transition to survivorship had not gone well for Jenny. When she joined the OtSC sessions and participated in the PRP, Jenny had been diagnosed with clinical depression. During the first of the OtSC sessions admitted to the group that she had attempted suicide twice in the several months between her interview with me and this first OtSC session. Jenny said she had used prescription medication in her suicide attempts in an effort to “*stop the pain*”. Initial optimism in the year since treatment, was replaced with a conviction that she had “*completely lost trust and connection*” with her body. Jenny also spoke of her depression as meaning she was no longer able to understand or regulate her emotions.

Some women disclosed that the relationship with their body prior to BC was one characterised by lack of awareness and lack of attention to the physical self. Some participants commented that looking after their body had not been a

“conscious choice” whereas post-BC there was a clear consciousness to focus on nutrition and weight control. For example, in talking about her relationship with her body Nicole said that prior to diagnosis:

*I probably wasn't extremely respectful of it ... yeah ... I would work hard. I played hard ... I did have an awareness of it because I had hypertension ... but I didn't really respect it that much ...*

Nicole went on to explain that prior to BC she was a person who, when her hypertension was at its worst would “*just take my tablets and get on with it ...*”. The experience of BC had changed her relationship with her body, primarily because of the onset of menopause. Menopause was a very challenging experience for Nicole who stated that on the ‘bad days’ her emotional state was like “*killing yourself because you don't want to do it anymore*” and “*you wish you were dead*”. Eventually Nicole emphasised that since having BC she now talked with her body. BC had brought to her awareness the need to be more considerate of the limits for her physical being.

Wendy talked about her post-BC vigilance about aches and pains that she would normally have dismissed:

*I've always not had to worry about my body, I've been very fortunate I've never had to worry about my weight, I've never had to carry negative body image before, but now it's probably ... I am very in tune with it and ... I will even think I really feel like a certain vegetable or a juice, and I'll go and do it ... I'll listen to [it] ...*

Prior to having BC Geneva said that she “*probably didn't give ... much thought*” to her relationship with her body. She admitted that the relationship with her body was one in which she would not worry too much about it and was “*probably taking it for granted*”. Post-BC her awareness had been raised so that Geneva felt more aware of those aspects of life that “*impinges on your body*”. She now was aware of the need to monitor and maintain nutrition and exercise. However, she indicated that “*I still don't look at myself very much*”. As a woman married, with adult and teenage children, a grandchild, and the responsibility for daily care of an aging relative, Geneva hinted at not having time to devote to a relationship with her

body. It was only some time after treatment had been completed that she felt able to take time to focus on her body. Opening up more about her physical wellbeing Geneva did say that because she knew other women whose BC had resulted in a mastectomy, she was easily able to “*rationalise*” the fact that one of her breasts was “*half the size of the other one*”. However, she was aware that “*I still don’t look at myself very much*”. Geneva felt she had not yet reached the point of feeling as though she was in a positive, healthy relationship with her body:

*I’m still not there but I understand the impact much more I think, even though beforehand, you know, theoretically, that all of these things are good for you it’s only now that ... I actually have the time to myself because other things have been going on in my life ... to actually start to think about things ... whereas ... other people have done [things] that way, you know, almost from diagnosis. But I don’t feel like I could’ve done that.*

The relationship Shirley had with her body was connected to how she felt she looked. When her body looked good Shirley felt good about herself. She “*liked to watch my weight and make sure that ... and I always had good bras, and ... so I... I knew that I looked ... good. I just knew I was OK*”. Shirley echoed Geneva’s comments about not feeling as though there was time to look after her body. She explained that with children and then grandchildren “*I didn’t really have time to think ... is my body ok, or, do I look glamorous*”. Shirley talked about the need, in the past, to “*always ... look nice*” at business functions for her husband’s employment. “*And now*” she said in a final comment about her body, “*I think, well, I’ve been through this little crisis. Now we’re going to get on with life. And that’s what I think ... I’m .... getting on with life.... and I’m making the best of a bad body. Well... It’s not a bad body (laughs).*

Lara was a slightly built person, and, similar to Shirley, talked about the clothes she wore and the pleasure she experienced when she lost a significant amount of weight in the year prior to diagnosis. She said losing weight meant she “*felt better about myself that I’d lost the weight and I felt better about having photos taken because I hated photos taken when I was much heavier*”. In discussion about her relationship with her body Lara said, “*I get angry with it sometimes because it can’t do the things it used to do*”. Physical endurance and strength was important to Lara

as with a husband who was often away with his work for extended periods of time, she had taken on responsibility for household repairs and maintenance. She commented that in times of doing hard physical work around her house she had felt exhausted but then unable to sleep. Those times of physical exhaustion coupled with insomnia left her feeling unsettled emotionally. Lara talked about being the one in the household who had always done the painting, paving, fixing the pump for the water supply, as well as mowing the lawn, although she admitted that since having BC she no longer mowed the lawn.

Overall, Lara was pleased with her body's capacity to still have a "*massive spurt*" every now and then when she could undertake maintenance work around the house. Some tasks involved her climbing "*up on the roof*", "*moving bricks*", and "*shovelling gravel*" and she talked about feeling angry with her body when "*it can't do the things it used to do*". Mental determination was highly valued by Lara and she clarified this by saying that "*the determination to get things done gets me through, and then I fall in a heap*".

Weight loss was also a topic Beverley spoke about although her determination was channelled in to a different focus to Lara's. She had undergone a hysterectomy six months prior to diagnosis. Prior to that surgery she felt "*I really was in a very good condition*". After abdominal surgery she felt that her body was no longer "*in tune*" and when diagnosed with BC she believed her body had not yet regained its pre-surgery healthy form. Beverley talked about the challenges she felt in relating with her body since BC. The experience of "*a period of ignoring it and just not looking in the mirror*" because of physical changes post-BC was a time when Beverley said she "*didn't want to have to worry about*" her body. She explained that her focus was "*more concerned with my mind and meditating and being able to cope mentally and emotionally*". Maintaining a weight loss, healthy eating, and exercise regime was something that Beverley was aware "*you're supposed to do*", however, she added that "*sometimes it's just too hard to do everything*". She made it clear, however, that her prime concern was to be able to function well mentally.

Terri stated clearly that she said she did not have a relationship with her body. And yet, attention to wellbeing and what was necessary for physiological wellness



was of particular interest to her. She laughed as she explained that her self-perception was that she was not “*pretty ... sexy or gorgeous*”. Instead, her perception was she was someone who had been “*ugly*”, “*fat*”, “*short*” and who “*never had any boobs, and still haven’t*”. As someone who “*stopped growing at about ten and a half*” when she went to boarding school, and who had neither the small waist nor generous breasts she desired, Terri carried the legacy of feeling that, when growing up “*it was always the pits having no boobs*”. She then talked about a less than adequate diet for a growing girl in boarding school, and that during those years she “*just had lots of medical sort of things*”. As a consequence Terri did not like “*feeling sick*” and credited her school experience with leading her “*more into a healthy way of living*” in her adult life. She talked about feeling extremely sick after chemotherapy, but then countered that comment with an assurance that not every experience of treatment was negative:

*that was probably the worst ... just the sick feelings ... I didn’t really bother about my hair falling out ... it was the least of my problems, I had a lovely wig ... my sister had jazzed me up with all these scarves and I actually felt better than when I had my own hair ... (laughter) ... the hair was never a problem because I knew it would come back one day.*

Since completing treatment for BC Terri felt that her relationship with her physical self had not changed. Her most important consideration was “*as long as I feel well in myself ... then the rest doesn’t matter so much. But I just don’t want to not feel well*”.

### **6.3.8 Self-worth, self-blame and BC: “*We’re over-generous givers*”.**

There was a strong link between the evaluation the women in this study had of themselves and the self-worth derived from being helpful to others. Several participants hinted at the challenge in ever making a commitment to a life-long caring and respectful relationship with themselves. They suggested their self-talk was more often than not linked to what they should or could be doing for others – children, partners, close relatives, friends. An interesting finding was that the interviews with Significant Others also featured the notion that women held a very strong commitment to care for others that was life-enhancing for those others, but less so for themselves. A summary of the eighth theme would be that women in this

study were willing givers with recognition that they were over-generous givers. They drew attention to their perception that while women saw themselves as ‘givers’, men did not experience themselves in the same way.

Beverley voiced a clear opinion about socially-condoned beliefs she felt were unfair and unjust for women. She used the term “*over-generous givers*” to describe her observation that women, generally speaking, think of others first, tend to seek approval through doing, and seek to avoid self and other criticism. Beverley’s observation seemed to highlight the core of this eighth theme. She talked about the women with BC whom she had met:

*I think from all the women I’ve met with breast cancer they seem to be the most loveliest women and they seem to be downtrodden ... you know ... they are the women that are too nice, they don’t stick up for themselves, they do too much ... you know ... they are looking after everybody else instead of looking after themselves.*

Beverley had realised that she experienced a feeling of tension in her body when she was attending too much to others’ needs. Post-BC she now called it “*that cancer feeling*”. It felt uncomfortable for her and it was this tension that was a warning sign for her. Beverley wanted to eliminate the that cancer feeling from her bodily-felt experiences because:

*My body let me down, because the way I’d been living was ... that was ... gave me ... That’s just my little ... what’s it called, my theory ... I’ve met lots of women. They all say I’ve done too much and I’m not looking after myself. Many ... not all of them ... And living their lives for their children.*

Extending her description of characteristics of what she called an over-generous giver, Beverley clarified her reflection by saying she felt that women were more willing and capable than men of:

*over-generous giving and denying themselves ... and their life and their needs, basic needs, they are very important. And not feeling worthy enough to speak out ... and have their needs met, you know, in an unequivocal sense.*

Beverley added a caution to her expression of concern about the ways women relate with themselves. She commented that:

*it's so easy to fall back into the role of looking after everybody else ... it can happen in a discussion or in a telephone call ... you can do it without knowing, it's so ingrained ... in your psyche ... very scary.*

Jenny described herself as a person who was “*so hard on myself*” and sometimes driven by “*perfectionism*”. Jenny talked about “*still trying to do all that I used to do*”. As an example, Jenny mentioned a number of projects she had embarked on, one of them being “*making pyjamas for all my grandchildren*” during her radiation treatment. She stated that she had sewn turbans for other women with cancer, and created handmade Christmas gifts for family and friends. When it came time to consider a return from sick leave, Jenny said she felt “*in no fit state*” to return to work. By this time her all-over body pain levels had increased.

During Wendy’s interview she talked about the way that BC had affected her children. Her comments echoed those from other women, especially those who had taken part in all phases of participation. When talking about the impact of BC on her children, her comments indicated that there was no ‘safety net’ for her to fall in to when things went wrong. BC meant that Wendy had the experience of isolation from any support:

*I was the person in the family who always held everything together ... I crumbled [because of BC] ... so there was no one there to pick up the pieces, really ...*

Stephanie talked in very certain terms about self-blame. With the following words she made it clear that she did not blame herself for having BC:

*My sister-in-law ... said to me that if I didn't fix my mindset that my cancer would come back ... she said that it was my .... it was my ... connection with my mother ... that gave me cancer in the first place ... and I was sitting there and I thought to myself you're nuts ... if I thought for one minute that I gave myself cancer in any way .... I'd go crazy, I would go nuts.*

Gemma held a similar view to Beverley, and also raised concerns from her experience that women were the ones who “*will often just ... it’s the serving everybody else ... it’s our make-up is like that*”. Gemma emphasised that her comments were “*very generalist ... I’m talking very much in general*”, however, highlighted “*but men: it’s me first and then I’ll look after everybody else*”. Growing up under the influence of a grandmother who “*had very strong beliefs*” and a personality Gemma described as “*very rigid and sort of very emotionally ... almost uptight*”, Gemma had finally reached a stage in life where she felt “*I’ve developed a bit more of a healthy self-esteem*”. Emotion was expressed through tears and long silence when Gemma spoke of her own growth and the realisation that her values and beliefs were worth fighting for, and that her opinion did matter:

*... and just learning you’ve actually got to stick up for yourself because if you keep trying to do something for someone else you totally can compromise yourself ... so I’ve actually had to learn to fight ... which is a big thing, because it would be the last thing ... I would never want to confront or fight. But then, I think what I’ve realised is ... there are things worth fighting about ... fighting for.*

Additionally Gemma was aware that she had grown personally to the point where “*I try not to be judgmental about other people’s good things and bad things, and just go ... it’s all ok*”. What concerned her from that statement was that “*I don’t say that to myself enough*”. Her commentary continued with a statement that women, in her view, tended to be nurturers who were more often than not inclined to regard the needs of others as more important than their own needs. As she spoke, Gemma acknowledged her impression that when a woman has a “*great*” need to do what she called the “*noble thing*” and relentlessly attend to others’ needs, then an external “*expectation*” can be unconsciously activated in the minds of others. In recognition of what she had just said, Gemma added what seemed a comprehensive perspective on life. In talking about the potential for resentment to Gemma stated that “*you’ve got to actually let some things go*”. Her idea was that being a little more philosophical about life and embracing a set of guiding principles was important “*to help you to step back, to give you something else to focus on, and also to centre yourself back in yourself*”. Gemma offered a sense of her own values and beliefs when she said:

*What I think I've learned is ... I didn't judge this before ... you can't totally blame ... if something doesn't work out and your expectations aren't fulfilled it may not all be your fault ... there's way more variables occurring that could have had something to do with that.*

### **6.3.9 Unexpected benefit: The gift of cancer: “It’s probably been more positive than negative”.**

The perspective that BC could be a ‘gift’ to the life of the person treated was spoken about by several participants. Of the 8 women who completed all three components of participation in this study, 6 had worked post-BC to create lifestyle changes that would bring health-related benefits. The ‘gifts’ they spoke about were improved diet, increased exercise and making more conscious choices around care for their physical body. Additionally, women in this study used the word “*gift*” when talking about their journey of self-discovery that had begun from having had BC. Even though each of the women had expressed challenges in adapting to their changed lives as a result of diagnosis and treatment, all but one found their experience of cancer presented an unanticipated opportunity for personal growth.

Geneva reported that in terms of her physical wellbeing as a survivor of BC, “*funnily enough its probably been more positive than negative*”. Geneva felt that overall her experience “*personally*” of BC was not a negative one. The entrance into her life of BC was the event that interrupted her regular routine, and:

*what its done is give me permission to do what I need to do to get myself into a better place. And a lot of people don't ever have that opportunity or that incentive. And so even though I'm not there yet, I still don't look on [BC] as a negative experience.*

Geneva admitted that a positive outcome was the loss of her hair, and this, she said, was “*fantastic*”. To clear up any misunderstanding about her comment, Geneva went on to say that “*now its grown back grey, and it's a nice grey, and I don't have to dye it anymore*”. Eliminating the need to continue to dye her hair was not the only ‘gift’ of cancer for Geneva. “*Being able to take time out for myself*” had given Geneva the opportunity to reach the conclusion that she was “*allowed to be there and listen to people*” without necessarily needing to have or express an

opinion. For Geneva, the realisation that *“I can just listen”* was *“really important”*. She talked about the internal struggle to give herself permission to step aside from being the person who could provide an answer for an emotional dilemma, or being the one to provide comfort for someone in distress. Geneva had the view that *“people aren’t static ... people are dynamic and they’re changing all the time”*. Her comment related to her own growth; she was growing and changing from who she was prior to BC. Geneva talked about being uncomfortable and comfortable with the changes in her attitudes and values.

Beverley did not use the term ‘gift’, however, she referred to a personal discovery from her time with BC that *“my closest relationship is with my husband”*. She felt their experience as a couple going through BC had helped her shift to a position of greater acceptance *“that he is who he is, why he is, and that’s just how it is, and he might never change”*. Beverley said she had discovered that to keep hopefully expecting something different from a long-term relationship than what is on offer is *“a definition of insanity”*. Instead, she felt that having BC had helped her to discover that the relationship with her husband is *“there to stay if I choose to want to continue”*. With emphasis she repeated *“ ... if I choose”*.

An unanticipated benefit for Beverley was the awakening of her spirituality. Being confronted with the prospect of death had brought her to the place where she was able to say *“I’m a more spiritual person now, and I’ve got a good understanding. I’m really very happy that I had that ... that I’ve gained that”*. The opportunity for Beverley to open to becoming a more spiritual person was an aspect to life that she said *“I think is really important”*.

Although she said her statement sounded like *“a cliché”*, Gemma said that she realised since having BC she was *“a bit stronger than you think”*. She spoke also of her recognition *“maybe that I can actually get through a lot ... and perhaps actually that I was a lot more practical than I would’ve thought”*. The ‘lens’ through which Gemma viewed life was one that drew her attention to wondering whether having BC would mean *“you’re gonna fall”* into a distressed emotional state in which she would become *“a mess”*.

Gemma was also thoughtful about not judging any other person's emotional expression. She advocated a *"non-judgmental approach"* before making a decision that someone *"is appearing to fall apart"*. Emotional expression she considered as *"maybe that's a good thing because they are expressing themselves and that is actually quite appropriate for what's just happened to you"*. In terms of her future, Gemma's characteristic philosophical approach to life helped her *"just go la la la"* and at the same time apply personal, internal wisdom to her situation. Her attitude was to find out *"everything you can"* but then to have *"the wisdom to go ... don't go there"*. From this thinking she had made a decision not to find out a prognosis for her BC, however, still felt confident that she was not ignoring reality completely:

*I might not be in that statistic ... you can't live your life what if, what if. You just have to go – I haven't got it right now. I just say I haven't got it, I don't have cancer and I'm not going to have cancer. So I don't even think [about] whether I'm gonna make five years.*

Carole's 'gift' was that she discovered *"I'm a fairly strong person"*. Because her marriage was breaking down at the same time as her encounter with BC she felt *"determined to get through this and be healthy again ... and I am determined to do that"*. Doing some of her own research about BC: *"what causes it, and what could possibly be the cause ... and so on"* became Carole's ally during her experience. She said, *"I did a lot of research"* and often found herself wondering why other people with cancer did not *"get out there and try"*. In addition, BC had *"made me a lot closer with my children"* Carole said. In particular she highlighted the relationship with her son who had changed from rarely making a phone call to Carole to calling her twice a day post-BC. An emphatic statement from Carole was *"I'm gonna beat this"*. As if to underscore the depth of her intention, this statement was repeated, and after a pause, was followed up with the words .... *"That's all"*.

Wendy spoke of developing *"deeper friendships with people who were not in my social group"*. She followed up this statement with a *"Yee-hah"* – a way of indicating that Wendy felt satisfied that her social connections were supportive for her. Two women Wendy had previously known but had not been friendly with, had become, post-BC her closest confidantes. She said she valued their honesty, openness, and capacity to talk with her about her feelings and her health in a

straightforward manner. Wendy intimated that since having BC she did not want to be forced, or convinced, to step out of a reflective, and sometimes melancholy, state. She found herself drawn to spend time with people who could acknowledge and accept that *“I still feel ... still sad in myself ... and I don’t feel happiness ... I really struggle with it [happiness]”*. Wendy had found herself avoiding social situations where there was *“all this positive stuff going on”*. For Wendy, self-nurturance was to be able to stay with her feelings and not try to divert herself from her emotional life no matter how challenging those emotions were.

Terri felt as though BC had led to developing closer connections with some friends *“who were really, really helpful”*. She spoke in a softer tone when referring to new friends made when attending a BC recovery group. In particular she talked about one younger woman she had developed a strong emotional bond with, saying *“if I hadn’t had cancer I would never have known [her]”*. The friendship and support received from others was something Terri regarded as *“precious”*. She also talked about the relationship *“between me and my sister”* as *“just wonderful ... absolutely wonderful”*. *“It [BC] changes how you relate to people”* she said. Terri associated the fact that people *“will open up more”* to someone who has had cancer with her observation that people in distress may be able to identify more closely with someone else whom they perceive has had to go through *“something that’s hard”*.

BC served not only to deepen and extend Terri’s personal connections with friends and family. Terri disclosed that she now realised the *“importance of listening to people”*. Listening was something Terri had recognised she *“never did before ... because I didn’t have time”*. BC had also had a positive influence on the relationship with her husband. Not only were there changes in a positive way in how her husband related with Terri. She said that because of her BC *“I really got to see that I was precious to my husband”*.

Lara’s sense of humour helped her talk about what she had discovered from her experience of BC. Even though there were *“annoying”* aspects of recovery and survivorship, Lara smiled when she said *“I sort of think, I look at it, and think ... and I think ... I’m above ground anyway”*. She pointed out that over the last twelve months she had started to express herself more assertively and be more vocal in



situations where what someone else was doing, such as smoking in a no smoking zone, was the cause of discomfort for her. Lara said that in relation to the way she would think about or judge situations she was *“starting to turn things around”*. She now was able to see *“there is another purpose and sometimes there is a reason things didn’t work out and sometimes it’s for the better”*. She continued by saying *“I look at cancer ... though it’s a stupid thing to say ... as a gift”*. Lara referred to cancer as *“the wake-up call I needed to have to change things in my life”*. She talked about BC as generating a *“major shift”* in her thinking. The major shift Lara experienced had helped decrease a tendency to ruminate and then empowered her to change aspects of her life that were unsatisfying and worrying. Lara had recognised that she was prone to investing significant amounts of energy to things that did not warrant such a substantial amount of her time and focus. Describing her time with BC she said *“for me it’s actually been a blessing. I’ve relished this time on my own”*. She felt that *“I sort of found myself, basically, in this last year”*, and had been able to recognise *“parts of me that I like and ... parts of me that I didn’t like”*. Lara expressed feeling more relaxed about life in general, as well as commenting that she felt more able to see life events and their purpose in a bigger picture.

Jenny echoed the comments made by other women, that *“I’m stronger than I thought”*. However, Jenny extended her comment by saying that through BC she had also discovered she was *“weaker”* than she believed herself to be. She became emotional when talking about feeling vulnerable and realising that a key task for her was not to push her body so hard, and to develop a kinder self-dialogue than in the past. Her father, she said, had represented the *“perfectionist”* in her family of origin, and Jenny had worked hard to emulate and meet her father’s standards. Having BC had confirmed for Jenny that she was accepted, completely, just as she was and that *“my husband loves me”*. She intimated also that her four adult children had demonstrated, in practical ways, their willingness to support her in any way possible. An example of this was their decision to shave their heads, wear pink and attend a social event Jenny organised to raise funds for cancer research.

Shirley felt lucky to be alive and felt grateful for the changes to her life since being diagnosed. By way of example Shirley commented that she and her husband had travelled more since her BC. She referred, in general, to life being too short to

use time and energy concentrating on aspects of life that had no meaning for her. Importantly, Shirley commented about a feeling she now enjoyed of being very capable to manage her own life. *“I do more, I stand up for myself more than I used to”*.

Participants in this study were determined in their resoluteness to acknowledge new-found personal resources and ‘strength’ as a positive additive to their life and their relationships. As one participant commented:

*I think what it does ... a little bit ... is it makes a little bit of you permanently grown up ... you know ... you’ve got this really grown up thing you have to deal with.*

### **6.3.10 Self-compassion – “Learning to say no”**

The concept of self-compassion was responded to by participants in two ways. One way of responding was from an understanding of the emotional implication of being self-compassionate. For instance, women talked about not treating themselves kindly. They voiced their concerns that being self-compassionate would mean selfishness, or facing an awareness of not having received compassion from those who could have or should have given it, and not knowing how to be kind to themselves. The second way of responding emerged from an intellectual understanding of the concept. In those instances the responses given gave a rhetorical comment that to be self-compassionate, that is, to think well of yourself and be kind to yourself, was considered a helpful resource for living well.

Self-compassion as an automatic aspect of the self-relationship was not an entirely welcomed, or open, topic for discussion. Fear and uncertainty about self-compassion, as well as fear of receiving too much kindness from others, found its way into interviews and group discussions. While the women welcomed support during the active phase of their disease, once treatment was completed and they felt as though life ‘should’ return to normal, there seemed a tendency to return to a state of being unconsciously less than kind to themselves albeit in subtle ways. The paradox that faced this research was that while SC has been found in research to be positively associated with relief from depressive symptoms, could SC be expected to

automatically decrease psychological distress through awareness of and practice of self-kindness and mindfulness.

Overall, however, the responses given by the women participants, meant this theme could be summed up as commentary on a process of the BCS learning to say ‘no’ to others in their lives. Despite this positive change, it seemed that the women were not yet able to say ‘yes’ to themselves. The commonalities in the participant’s experiences revolved around the capacity for self-criticism to be the source of motivation and suffering. Uncertainty about how they would feel about themselves if they eased their concern for others was another commonality in the reports from the women. The discussions about the meaning they made of the term self-compassion appeared to stimulate reflection on BC as a place to begin to know and understand themselves, maybe for the first time.

When asked for what the term self-compassion meant to her, Carole said that she thought “*some people might think it’s a woman thing*”. She continued by saying that she because her children were now older, being kinder to herself was more possible. Carole commented it would be very hard for her to be self-compassionate “*with children who were younger*”. Carole talked about thinking well of herself only since having BC. She said self care was “*something that I’ve learned to do ... I never understood any of that before*”. Prior to having BC, Carole said she thought taking care of oneself was “*a whole lot of hotch-potch and baloney, whereas now I strongly believe it*”.

Shirley’s translation of the term self-compassion was “*not to be too hard on yourself*”. With a loud sigh, she explained what she meant. “*I’ve always thought I had to do things, you know, I had to ... had to be the mainstay of things in the family*”. Shirley stated clearly that “*mothers do that*”, and recalled a time pre-BC when she had been hospitalised for several days with hepatitis. On returning home she was surprised when one of her adult children offered to cook the evening meal. Shirley’s immediate internal response to the offer was “*but ... I’m home ... it’s expected of me*”. However, she went on to state that she was able to accept the offer of help even though it did not feel ‘right’ to do so.

Shirley described being “*very critical of myself at times*”, and said she was a person who liked things to be “*right*” and liked things “*to be perfect*”. Locating her thinking to life post-treatment, Shirley said, “*but now, blow it ... if it doesn't get done, it doesn't get done. I've learned I can't do everything*”. At the same time, Shirley laughingly referred to herself as a person who was “*not very bright*”, and yet, when faced with a challenging task, Shirley said she found it helped to simply keep telling herself “*you can do it*”. The subtler self-talk in what Shirley said was that even though she may not be very smart, she could still achieve something or complete a task.

Shirley described a prevailing attitude in her earlier life as one where she “*always thought everything had to be perfect, and people always expected it of me*”. When talking about her relationship with her husband, Shirley recognised the feeling that she now had to be a perfect wife who could “*be there for him*”. She saw her role as being able to alleviate fears he had about her survival. Advised by a friend that her husband's concern and control of her was only because he loved her, Shirley responded with “*but that's not loving. I don't think that's loving. I think that's possessing*”. Shirley did not want to be regarded as someone who was now permanently unwell and yet this was a perception of Shirley carried by her husband. “*Smothering*” was a state that Shirley referred to as the thing “*I can't cope with*”. Specifically, she felt that her husband's permanent state of concern and worry about her wellbeing and her capacity post-BC to handle life was not helpful to her. Shirley said, “*I don't have to be looked after. I don't have to be told. I'm a big girl now. I can work it out for myself*”. Shirley was strong and clear when she spoke about the effect controlling behaviour can have on relationships. She did not like the feeling of being controlled and said, “*Why should I give up my life ... I just got it back... I've just got my life back!*”

To illustrate ways in which she had been able to treat herself in a kinder, gentler way in recent times, and work life out for herself, Shirley talked about now taking extra time to read a newspaper in the mornings, or giving herself time to complete a project. She mentioned allowing herself more time to complete tasks, and to illustrate her point, talked of Easter eggs for her grandchildren saying, “*I've still got the Easter eggs to give them ... and it'll be the middle of June and they'll get the*

*Easter eggs*”. She also gave an example of being able to push back against internal, an external, criticism when on a recent weekend away with long-term friends. Shirley decided to take on the task of cooking breakfast for the group of friends each day. When challenged by her husband that Shirley was not preparing breakfast in the same way as had been done by another group member (someone who had been the group’s breakfast cook for many years), Shirley simply said “*Well, X is not here, I am, and this is how I do it*”. This comment marked a significant milestone in Shirley’s willingness and capacity to step forward into a stronger sense of self. Shirley’s comments to her husband indicated that she was able not to take on criticism, but to be more self-compassionate and appreciate her way of doing things.

Gemma interpreted the idea of self-compassion as “*sort of like ... putting yourself first ... but also being a bit more ... well, perhaps its understanding ... of your faults and strengths maybe ... being a bit more forgiving of yourself perhaps*”. Gemma also said “*and I still don’t think I do that very well*”. She described herself as a work colleague always willing and able to get things done. Since having BC Gemma had observed changes in the way she related with her work and with workplace colleagues. She noticed that she was “*starting to say ‘no’ in the workplace a bit more often in small ways*”. Gemma tempered that statement with “*I don’t mean a big ... NO*”. But change was not easy, and Gemma explained that although she was making small changes “*I always fall back into the yes, yes, yes ... yes, I’ll do this for you and I’ll do that for you*”. What stood out for Gemma was that falling back into old habits and doing things for others only resulted in increased levels of stress for her. To her, self-awareness meant that:

*Recently, I’m standing back from it and seeing that you can sometimes be taken for a ride by people, and you don’t realise that you’re being led down a garden path. And you all of a sudden realise you’re in a stressed heap of mess in the corner, and you wonder how I got there. And you realise I should’ve said ‘no’ right at the beginning.*

As she talked, Gemma recalled the example set for females in her family. She felt that the pattern of caring for others’ needs had been “*hugely*” influenced by the example set by female members in her family of origin. “*There’s a bit of a thread ... but ... my Nanna to my Mum, to me, not so much my daughter .... I think it will finish*

*with me ... she's a different personality actually ... but you know my Nanna and my Mum and to a degree my Auntie". Gemma felt the example of being of service to others, particularly men, was, to some extent, gender specific and explained: "It's women who will often just ... it's the serving everybody else that you ... it's our make-up is like that". She was able to clarify her comment when she said, "I definitely think there's a family thread and it's almost hard to unlearn ... its almost like an accumulation of a family trait ... not even just your own nuclear family". Gemma went on to talk about the ways in which relationships and experiences of traumatic loss within her family had a negative influence on patterns of relating that had then been passed on to successive generations. Gemma became quite emotional when talking about deaths and losses that had shaped her grandmother's and mother's worldviews. She felt that self-compassion had been non-existent in her mother's and grandmother's time. Gemma did not want to be specific about the details of her comments about family tragedies. She simply wanted to make the point that she was convinced overwhelming grief from sudden and catastrophic loss for her female ancestors had robbed those women of being able to think of nurturing themselves:*

*I've talked about this a lot with [a relative] ... and what relationship she had with her mother who's my Nanna ... my Nanna lived with my family for about 34 years after ... so I've had a close relationship with [her] ... and when you hear everyone's life story ... there were things ... in different generations that influenced how that person is in their life and ... that consequently influenced that person and also what was happening at the time ... I'm talking like big world events ... like wars. and people being lost in wars ... and the threads of the families after that.*

With laughter and chuckles Beverley expressed a philosophical view of self-compassion being dependent on self-worth:

*it's sort of all screaming around in my head .... How nicely you treat yourself ... and I think that I haven't been really self-compassionate. I'm more compassionate to other people than I am to myself ... I think that's tied in with where I'm at with my feelings of worthiness, you know, if I'm feeling more worthy then I'm likely to be more compassionate to myself.*

Beverley talked about recent fluctuations in her sense of self-worth and highlighted that her participation in counselling had helped enhance her overall capacity to regard herself as of value. However, Beverley identified that her sense of self as valuable and worthy was not yet stable. She illustrated this point by saying that after initially doing well, *“then I hit a wall with all these other life situations. So that’s kind of plummeted a bit, and now I’m coming back up with that”*. For Beverley there was a certain and physically obvious discomfort with the idea of giving emotional support and compassion to herself. With lots of pausing, reflecting and searching for the right words, she said:

*If you start thinking about being compassionate to your self, then you might end up in tears ... because ... it might be seen as being sorry for yourself, you know, once you get a bit too close, and its ... oh ... being a bit nice to you.*

Beverley felt that having BC had changed the way she made decisions. She felt less critical of herself and *“less hard on myself”*. However, even though she had engaged in a personal counselling process to recognise and overturn a habit of not considering her own needs, she said, *“but I wouldn’t really call that self-compassion”*. A couple of moments later, after another long pause, Beverley said, *“... but then maybe it is...”*. Despite her willingness and capacity to review the basis for her decision-making, there was, for her, risk linked to being self-compassionate. Beverley’s concerns about what being self-compassionate might mean for her related to self-awareness. She realised that if she became aware of what she needed in life then by default she would also become acutely aware of what she was not getting from life. To willingly expose herself to emotional suffering by acknowledging the absence of self and other care for her, meant she would be challenged to take action to remedy or adjust her circumstances. Beverley commented in the following words:

*Then you know what you need, and you know what you are not getting ... and then that can make you feel very vulnerable. And if you feel too vulnerable then it might be too much ... then you can’t carry on with what you know, with what you have to do so, in a way, maybe ... that might be why I’m squirming when you say self-compassion.*

Comment from Wendy indicated that BC had forced her to question the way in which she prioritised outer demands. She indicated this with the following comment when she responded to a question about her understanding of self-compassion. In this comment Wendy acknowledged that before being diagnosed with BC she was a ‘giver’ who was a willing helper to others:

*I know possibly before I was unwell I would've probably given so much more to others than to myself ... [I'm] a very compassionate person ... but when you go through something like that [BC], if you don't have self-compassion I think you would struggle ... really struggle with your sense of who you are, just making yourself feel at ease.*

Wendy then said that on reflection, she had never regarded her needs as important. For her, parenting was paramount, particularly with a child with special needs. However, she was aware that self-care was important to enable her to care for her son:

*I think possibly that I didn't spend enough time with myself, prior to breast cancer ... I didn't really spend the time it took to nurture my body and my mind, like ... I felt I spent a lot of time parenting ... so what I learned about myself was yes, it's ok to go and exercise and the children will be fine ... and it's ok to go and do this ... it's giving myself permission to ...*

Geneva's understanding of self-compassion was linked to her decision to give herself additional time to decide whether to return to her pre-BC occupation. She was aware that no one else could either give her permission or refuse her the right to stay away from a career that she knew was both physically and emotionally demanding. To be self-compassionate for Geneva meant:

*Basically loving yourself for who you are, and having an understanding of how life works so you're not too hard on yourself ... and just being able to forgive myself the way I forgive others is another thing, I guess.*

When the interview drew attention to times of self-compassion, Lara asked what the term self-compassion meant. Her interpretation of the term was that compassion meant “*how you feel about yourself, whether you can do the self-nurturing side of things*”. The term ‘self’ to Lara meant something related to “*how*



*you pamper yourself*". Her decision not to return to work, despite the fact she said she had "*fought heart and soul*" to continue with her career post-BC, was a situation Lara looked upon as being self-compassionate. Lara also talked about the point she had now reached where she had told her husband and family she was not willing to be the person to prepare and present "*a full-on English Christmas, you know, turkey, the whole works*" every year. She mentioned the Christmas season as her most "*physically exhausting*" time of the year because "*I'm doing the shopping, I'm getting the house decorated, I'm cleaning, I'm cooking*". Confessing that "*I'm sick and tired of doing Christmas*", Lara pointed out that since having BC she had found herself able to retreat from being the one whose efforts make Christmas a special event for everyone in the family. She mentioned that although it had not happened yet, "*I expect one of my children to take over ... because I did for my mother*". She also indicated that she no longer felt guilty about shifting her focus at Christmas, from others, to herself. Self-compassion for Lara meant taking a step back from feeling responsible for others' wellbeing.

Carole said she had "*not thought of the word self-compassion*" and highlighted that some people might interpret self-compassion as being self-indulgent. She talked about self-compassion in her life in terms of her focus on healthy eating and taking care to look after her physical needs. She commented that physically, BC had "*taken ... years to get over*" and that it had "*taken a lot out of my heart*". This comment was Carole's way of saying that all her energy had been spent in recovery. Physical stamina was important to Carole and five years post-treatment she said after-effects were only then beginning to diminish in ways noticeable to her. Fatigue was one of the residual concerns for Carole. From her comments, it seemed that being self-compassionate would have been difficult to integrate into daily life up until the time of Carole's participation in this study. It seemed as though Carole had only enough energy to manage day to day tasks without what might have appeared to be an 'add-on' to the work of survival. Towards the end of her participation Carole announced to the PRP group that she had decided to take an overseas holiday on her own – something she would not have previously imagined having the energy to do. For Carole this was self-compassion; to trust herself and her body, and to reclaim joy.

Self-compassion was something Jenny said *“hasn’t been very high because I’ve been caring for everybody else”*. She emphasised that with her diagnosis she felt other family members *“didn’t know how to cope with it”*. The result was that Jenny said she was the one to take care of other people’s feelings. She indicated that throughout her diagnosis and treatment she was the person who supported other family members through their distress.

Jenny’s internal dialogue left her somewhat confused about her emotional experience. At times when she felt there was minimal feedback from those around her to let provide evidence of their awareness of what she had been through, self-compassion was obscured by self-doubt. Jenny would query her reaction and ask herself *“how can you be so upset [by] how other people feel, it’s not about them”*. She admitted she would then internally question herself and engage in self-criticism for feeling the way she did:

*Then I start thinking, oh, maybe it’s not as bad ... maybe I’m overreacting, and what’s happening to me isn’t that significant, maybe just overreacting ... and I shouldn’t have these feelings. I’m fine ... build a bridge and get over it.*

When self-compassion was mentioned Stephanie said honestly that *“I’m not quite sure what that is”*. She then defined self-compassion as *“how I think about myself, or do I blame myself, or do I look after myself”*. She felt that she could be self-compassionate by making sure:

*I’m thinner, fitter healthier ... that I don’t drink alcohol, that I don’t smoke and that I live the rest of my life to the fullest, so that however many years I’ve got left - 5 minutes or 50 years - I get to the end of my life ... and go, yep I did that, I lived my life the way I wanted to, rather than get to the end of it, and go, uggh, didn’t quite do that.*

Nicole responded to the term self-compassion by defining it as *“giving yourself a break ... allowing yourself to feel upset, or accepting whatever ... about your health and your body”*. After an extended pause in the conversation as she began talking about her love of going shopping and her peace of mind that her husband was supportive of her being *“a bit of a mall-hopper”*. We came back to the

question of self-compassion and Nicole used that as an entry point to talk about her main concerns prior to BC had been her teeth and her weight. The topic of self-compassion was clearly one that had made Nicole feel a little uncomfortable. The topic was not raised again. When Nicole resumed the conversation she talked about judging herself for not getting better quicker. She commented that she had expected that she would recover more rapidly and be able to “*get back to work and contributing*”. While not talking about self-compassion Nicole also talked about having had 5 children, moving house and having a “*meltdown*” that resulted in her taking two weeks off work and making changes to her work hours. While the formal term self-compassion may have activated some vulnerability, Nicole’s story did indicate her capacity to stop when things were not right and make necessary adjustments to ease any stress.

### **6.3.11 What women need.**

What women participants found to be helpful for themselves, and what they felt women, in general, needed was one and the same thing. Their ideas emphasised the value of interpersonal aspects of relational experience. What they felt women with BC needed was a way to remain consciously connected to self, one’s body, loved ones, family life, and even their workplace as they move through an experience that could generate a state of chronic disconnection from self, the body and others. As a group, the women highlighted the socialisation that had happened in their life. That socialisation led to a sense of responsibility for taking care of others in practical ways as well as caring for others’ emotional life. The result was an inclination to engage in relationships where they were the ones to provide empathy and emotional nourishment. Counting on others for help was, in general, not the preferred model for living life pre-BC. Therefore, a capacity and willingness to allow themselves to receive care and empathy brought the opportunity for growth and development.

Beverley had a background in nursing and prior to her own diagnosis had nursed in an oncology ward. She remembered carrying out suture care on the staples used in mastectomies and felt that the women needed psychological care. Her observation was that what the women needed most was time to talk about their experience with someone who could listen. Beverley’s impression was that “*I think women do like to speak, they like to be heard*”. However, as a nurse, when caring for

women with BC she said *“there was no time to sit down and have a chat”*. Beverley felt strongly about not *“pointing the finger [of blame]”* and expressed caution about any suggestion to a woman *“you’ve got breast cancer because you haven’t been looking after yourself”*. Beverley’s opinion was that society was quick to *“put the cart before the horse”* and, in general, was slow to accept that BC was not a by-product of failure in women to take better care of themselves. Beverley suggested that what was needed was change to societal attitudes about women’s illnesses *“that’s a very big thing to change, isn’t it ... because this is the way it always is”*.

Lara regarded *“support-type groups”* for women with BC as *“just the best thing”*. Her idea was that it was highly beneficial for women to be able to get together and share their experiences. Lara also highlighted the difficulty for a person to talk honestly and openly about their cancer experience *“with someone who hasn’t been on that journey”*. She felt that no matter how understanding and supportive other people wanted to be, a depth of connection was really only able to be encountered with another person who had gone through BC and could say *“yes, this happened [and] I found this invaluable”*. Counselling groups, and self-help or personal-growth groups where women could share their realities, particularly the highs and lows of their journey with BC were avenues Lara said could be helpful for women. However, she also highlighted Australia’s geography and the ‘tyranny of distance’ when she remarked that for some women to travel any distance further than 20 kilometres to participate in support groups could mitigate against regular involvement.

Carole had come to recognise that her interpretation of the often-heard statement about ‘losing the battle with cancer’ meant, for her, the fact that *“the disease has taken over so much of your body that it’s very hard to fight it”*. The wisdom of her personal experience was that *“you do have to fight it, you do have to get in there and ... you have to work at it ... and you’ve gotta eat well...”*. Overall, Carole felt that what would help women with BC was *“mainly just someone there to listen [and] not to be judgmental”*. She went on to say that *“some days are bad, some days are not so bad”* and, that ideally, *“society”* should have a more comprehensive understanding of the process and time needed for recovery from BC.

*“But” she said, “I don’t think people really, really understand what its like. They have no idea”.*

Referring to the women she had met through a BC support group, Shirley said that *“treatments were all different, our cancers are obviously all different, and we’ve all coped differently”*. She talked about feeling *“close”* to the other women in the BC exercise group she participated in for 8 weeks. In addition, she talked about women understanding practical aspects of BC that impact on their wellbeing such as burns from radiation, finding a post-treatment medication most appropriate for the individual, eating well, and checking vitamin D levels. But, Shirley said, *“what I really would like to do ... go to a .. getaway thing for women and just be pampered and not be told you must eat this and you musn’t eat this”*. Shirley commented that women with BC would benefit from taking time to *“walk in the bush”*. She felt that any support should not be given in a regimented or rigid way and that women would feel more supported if they were encouraged to *“be gentle”*.

Geneva’s recent participation in a brief counselling and exercise program for women with BC had led her to believe *“people wanted to talk about things ... and go into more depth”*. Her understanding was that to feel as though you were being listened to and heard was an important way to support women. She added, however, that human beings are not predictable nor one-dimensional, and that one person’s experience *“isn’t always the way [other]people go through things”*.

Jenny had worked hard to support BC care groups. She had made turbans, had held fund-raising activities and in general, was positively motivated to be *“involved in support groups”*. However, she had experienced the cancer support groups as *“very challenging”*. Jenny said she felt mentally and emotionally confronted by being in a group with women who had recurrent BC, or women whose diagnosis was terminal. The open nature and changing membership of BC support groups was uncomfortable for Jenny, especially when the group *“was just coffee”*. She found it difficult to connect with others she said, when the approach to the group was *“casual and not having some sense of purpose”*. Her comments referred to Jenny’s desire that BC support groups be more proactive in their supportive role. Her unsatisfactory experience had led Jenny to undertake training to become a group

facilitator for BC support groups. Despite attending training and despite having a strong desire to facilitate recovery groups for women with BC, Jenny reported that *“that really dark time”*, when she attempted to return to her usual employment, had left her feeling intensely vulnerable. She said she had come to the realisation that the time was not yet right for her to offer to facilitate BC support groups. This lack of taking active involvement in facilitation had a negative psychological impact, and had led Jenny to *“feel like a failure though”*. She said she felt *“like I’m not achieving what I set out to do ... I feel like it’s something God gave me, and I’m not being good by not doing it”*.

Terri had a vision of offering weekly groups where women with BC could do specific exercise classes that were matched, at commencement, with the state of their post-BC health, with consideration for their physical capacity to engage. Having taken part in an 8-week BC recovery program involving exercise and group counselling, Terri had the beginning experience of feeling uncertain of the extent of her physical strength. Through extending herself each week at exercise class she was able to move through to recognition of feeling much stronger in her physical body. Her vision for helping women with BC was something she felt both excited about, and, at the same time, felt somewhat downhearted. Her vision was of *“Terri’s exercise class every week”* that could include *“some raw food cooking”*, and she said, *“I reckon we would just have a ball”*. Terri said *“I would love to do it, but I’ve got no qualifications and so I can’t”*. Terri explained that what she had in mind was time to come together to enjoy, share, and to encourage each other; a time that also *“would just lift your whole spirit”*. Her idea was to create a group that would foster strong inter-personal connections where women with BC could *“build up a link to someone who you can then go to when you need to”*. Terri’s sense of humour helped her enjoy her excitement, and also take herself lightly, rather than feel contained and restricted by not yet being able to materialise her vision.

### **6.3.12 Section summary**

Women who contributed their BC narratives to the findings in this study held the view that women were the relational givers and the ones who would strive for harmonious balance in family relating. This finding was consistent with research findings that highlight that in a gendered society women tend to put the needs of the

family above their own needs (Mackenzie 2014). Mackenzie (2014) found that after BC women felt tension between wanting to live into the ‘new’ self, and feeling as though they needed to continue to meet the expectations of their role as a mother, a wife and person with extended family. Meeting gendered expectations was a persistent theme in the women participating in this study. While they reported feeling psychologically stronger and able to redefine some boundaries in their home life, or to relinquish their paid work, putting themselves first remained difficult. The tasks they had performed within the family prior to BC continued after their treatment. While they had changed, family members were still to ‘grow into’ the new normal.

Being self-compassionate and having a capacity for self-compassion seemed dependent on a range of pre-existing factors. Those factors included issues that are not the province of this thesis. For example, the issue of insecure attachment (Joeng et al., 2017), a history of childhood maltreatment (Barlow, Goldsmith Turow & Gerhart, 2017; Boykin et al., 2018), or lack of parental warmth (Kelly & Dupasquier, 2015).

Across all interviews women expressed a strong desire to help other women who would be diagnosed with BC. There was an expressed desire to give compassion to those who were presumed to need it during the journey through treatment for BC. An implication from what could be regarded as an urge to help other women, and perhaps provide to other women what they may not always provide to themselves, is that their participation in this research could be regarded as part of that desire to make meaning and to have a sense of purpose about what they had experienced.

#### **6.4 Findings from Significant Others**

Thirteen major themes from semi-structured individual interviews with three males who were a significant other in the life of a woman with BC were identified through the strength of focus.

Prior to interviews with three significant others (SO), the researcher had no personal or professional contact with Chris, Rob and Garrett (pseudonyms used). Aged between 40 and 55 years of age, they were recruited by the researcher using professional networks as well as in response to the question of recruiting an SO from

amongst the women participants. At the time of the interviews, Chris was working as a medical practitioner, and Rob was unemployed, although prior to his wife’s BC he had enjoyed an extensive career as a teacher and high school principal. At the time of interview, Garrett was changing careers. Currently he was completing the second year of a three-year undergraduate degree in counselling. Garrett had previously worked for a number of years in middle management within the finance industry. One couple had no children. The two other couples had children who were between 18 and 30 years of age. Relevant demographic data of the participant significant other is presented at Table 4.

<b>Name (pseudonym)</b>	<b>Partner’s name (pseudonym)</b>	<b>Relationship to BC survivor</b>	<b>Outcome of BC for Partner</b>
Rob	Jenny	Married	S
Chris	Terri	Married	S
Garrett	Louise	Married	NS

S = Survivor NS= Non-survival

**Table 4: Demographics of Significant Others**

For Garrett, the journey with BC had resulted in his wife’s death. Our conversation about BC was then related to the more immediate experience of her journey from diagnosis to death. Rob’s wife Jenny had initially emerged from treatment optimistically. However, over several months post-treatment Jenny’s earlier positive psychological adjustment declined and she developed clinical depression which resulted in Jenny making several attempts to end her life. At the time of writing this study, Jenny and Rob had begun to emerge from the impact of depression, and Rob indicated that Jenny was willing to engage in life once again.

Chris and Terri were a couple who were noted by Chris as being willing to engage in meaningful cancer conversations from the outset. They made the decision together to navigate diagnosis and treatment with an optimistic outlook and, when interviewed for this study, were looking forward to maintaining the changes they had made post-treatment to ensure physical and emotional well-being.



Interviews lasted from an hour and a half and two and a half hours. The following extracts from the interviews provide a narrative of experiences and perceptions of three SO of three women treated for BC. The focus of the interviews was to discover the perception SO had of their loved one's experience of BC, her self-image, their understanding of self-compassion, and their experience of their wife's self-compassion as she navigated the challenges of a life-threatening illness.

The thirteen themes were identified from the interviews with three significant others are listed in Table 5 (p. 248).

<b>Major Themes from Significant Others</b>	
1 Confrontation with the disease: <i>"Like having the ground fall away from under you."</i>	2 Being the strong one: <i>"I really needed to be as strong as possible for her."</i>
3 Disorganisation and unrest: <i>"She was very keen on things being as normal as possible."</i>	4 Turbulence and treatment: <i>"If its tough stuff, you may not hear it."</i>
5 Caring for ourselves: <i>It's a shared journey.</i>	6 Self-image: <i>"I'd say - the place just lights up when you walk in"</i>
7 Intimacy, sex and sexuality: <i>"We'll find other ways of connecting."</i>	8 Emotional support: <i>Support for me, support for us as a couple.</i>
9 Grief and talk of death and dying: <i>Making every moment count.</i>	10 Self-compassion: <i>Living an authentic life.</i>
11 Back to basics: <i>"Its letting go of projects, plans, activities and thinking more in terms of the people."</i>	12 The future: <i>"It doesn't stay dark forever."</i>
13 What might help: <i>"The medical side is needed but the psycho-oncology is really needed too."</i>	

**Table 5: Major themes from interviews with significant others**

#### **6.4.1 Confrontation with the disease: *"Like having the ground fall away from under you"*.**

For each of the men interviewed, the memories of receiving confirmation of their wife's diagnosis was firmly etched in their memory. Hearing the diagnosis was a particularly confronting time for each of the SOs. Garrett expressed a sense of

shock and a type of speechless dread when receiving the diagnosis. He referred to that moment as:

*it was like having the ground fall away from under you or having the rug pulled from under you or something, you know ... where its just that feeling of everything's just changed.*

Garrett spoke further about a feeling that could be likened to a temporary state of cognitive dissociation. From his report of what happened he was unable to process the information in the moment. He said *"it was almost numbing"*. Talking more about the numbed state and about the feelings of unreality of the in-the-moment experience for him and for his wife, Garrett talked about a mutually protective state he and Louise automatically entered when the diagnosis of BC was confirmed:

*We were driving back home and we were almost talking to each other like ... this wasn't really happening. And we ended up stopping to have a ... get a glass of wine and just gather our thoughts about what does this mean, what do we have to do...*

Chris, a medical practitioner, felt that his medical training and years in practice did not offer insulation from the intensity of shock and anxiety on hearing the news of his wife's BC. He commented that he *"certainly had a fair bit of anxiety ... about the diagnosis"*, saying, *"It was quite confronting initially"*. Despite his education and *"insight"* into the practicalities of the medical aspects of cancer, Chris said that his response to diagnosis was *"exactly the same as everybody else. And so I acknowledged that was what I was doing and that was actually quite helpful"*.

Chris was able to acknowledge his reaction was one of personal anxiety as well as professional concern. This awareness energised him to mobilise his resources, and while he had unsettling questions such as *"What did it mean"* and *"What was the future going to hold, for her, for us"*, he urgently prioritised his thinking. Chris was able to galvanise his concerns into action and *"took control of the process at this point and plugged her into this specialist I thought she should see"*. One of the critical aspects at the beginning of the journey for Chris was to know Terri was provided access to the best medical care available. Chris was also able to reflect on the condition of his relationship with his wife and concentrated his

attention on *“probably the very next thing ... the very next thing I thought was, well, how can I change my way that I relate to her to help her?”*

Rob and Jenny began their experience of BC taking somewhat different action. After initial investigation into her symptoms Rob said Jenny had intuitively felt that *“it was going to be bad news”*. Exploring his personal experience, Rob recalled an unexpected stressor:

*the biggest impact on me ... was in terms of your ability to concentrate and to remember things. Because you have got at the back of your mind ... you're preoccupied with what has happened ... and what lies ahead.*

Despite his fears, Rob's commented that his years of experience in the field of education meant he hoped the experience of guiding and advising others would help him navigate the situation. Rob said his response was to immediately take on the role of the *“moderating husband”* and in that role *“its my job to put the counter ... you know ... in most cases it's 50/50 - whatever it is, if it's a cyst, [maybe] it's not cancer ...”*. Rob's concentration appeared to be that he was focused on bringing a steadying influence to what he observed as Jenny's fear. Casting a protective shell around his own thinking, Rob worked to allay any tendency for them to engage in worst-case scenario thinking. His focus was for Jenny *“not to jump to conclusions here”*.

The desire to remain a moderating influence changed quickly for Rob when it came time to receive confirmation of the suspected diagnosis and he spoke of his recollection of going with his wife to the breast clinic. Talking about this first visit to the hospital generated strong emotional expression in Rob as we spoke. Asked if he wanted some pause time so as to stay with his feelings Rob indicated he was willing to continue. He said *“No, no... A little grief comes out when it comes out. Cos it's not a bad thing. I haven't really had much chance to tell the story from my perspective”*. Rob also commented that the visit to the breast clinic *“was a confronting journey”* and that at first *“we're going with the general stream of traffic in to [the hospital]”*. The shock of reality about why they were at the hospital jarred Rob's moderating mindset:

*And then you turn left for the corridor that takes you to the breast clinic and suddenly ... and then you turn left and right again and you walk in and*

*there's a room full of women with a small smattering of men there as support. And you think, "This is serious".*

Rob quickly realised "*there's a fair degree of anxiety in the room*" and he recalled the disturbance in his own thoughts in that moment. "*If you're allowed to swear [during the interview], you go ... oh shit ... you go ... you say oh no ... this is ... this is fair dinkum*".

Coping with BC required each of the three couples to come to terms with diagnosis on an intellectual level within a short timeframe, to make decisions that would have lifelong implications, and to emotionally adjust to now having BC as a permanent 'partner' in their everyday existence. Integrating BC into their thinking about life expectancy, relationships, career family, finances and faith faced three significant others with the task of "*getting my head around all this*".

#### **6.4.2 Being the strong one: "*I really needed to be as strong as possible for her*".**

The ways in which Chris, Garrett and Rob processed an unwelcome diagnosis were dissimilar in some respects and similar in others. What stands out is that each husband chose to focus on different aspects of the physical, emotional, social, and practical, tasks ahead. Terri's work as a laboratory technician meant Chris and she were able to understand the biomedical implications. From the position of at first thinking she had a malignant melanoma, Chris commented that he felt Terri was able to acknowledge and come to terms with BC. Her acceptance of the situation was buoyed by her Christian faith and she "*prayed a lot... she committed it to God*". He also explained that Terri was able to include significant others in her daily life as a way of allowing emotional support. She "*allowed her sister and other friends to be around*".

Talking about cancer was difficult for Garrett and Louise. They had communicated sparingly about her BC until they both arrived at a mental and emotional acceptance of the inevitable. Garrett explained that he quietly took on the role of a researcher, finding out whatever he could about something that he "*never had known ... about breast cancer ... other than try and get it early, people have mammograms and all that sort of stuff*". At the same time Garrett exercised caution

about sharing what it was he began to discover and learn and the meaning he was making of that information. *“I suppose as I looked up stuff I could see this is really, really serious”*. He went on to say *“I needed to just get my head around all this ... so, I’m on the internet, I’m finding out stuff ... while she was just dealing with the whole ... just what it meant to her ... for her... the whole emotional impact of it”*.

Garrett talked about his uncertainty about what to say or not say in initial post-diagnosis conversations with Louise. He was deeply concerned about the perceived crisis that was unfolding, but at the same time did not want to overburden Louise or destabilise her sense of coping by an imposition of his need to discuss what he was finding during his internet searches. Garrett’s ongoing hesitancy to be the one to initiate cancer-related conversations with his wife related to his perception of her fears of death. He was deeply concerned about what would happen with Louise’s realisation of the truth that the BC was, for her, terminal.

Garret’s sense of personal loss was evident during the interview as he described the relationship between he and Louise as strong, loving, and supportive *“from our marriage point of view we’d probably got ... in the months leading up to finding out she had cancer, we were sort of feeling like we really had made it and in the best place we’d ever been as a couple”*. In a comment about having been a successful businessperson and able to provide well for his family, Garrett also said *“Yeah, it was good. We didn’t want for anything”*. However, diagnosis and treatment significantly influenced, in a negative way, that sense of being in the *“best place we’d ever been”*.

For Garrett and Louise there was not going to be a positive outcome; there was no way to appraise a terrible situation in a positive light, and Garrett decided that he would be the one in the partnership who would provide the emotional strength for them both. Garrett’s willingness to become strong for his wife at a time of extreme vulnerability was highlighted when it came time to share the very difficult news with family members:

*...there was a lot of emotions going around ... angry, you know ... but I do remember though, like when it came to telling my wife’s family and that, I was very much the spokesperson and I felt that I was ... I had to be as strong*

*as possible for her so ... and I sort of felt that very early, on that I really needed to be as strong as possible for her ... um ... that was a real challenge to me, to be as ... to be on top of things.*

Similarly, Chris was aware that going through stressful events “*can make or break a relationship*”, and this gave him the impetus to choose to review the way he related with Terri and create change. He said this was “*a big change*”. To promote change in the relationship meant Chris was willing to re-consider the current structure of their lives and BC. At first thinking about Terri’s illness and how he could help her, Chris found himself wondering “*where’s that going to fit into what I do with myself*”. With awareness that concentrating on his relationship with Terri would mean, “*I would [need to] give up certain extra-curricula ... things that weren’t work-related necessarily*”, his ultimate decision was that “*I would put that [their relationship] as the highest priority in my day-to-day life*”. As a consequence, Chris reduced the amount of paid work he was willing to accept.

Rob and his wife held “*a basic set of values and beliefs that resonated together*”. He explained “*We’re both Christians and have Christian values as anchor points to our lives*”. At the outset Rob and Jenny felt they had assurance from God that the outcome would be positive for them. The strong Christian faith they shared had the effect of guiding the attitude Rob and his wife had to her situation. On the path that lay ahead they felt able to draw optimism and emotional resilience from their faith system.

In summary, the way each of the three husbands managed the task of needing to “*get my head around all this*” reflected that each one called on previously relied-on internal and external resources to help process the event. The resources they drew on included the capacity to understand what was needed physiologically and to assemble expert medical care, the capacity to be able to enact rapid change in the way of relating, and the capacity to glean information from a range of sources and collate a personal management ‘strategy’. Another resource for two of the couples was their strong Christian faith and connection with the God they believed in. All of these resources were utilised in an effort to maintain life in as normal a state as possible. Normal for each of the couples was a world that did not include BC and in

which there was familiar processes, balance, and being in control. SOs reported that since diagnosis life had unfolded in an unfamiliar and ‘alien’ world.

#### **6.4.3 Disorganisation and unrest: “*She was very keen on things being as normal as possible*”.**

When describing their overall experience of supporting their wife during treatment and beyond, all of the husbands reported making efforts to maintain as normal a life routine as possible despite the disruptive changes occurring. Chris portrayed himself as a person with a tendency to “*become a little bit anxious as a personality*”. Referring to his capacity to quickly assemble expert medical care, he found that “*doing the thing with the doctors actually was quite useful in terms of dealing with that.... because that reduced my stress levels*”.

With two teenage sons to consider, Garrett and Louise chose to inform their sons about aspects of the BC trajectory only on a ‘need to know’ basis. When thinking about changes made Garrett said Louise “*wasn’t one to just change things totally, at first*”. Garrett admitted that if Louise’s blood test results were optimistic the boys were told this fact. However, results that indicated a downward trajectory were not shared. This way of communicating with their sons was adhered to in an attempt to maintain a balance between living under the shadow of a terminal prognosis and keeping some sense of normality in the family unit. “*She always was very keen on things being as normal as possible*”, said Garrett. A complicating factor for Louise was the death of her father from prostate cancer three months after she received her initial diagnosis of BC. When her prognosis was announced as terminal, the idea of sharing the bad news with family at a time when processing the loss of her father was a powerful challenge for Louise:

*[It was] was pretty hard for her to see her father going through the end of his life from cancer having only recently been diagnosed herself. So it was a bit of a blow to everyone. No-one really saw it coming.*

From his comments, it seemed no adequate or relevant words could describe the depth of how Louise and Garrett were feeling when they knew they would be adding to the burden of loss and grief for everyone they loved. Louise and Garrett were in unison when they chose who they would tell, or not tell, about her terminal

BC diagnosis. As a couple they decided to be significantly restrained about which significant others would be informed as to the seriousness of her illness. Garrett was clear that Louise did not want to add the burden of further strain, despair, or sorrow to her family's grieving process. In particular Garrett felt that Louise's mother was scared of cancer and would therefore find it difficult to know her daughter was also going to die. He summed up his observation: *"I think [her] mum just couldn't deal with it ... just couldn't deal with it. And of course she was gonna do the same thing when she found out about [Louise]"*.

Garrett said Louise found ways to try and maintain the essential elements of a normal life. He commented that she had awareness of the fact that attending treatment appointments always meant he would necessarily be absent from work for some hours or perhaps longer. In this regard Louise encouraged him not to take any more time off work than was absolutely necessary. His comments emphasised that Louise: *"was always very practical on things like my career and all that, so she wouldn't want me to be away from work any longer than I really had to be."*

Despite the suggestion of fear about a prognosis, Garrett intimated that Louise consistently demonstrated a stoic approach to her BC treatment regime. This appeared to have been linked to the expressed request from Louise that they maintain outward signs that daily life be lived as normally as possible.

Rob highlighted that his full-time teaching position imposed the need to consider how to find a way to balance commitments to his professional life and personal life. In weighing up the varying demands of his work, a desire to be supportive for Jenny, and his commitment to overall family harmony for their four adult children, Rob made efforts to maintain a steady emotional presence for Jenny. He also sought to facilitate supportive communication and provision of what seemed emotionally helpful for Jenny. At the same time, he expressed clearly that in the initial stages he did not want to wrest control of her life away from his wife:

*So how do you do that when your partner's going through this really significant thing? When do you need to take control? When do you need to be leaving space? So... its that ... call it a dance if you like... that whole process. Give and take. When is it supporting, when do I take the lead?*



However, Rob also acknowledged that Jenny might not have felt supported by his choice to attempt to seamlessly integrate into the routine of daily life, the emotional, physical, financial and everyday household demands they, and the family faced:

*I was still teaching - full-time teaching; [the] school was pretty good. I could take time off when I needed it - in short bursts and what have you ... Was there any point in taking 2, 3 or 4 weeks of sick leave. At what point do you take it... and suddenly when you do need it ... to support your partner ... you've used it up already. And, also trying to maintain my commitments at school, students' exams, and all that sort of stuff. I think Jenny found that a little bit hard. I think she ... maybe I had misplaced priorities... but I thought, no, I've got to keep life going as normal as possible here.*

Rob expressed an overall perspective on supporting his wife through BC and how important it was for him to remain mindful that “*you could say it's a life-defining event, a life-changing event, but it doesn't have to be a life-destroying event*”. Where his perception differed from that of his wife was that her personal experience of BC may have been that it definitely was a life-destroying event.

One of the ways of keeping things normal throughout the treatment regime and beyond involved conscious efforts on the part of the women to maintain their appearance. Chris and Garrett both spoke about the fact that treatment did not leave their wives looking especially ill. Rob also spoke of his shocked surprise at the way his wife maintained an energetic physical presence almost immediately after she emerged from the mastectomy and reconstructive surgery. The perceptions of each of the husbands spoke strongly about the way each couple approached coping, adjustment, and external appearances during their wife's challenges with treatment for BC.

#### **6.4.4 Turbulence and treatment: “*If its tough stuff you may not hear it*”**

A significant theme was related to the experience of treatment and the perception each husband had about how their wife navigated the treatment regime. Two women had, in their husband's opinions, been able to maintain an outward appearance of normality without, in the beginning, significant change to their daily

living. However, Garrett and Chris talked about their understanding of the fear and anxiety felt, but not outwardly expressed, by Louise and Terri.

Firstly, Garrett spoke of the need to keep in mind an ever-present fear of the unknown activated strongly by each subsequent visit to the oncologist. He talked about the value, for the person being treated, of having active engagement from a close family member who was willing and able to provide support by attending appointments with specialists. For Garrett what was significant was the need to keep in mind the cognitive disorganisation that can accompany the shock of hearing bad news:

*I think its very important to have somebody there with you, cos if its tough stuff you may not hear it ... um... you may not actually... I think it's always good to have an extra pair of ears.*

One of the most incongruent aspects of his wife's experience of BC for Garrett was the fact that over the course of her illness, Louise did not look as he had expected. Externally she did not appear to be a person who was dying. His words illustrate the puzzling truth:

*But physically ... and this is the thing ... and even til only weeks before she died... you'd never really know there was anything wrong with her... she never looked ... we never got to where she would lose her hair ... We never even got to that level of chemo .... Well, she lost a lot of weight in the last handful [of weeks] ... but that's another story.*

Talking about Terri, Chris commented that overall “*Physically ... she didn't look particularly unwell*”. His comments indicated that Terri was able to maintain her outward appearance with very little alteration. However, Chris did disclose his observation that in her own mind things may have been different. Her response to hair loss and other outward signs of BC meant her emotional pattern was to quickly moved to worst-case scenario thinking. Chris commented that Terri's tendency to ruminate was tempered by her strong desire not to “*drop her bundle*”:

*She got some unpleasant side effects. She didn't like her hair all falling out ... um ... and she didn't like things like ... numbness in her toes and fingers. She tends to catastrophise ...I think that's the word ... a little bit*

*with these things ... [imitating a very distressed voice]- “I’ll never get my fingers back, my fingernails will never come back, my hair will never grow back” ... those sorts of things. But other than being a bit anxious about those aspects of things she actually did rather well. And she did not drop her bundle at all.*

Rob’s wife underwent a simultaneous mastectomy and TRAM-flap reconstruction. In the days immediately following her surgery Rob was extremely surprised, and cautiously optimistic, when he observed her self-stated limited need for post-operative pain relief. Aware of issues such as fatigue and fear, Rob said he was “*gobsmacked*” by Jenny’s capacity to recover physically and to display energetic resilience by engagement in physical exercise so soon after the devastating news of BC and subsequent major surgery:

*...then I went in the following morning, and I’ve gotta be honest ... for me ... I would’ve been lyin’ back on that bed pumping that morphine in, doin’ whatever. That’s the way I imagine I’d be going ... but I could hear ‘Jenny’ talking. And I walk around the corner. She’s out of bed, she’s sitting up in a chair.*

Rob’s response was to again attempt to bring a moderating influence to his wife’s comeback from surgery. He spoke briefly about his own trauma from his past, but did not enter into specifics, when his teenaged sibling had surgery. Thus Rob expressed confusion and discomfort as to how Jenny could really be in such a positive mental and physical state:

*And, within a day or two, she’s going down the gym, and she’s doing walks. And I am like gobsmacked. I am sort of thinking “alright, ok, but ... just take it easy, take it easy”.*

The experience of treatment for Louise and Garrett involved variability in results. After initial treatment “*she responded really well ... and actually went into, I suppose what you’d call remission, where tumour counts went right down*”. At that time Garrett disclosed that he and Louise had a type of subtle, unspoken, but reciprocal, agreement about not asking questions of each other or of the medical

team. *“But I think it was a bit ... certainly on my wife’s part she was a bit scared of asking too much stuff ... you know, like the idea of getting a prognosis ...”*.

As the disease progressed Garrett was aware Louise was not one to want someone sitting holding her hand or offering commiserations, instead she again encouraged him to continue to work. *“And that even happened later on when we had some bad scans, you know, she’d still be choofin’ me off to work, you know, saying “you don’t have to hang around”*. Amazed at her capacity to manage pain levels and to tolerate extremely unpleasant medical interventions Garrett commented about his ‘role’ as onlooker to Louise’s endurance:

*I mean, I was amazed at how many needles she had to have. I mean every time we went in ... we had to have another canula put in ... but she was determined not to have a port put in. ... so I had to sit there and watch it happening ... when she had to have needles to kill off any oestrogen ... but this huge needle, just looked like a prong stuck in her stomach.*

Despite Louise’s insistence after a radiation treatment that *“You can head off now ... I’m OK”* Garrett found himself prioritising his attendance at her treatment sessions. For him it was important to be present to the ‘process’ so Louise would not have to face the rigours of treatment alone. Garrett’s way of bringing a sense of normality to unpleasant chemotherapy sessions was *“We just made it a bit of a thing”* - *“I’d go and get a couple of coffees”*.

Given that fear, anxiety, distress and disruption have been chronicled as persistent experiences for women and couples coping with BC, the ways in which the couples cared for themselves and each other as they moved through treatment and then adapted to living with BC is important to understand.

#### **6.4.5 Caring for ourselves: *“It’s a shared journey”*.**

In terms of care for themselves, practical considerations such as work demands, family needs for support, and strategies for managing change, had to be taken into account. For Rob, Chris and Garrett these were interwoven with previously accepted norms in the couples’ relating as well as their expectations of

themselves, and how they could now manage to reshape their lives to fit around the BC experience.

Alleviation of their significant physical and emotional distress, or limiting potential for exacerbation of that distress, was managed by positive efforts at self-care. In coming to a realisation that reorganisation of diet was one way to proactively resist the effects of cancer, two of the couples made contact with a cancer-focused retreat centre. The retreat centre offered the opportunity to experiment with adjusting their diet. The revised focus on vegetarian food, extending their knowledge about reduction or elimination of certain elements of their diet, and an overall more intense investment in self-care meant these two couples engaged in lifestyle changes that anticipated positive effects on their well-being in the early stages post-treatment.

On receiving the diagnosis, Chris reported he and Terri began to make immediate lifestyle and relationship changes. Chris emphasised that prior to her diagnosis Terri had held a long-term interest in preventative health issues. In terms of his own stress levels, Chris outlined an unexpected positive side effect of being willing to substantively revise his life priorities:

*Making [Terri] the priority was incredibly helpful in dealing with that because I felt that ... I felt some sort of a peace about that ... that that was the right thing to do ... and I could do that ... so yeah ... I felt empowered.*

On reflection Garrett admitted that he and his wife had tended to overlook, during the first year post-diagnosis, self-care strategies such as the possibility of making adjustments to their diet:

*And I know it seems silly that we'd been going sort of 13, 14 or 15 months, but it was just the way we were I think. She was doing the treatment and looked after herself by leaving work and that sort of thing, but that's when we got really dinkum as far as diet and ... what else can we do?*

Eventually, Garrett and Louise payed much more attention to the impact of diet. As part of their efforts to help her feel as well as possible, physically and emotionally, they did choose to attend “a five-day retreat ... and we changed our

*eating habits*". Although a year or more had already passed by since diagnosis, once Garrett and Louise made that decision to explore additional ways of maintaining everyday wellness, Garrett reported he was able to make consistently healthy choices for their diet. Attending the retreat had a direct effect on their sense of taking control.

Rob commented that he felt a working alliance between couples was desirable for successful outcomes to BC. He emphasised his view that "*In marriage you do become inter-dependent. There may be some co-dependency that people ... that some people want to be dismissive of. But you have to create opportunity and vulnerability in your life*". In relation to living with BC Rob felt that "*the more it's a shared journey ... it is never one person's journey. It's the family's journey. It's the journey of the significant others*". The role of nurturer for the family was one that he had been willing and able to take on. This role became more significant as Jenny's mental health declined in the year after completing treatment.

#### **6.4.6 Her self-image: "*The place just lights up when you walk in*".**

When speaking about his wife's self-image Garrett commented that "*I wouldn't say she had low esteem, that's not quite right. Cos she was actually fantastic ... and very well loved*". His perception of his wife's self esteem seemed positively influenced by the nature of their relationship in addition to responses towards Louise that he observed from others within the family and in social settings. Garrett's comments highlighted a wistful sadness about Louise's self-perception:

*I would often try and tell her ... Obviously I was biased, I was her husband, but I'd ... she just wouldn't have it when I said, you know, you walk into the room, and I'd say "the place just lights up when you walk in", and she just wouldn't have it. She would always come up with some negative comment to any compliment.*

In this next statement the indication was that Garrett was genuinely bemused by his wife's inability to regard herself as positively as he and others did including her ongoing issues with her body image:

*I used to tell her, you don't know it, you don't realise it ... just how beautiful you are, and how well loved you are, and how you light up a room. Because ... she had red hair and it was just natural, and she had freckles and*

*she was never what she would want ... you know ... she was never petite or anything ... so she was very down on herself a lot over how she looked. ... so she had a lot of body image issues, well and truly.*

The topic of self-image was one Garrett spent some time discussing. He talked about the image Louise had of herself and how she came to relax the desire to be different. A poignant statement from Garrett illustrated this change: “*before she had cancer she was worried about her freckles*”. In reference to the problem posed for him by Louise’s persistent negative self-perception, he talked in particular about one emotionally ‘painful’ consequence:

*... when we look at photos and home movies and photos and that ... there were so many where she was always the one behind the camera ... she didn’t like it being on her ... and actually a couple of times I put it on her and she’d snap at me about it ... she became far more ready to have her photo taken ... later...*

As well as talking about Louise, Garrett also mentioned the change in his own self-perception since Louise’s death. His self-image had been adjusted significantly from his realisation of the depth of Louise’s struggle with her sense of self. As an example of how he had changed to a more positive self-image, Garrett talked briefly about his decision to enrol in tertiary study. He talked about how he had at first felt a “*fraud*” who had “*got by maybe on someone else’s coat tails*”. This was similar to the low self-evaluation that Louise had battled with up until her death. Receiving praise for his work meant feeling “*embarrassed*” at first, although Garrett said he had recently begun to think “*maybe I actually do have something ... maybe its all true and I just didn’t know it*”.

Rob described Jenny’s self-image in the following way:

*Always been a pretty energetic person. Very creative. Usually good fun. Can be spontaneous. And... enjoys a bit of flexibility in life and unexpected things. Probably tended to be a bit driven... Some of that, I think, had to do with ... her age when we first met... She was 15 and I was 19 when we first met.*

Rob made further comment about positive aspects he was attracted to in Jenny around both her personality and their shared values and beliefs:

*The things that attracted me to [Jenny] was the fact that she is an outgoing person, she was musical, we had a basic set of values and beliefs that resonated together. We're both Christians and had Christian values as anchor points to our lives.*

Referring to his wife as a person who was a high achiever, Rob also said that his observation was that Jenny was “*a little driven ... she felt quite driven to excel*”. He stated that Jenny had a “*bit of a breakdown*” and felt “*emotionally overwhelmed*” when her father was killed. Jenny’s father’s death coincided with her birthday and this, Rob said, was “*a pretty significant trauma for her*”. Rob then made some observations about Jenny’s strategies for coping with stress:

*[She] can be reactive to things ... if you're the husband, or the male, you just have to cop it sometimes ... it's a bit like an unexploded bomb. I have to put all the safety gear on. And it doesn't matter how hard and how careful I approach it, it has to explode. It's just part of the deal. If I defuse it without it exploding then I haven't done my job properly.*

Chris also commented about his wife’s self-image but said that having BC had confronted Terri with issues of feeling that “*she was not a worthwhile human being*”. He recalled Terri saying to him that she felt as though she was a “*waste of space*”. Chris highlighted that Terri never felt as though what she was doing or had done was “*worth very much*”. He summed up her self-image in the following way:

*I think she had some real issues of self worth. I heard a lot of negative statements about herself... about ... especially when she didn't do things according to the standards that she set, which were high. She would say she was useless and worthless, and those sorts of words... well not particularly those words, but they're the sort of ... the meaning of the words.*

#### **6.4.7 Intimacy, sex and sexuality: “*We'll find other ways of connecting*”.**

Changes to their relationships in terms of intimacy and sexuality was a topic of concern for each of the husbands. They spoke of the need to negotiate and accommodate



changes to their physical relationship. In particular, Garrett mentioned the negative side effect of the medication:

*there was a side effect to that in that it certainly had a big impact on her libido and I know she worried about that, and I sort of said, that's ok ... we just had to live with that. And that was OK.*

He continued to say that during her treatment for BC he and his wife had to re-shape the form of their intimacy, which meant, “*Well, it was just a cuddle*”. This comment was followed by some moments of reflection and tearful expression of emotion after which Garrett quietly said, “*I'd be happy with that now*”. The dilemma for Garrett was that Louise's death brought such an untimely end to the joy of that shared physical contact. However, he was clear that once Louise had been diagnosed their sexual functioning was something that was a focus for neither he nor Louise. Once her diagnosis became terminal Garrett was clear that they had a more critical issue to face in how to move towards the end of Louise's life.

Rob also talked about significant changes to the sexual relationship with his wife. His perspective on communication about changes to sexuality and sexual functioning post-BC was that “*I think it's an important issue. And I think it's a thing that people don't always talk about*”. Post-treatment Rob and his wife did discuss intimacy and their sexual relationship. Rob's perception was that he and Jenny were willing to accept change and regularly assess their needs and adjust the way they expressed intimacy. He mentioned the need to be able to support Jenny even though there was “*the loss of certain aspects of that relationship and ... doing the readjusting ...*” Rob commented that for him, readjusting meant being acutely aware of how Jenny was feeling at any point in time so that he felt that couples needed to be able to remind themselves that “*... I can't be making these sorts of demands ... you know ... where is my partner at in terms of her headspace and how she's feeling?*” In response to the personal distress Jenny felt about the change in their sexual relationship, Rob offered a solution. Knowing his wife loved the game of Scrabble, he said to her “*look, what we'll do is we'll play Scrabble and we'll just be really good friends. We'll find other ways of connecting and keeping things going. Even that we can manage*”.

However, Rob felt less optimistic about Jenny's adjustment to the changes in their physical relationship:

*I think she's in another place where she doubts her desirability and she also feels flat and unhappy that she's not able to be more sexual and not more overtly involved ... the colour's gone out of it ... and it's not necessarily the most enjoyable experience ... even for all the work we put into it.*

Chris spoke about the relationship with his wife in more abstract terms:

*I think all relationships are unique anyway, but ours... we haven't had children, and that ... that was something we dealt with in the 80s. As we tried to have children and were unable to ...*

Chris was also clear about the value in his relationship with Terri of having been able to enjoy interests in common:

*We didn't have children but ... therefore we've spent a lot of time together. We developed interests in common. Bushwalking especially was something that we found, 'cause we did have to find interests in common and that's one of our better ones because we can spend a lot of time out bushwalking and really love it.*

Changes to sexual expression in their physical relationship was not the only thing Chris and Terri, Rob and Jenny, and Garrett and Louise were coping with. The world of BC brought with it, at worst, the fear of death, at best, questions about life post-treatment. Chris stated that he was aware in the bigger picture “*we don't know how long we've got together*” and because of that he felt “*we've got to make every moment count*”. Making every moment count meant re-organising thoughts about how life was expected to progress, having difficult conversations about the reality of the situation, and how to interpret what is happening for their wife and themselves.

This theme highlighted that the husbands in this study worked with their wives to be able to revise intimacy and sexual expression. The outcome was that this part of their relationships became ‘relative’ to the bigger issue of the giving and receiving of love, care and support. Intimacy was expressed not so much in physical

ways but in the sharing of as much love, presence, and acceptance of the situation as they were able to give to each other under the circumstances.

#### **6.4.8 Emotional support: *Support for me, support for us as a couple.***

A supportive relationship can provide a buffer against development of negative mood post-treatment. Although each couple had their own distinctive experience of BC, the experience of BC was pervasive in the lives of each of the couples. Uncertain at the start about the new reality that was to unfold in their daily existence, Rob, Chris and Garrett had little or no preparation to emotionally absorb and then integrate the meaning of BC for them; that was to happen as they were swept along by a fast-paced response to diagnosis.

Chris, Garrett and Rob each spoke about the emotional support they wanted to, and felt as though they were able to offer their wife. With an overall understanding that life would never be the same again, the task of managing and supporting the emotional needs of their wives was handled in different ways by each of the husbands.

Rob reported that having been a couple since Jenny was in her mid-teens, he felt he knew Jenny very well. He described Jenny as presenting the image of being “*outgoing*” and “*usually a pretty competent and confident person*”. Rob commented, however, that in reality, for emotional and practical support, Jenny “*relied on a fair degree of support from me over the years*”. Rob commented that because he and Jenny had become parents when Jenny was in her teens, he had to become capable to help with day-to-day care for their four children. He talked about his ability to cook meals, manage the children’s arguments, and “*do all of that sort of stuff*”. Rob talked also about his capacity to offer a stabilising emotional influence for Jenny since the death of her father.

Rob talked about anxiety and stress Jenny experienced due to a workplace event in the year prior to her diagnosis. He stated that Jenny “*has said a few times that her cancer was caused by the stress of this event*” and spoke of the emotional fallout for them as a couple from that workplace event. He observed that Jenny began to lose sleep and become highly anxious. In talking about Jenny’s emotional needs

Rob commented that Jenny “*doesn’t like anything hidden*”, and “*she requires a high level of transparency, engagement and connectedness*”. Rob also talked about feeling some confusion about how best to support his wife when he said:

*And ... the other interesting thing is how do you support someone who’s used to a reasonable degree of independence ... I’m now faced with a confident and competent person who is now working through a significant life event which understandably is going to impact her ability to meet some of the challenges of life. I can’t just go in and take over.*

Rob commented that a husband needs to have “*the psychic ability to recognise when he needs to be the listener only, to perhaps feed back what she’s heard*”. For him, there were two distinct support roles he needed to be aware of, and he needed to be able to distinguish between. Rob stated that he had to be mindful of when Jenny was needing to emotionally “*discharge*”, as opposed to “*when she’s asking for Mr Fixit*”. This meant that he felt he had to be available for her to explode at as well as be the person who could fix whatever practical matter required attention.

In describing Jenny’s emotional needs Rob talked about the fact that in the early days post-treatment he felt that “*we’re coping, we’re coping really well*”. However, in observing what he named as Jenny’s “*manic up*” after completing treatment – a time she herself had referred to as being on a huge ‘high’ - Rob admitted that he had wondered about whether BC conferred some type of specialness on some women. He wondered if there was, as he put it, a “*celebrity status associated with the illness*”. Rob said that when Jenny returned to her usual daily routine, he became aware of the difficulty she went through as she transitioned from patient to survivor. In the interview Rob also disclosed that for Jenny a perceived social invisibility of trauma she personally had experienced with BC seemed to cause her considerable personal suffering. He used the following words to sum up what he observed as the lack of outward signs of having BC. In particular, he highlighted common and highly visible signs of BC such as wearing scarves and turbans. He reflected that for Jenny this meant:

*She’s gone from someone who’s obviously a cancer sufferer and getting treated, to somebody who is now looking [physically] pretty normal, and didn’t have anything that sort of told everyone that she had cancer. So*

*suddenly she's getting back into the normal routine of life ... but not feeling normal.*

Rob commented on his attempts to help Jenny arrive at some degree of control or mastery over her increasingly depressed mood and frequent times of crying. He said that he tried to help Jenny understand that crying was 'normal' and that *"what you're doing is healthy"*. Rob felt he attempted to alert his wife to his perception that her mental wellbeing was declining. Nevertheless, a depressive state began to overwhelm Jenny. Their focus on survival became less concentrated on the BC diagnosis and more connected to maintaining Jenny's mental health. Rob recalled times when Jenny was *"fairly reactive"* and *"highly strung"*. He spoke about his growing concern about Jenny having a *"major meltdown"* at some time; about his allowing her to *"sort of vent and let all the emotions out, and again trying to say [to her] well, again, 'this is something you've gotta ... you've gotta let the grief out'"*. In an effort to validate her sense of isolation and aloneness in returning to everyday life, Rob talked with Jenny and recalled that he had acknowledged *"it is your life, there's no going back, and it's no-one else's and you have to live with it ... that's the place we've got to come to ... that this is reality"*. Rob commented about feeling compassionate about Jenny's suffering. He referenced a time when on a brief holiday he would often look to see if the emotional pain of what had happened was still reflected in Jenny's eyes. Rob's observations were that Jenny's suffering did not decrease but steadily escalated.

What lay ahead for Rob and Jenny was, he said, *"pretty confronting"* as Jenny became psychologically unwell. The result of her mental un-wellness was that she spent some time in hospital. Rob reported that despite Jenny trying to see things in a positive light she was *"struggling to function"*. Throughout subsequent suicide attempts and electro-convulsive therapy Rob said that as much as he could he *"tried to keep the routine and the normality of life going"*. He felt that in keeping the daily routine of going to work and attending to family was his role. Rob reported that he was keen *"to continue to support, to be there for the other person"*.

In talking about their capacity as a couple to support each other in difficult times, Garrett said he was proud of the relationship he and Louise had developed. He

describing Louise as “*a very strong woman*”. However, he also spoke about the deep sense of loss for Louise once she was diagnosed; the loss of a life lived without cancer. As a couple, the grieving process was something they shared with each other but not with others. Garrett’s observation of one significant aspect of their support for each other was that they could have spent more time talking with each other about how she was feeling. He said:

*She grieved ... when we had our times together just sitting and talking ... it probably wasn't enough ... but she just grieved for her old life ... she just wanted her old life back when she didn't have this thing hanging over her. Yeah ... I can remember her saying that.*

After talking briefly about that grief, felt so strongly by Louise, Garrett then changed his tone of speaking and made the following comment: “*but yeah, I suppose the difference was she had more visitors.*”

Without focusing on whether he too had grieved for their old life, or whether he had explored, in his innermost self, the poignancy of Louise’s statements about being forgotten, Garrett moved to talking about a positive aspect of their relationship. He said their marriage had grown to a point where:

*[in] the months leading up to finding out she had cancer we were sort of feeling like we really had made it and in the best place we'd ever been as a couple. We could go away, just the two of us, and really enjoy just going away.*

In terms of support from others Garrett highlighted a “*weird*” feeling for them as a couple in the weeks soon after Louise was diagnosed. He remarked that they felt “*it was like someone had died. We had people, flowers ... and people there all the time*”. At that time neither Garrett nor Louise had come to full acceptance and realisation of the eventual outcome of her prognosis.

Positive support from family members prior to Louise’s diagnosis was a solid part of life with Louise’s family. Louise had “*a pretty special relationship*” with some members of her family, especially her two sisters, and this was expressed in emotional support for Louise and for Garrett once her diagnosis was made known.

As an example of the support they received Garrett recalled that one cousin was able to provide Louise with Reiki sessions in an effort to help her stay on top of the effects from BC treatment. When the full extent of her prognosis was known Garrett and Louise along with several of her family members embarked on an extended holiday to the USA with the decision to have this last family holiday being made by Louise.

Overall, each of the couples had been able to receive support from family during the time when the wives were in treatment. For two of the couples the woman with BC struggled with a change in support that they experienced once treatment was completed.

#### **6.4.9 Grief and talk of death and dying: *Making every moment count.***

The question about how and when to open conversations about death and dying was highlighted by Garrett in sharing his eldest son's response. After his mother's death, Garrett asked his sons about their experience of learning their mother had a terminal diagnosis of BC:

*I actually asked them recently ... the eldest son ... he sort of reacted ... he said, "well, I knew it was bad", he said, "but you and mum seemed so ok ... like it was gonna be ok and that, and so I just thought it's gonna be alright.*

Garrett spoke further about feeling disappointment that he and his wife had not made time to talk privately with their two sons before making the announcement to the wider family that Louise would not survive the disease. In the first instance Rob and Louise alerted their sons to her diagnosis. Rob recalled that "*they came home in the afternoon, and we told them then ... and of course at that stage we didn't know how serious it was.* However, once the situation for Louise's outlook had deteriorated:

*I would certainly tell them differently though. All the family was again waiting at [wife's] Mum and Dad's place, and the boys were at home. And I just sort of rang the eldest son and said "you and [your brother] ... wanna drive over now?". The both of them said we felt like everyone was looking at us, and we didn't know whether we should be crying, or not crying.*

Rob expressed sadness that he had not thought of the emotional reaction the two boys would have to the news that their mother was going to die. It seemed as though Rob and Louise tried to convince themselves the news was a case of information exchange rather than a devastating blow. Rob completed this part of our conversation by saying *“If I had my time over again, I would have a quiet time with them”*.

Garrett explained that he often found himself drawn to concern about the future *“on days when I was on my own, driving to work, or driving home from work I would be thinking about what it was going to be like, what was gonna happen”*.

Another aspect of support mentioned by Garrett was related to comments his wife had made about people’s ability to remember, and to be able to support those suffering loss and grief. Garrett summed up his recollection of Louise’s comments in the following words:

*Having cancer herself and seeing how people, even close family, still went back to living their life and life going on, she would say “That’s exactly what’s gonna happen when I go. She had this idea that “see, people don’t stop”. People just get on with life when you go ... they forget about you.*

Trying to think and act in his wife’s best interests meant that Garrett avoided being the one to open a conversation that might lead to the topic of death and dying. *“Oh, we didn’t talk enough about it. Its something ... it’s the one thing I regret”*. He pointed out that his desire to avoid talking about cancer and death so as not to create additional emotional distress actually resulted in temporary disconnection between he and his wife: *“so, it was a handful of times where she really blew up at me ... which she’d always say sorry for after, but ... it was that no-one would talk about it”*.

Garrett talked about the emotional challenge as he balanced the tension between being open and honest, with times of attempting to shield his wife from further distress. He also talked about his wife’s perspective on communication about her cancer with their sons. Speaking of his wife’s wish to protect their sons from suffering by not telling them what was actually happening until very late in the process, Garrett said her idea was *“it was very much a case of ... they didn’t need to*



*know stuff*". In hindsight, his reflection on the way he and Louise communicated with each other and with their sons about her terminal BC, brought a comment from Garrett about the tension between giving space and time for emotional expression, as opposed to being emotionally strong and thinking that was protective for others. The question arose from his conversation about who was being protected by the resistance to sharing factual information. Garrett talked about his conviction that he needed to be strong for Louise, and his confusion, on reflection, about a choice he now considered as not helpful for anyone - in the bigger picture:

*I know now ... I'm an expert on it ... that's not helpful ... for anyone ... the chance to be able to express yourselves emotionally ... and I still had ... felt ... this need to be as strong as I could be ... so I didn't.*

Garrett talked about the change in an attitude he had that to be the husband mean he needed to be 'strong'. He commented this was an attitude that had changed only since his wife's death:

*It's not always easy, but I'm more inclined now to go ... instead of worrying about what so and so are thinking ... which they probably aren't ... I'm more likely to say ... aaah ... you don't have to ... you don't have to ... take it easy.*

Garrett also had some questions about what inhibited friends and family from communicating more frequently with him after Louise's death:

*Is it ... I dunno ... are they so scared of trying to be able to say the right thing. And eventually it gets a lot easier just to stay away, and then it becomes too long that you've stayed away, and then it becomes too hard to show that it's been wrong staying away so long?*

Because Rob and Jenny felt optimistic from the outset that her BC was not going to be terminal, fears about death and dying seemed to be expressed more often in emotionally-charged expressions of anxiety. Rob spoke about the change in his wife from a position of strength and optimism to her entry into a deep and unexpected depression. He referred to a conversation with Jenny in which he attempted to help her understand the emotional process she was going through:

*She's still on the high, but things are starting to change. ... I'm telling her 'what's happened to you is a significant and traumatic event, and you have to allow yourself room to move through this and to grieve and then to accept and reconcile with what's happened'. I said this ... 'You can't get away with anything for nothing'. I said [to her] 'there's an emotional cost to this and you have to work through it. You've gotta grieve, otherwise you're living in a different place'.*

Chris mentioned that without children he had “*tended to be a little more selfish perhaps*”. He recounted that “*my mind was often occupied with things to do with myself and my endeavours and although ... I tried not to ... I would have tended to have taken her a little bit for granted I think*”. Living with the uncertain future that BC forces on a couple had forged a change in Chris. He no longer felt there was time to be complacent or ignore things important to Terri:

*I actually do think about her more often and what is helpful for her. Ah... there's this thing about blokes coming home to The List (laughter) and the guys wanting to sit down and watch the footie ... but I see 'The List' now... not that there's a physical list ... but the things that she wants ... as a positive.*

Chris clarified this thinking further by saying that anything important to Terri had become:

*A thing I want to do to enhance her life because she really enjoys that ... she really appreciates those things ... and that's half the value of doing them. Whereas I wouldn't have seen that before. I'd think 'oh, we'll get that done [eventually] and ... you know ... I didn't want to go and do that other job [that Terri needed done].*

Chris commented that the consequences for him from the disruption BC brought to everyday life, had, he said, caused him to question previous assumptions about the value of activities in life to which he had devoted time and energy. Finding new meaning in his life involved integrating Terri and her illness into his thinking so that she was a more ‘visible’ part of his considerations. The degree of change has resulted in Chris having a sense of constructing a more ‘holistic’ lifestyle:

*But now I [think] that's for her ... [and so] that matters ... and I think I want to help her more now. That's actually been quite a good thing for me because I'm less stressed about not achieving some of the other goals that I had that I don't think mattered anyway. Yeah ... so I'm quite happy about that.*

The three participant husbands (SOs) were able to talk about how BC had affected and changed their lives, and the loss, of certainty and expectations about life they had enjoyed prior to BC. These SOs were also able to discuss the understanding and knowledge they gained as a result of the experience of BC. That knowledge and understanding was relevant not only to their relationship with their wife, but also to their relationship with themselves.

#### **6.4.10 The meaning of self-compassion: *Living an authentic life.***

A theme that emerged as significant for each of the SO's was that of creating a post-BC life that was authentic for each of them. This desire for authentic living seemed to stand in contrast to the life two SO's had created prior to their wife's BC. For Garrett and Louise, Chris and Terri, and Rob and Jenny, BC involved the necessary accomplishment of important and unpleasant tasks that were stressful. The consequences of any tendency toward procrastination were untenable. Chris was able to find the way to relinquish projects, reduce his workload, and weigh up his commitment to interests other than those that he felt were beneficial to Terri and himself *"for me its letting go of projects, plans, activities and thinking more in terms of the people and the values that will improve quality of relationships in your life"*.

Kindness and self-understanding of what he and his wife needed was demonstrated by Garrett when the *"redundancy door was left open for me and I took it"*. Without another job to go to Garrett and Louise were able to accept that the time they had left together was important. *"We were just walkin' on the beach one day and we said "we'll be ok" and so it was great ... we had time to ourselves"*.

The concept of self-nurturance brought forward this comment from Chris *"Self-compassion, that's interesting ... I'm not sure. I try to relate it to myself ... I*

*don't know ... looking after myself ... Yeah ... [pausing for a moment or two] ... I think that is true".*

Similarly, Garrett felt that development of a kinder self-relationship meant a release from an old pattern of always thinking about judgment from others or the needs of others. He talked about being able to accept that he deserved to feel free in himself:

*I think, for me personally, it's almost like being able to give myself a break, being able to forgive myself and accept that ... actually tell myself, you know, you've been through a lot ... you deserve ... whatever you wanna do, you deserve to do it. Rather than always worrying about what other people might be thinking.*

Rob's many years in the teaching profession had helped him develop a sense of boundary between what he was responsible for and what he could not control. He remarked that 'professional wisdom' had taught him that he could not control others, and if they acted out in extreme ways, that was not his fault. "*What I'm responsible for is how I manage that situation*". Rob also commented that he understood when "*your rational part of your brain says ... you need to take some time out for yourself ... you've got to recognise and listen to that*". On balance, he considered that there were both benefits and risks to being self-compassionate. He made a clear statement about what he saw as a need for "*realistic assessment*" of one's needs and motivations rather than using the idea of self-compassion as a convenient mask for not doing what needs to be done:

*Compassion ... [pause] ... self compassion is interesting because there is a genuine, realistic assessment of where I need to be kind to myself, where I need to say, whether we use the analogy of the adult or the child, and looking after the inner child ... But where you're rational part of your brain says actually you need to take some time out for yourself ... you need to find a place to have a good cry ... that there is a degree of compassion which is connected to your ongoing survival and you've got to recognise and listen to that.*

Rob offered his notion of when self-compassion might not be useful or helpful to a person:

*There is the opposite compassion which is the emotional indulgence, you know, where you give yourself over ... it's a tantrum type thing ... it's the child that goes to the extreme ... so, self-indulgent compassion is a form of narcissism. It can become destructive because you're overwhelmed by your own grief.*

Rob went on to talk about the problem of “*not allowing yourself to feel ... where you become too stoic*”. He said, “*that's not good either because that will be acted out*”. Overall, Rob summed up his statements with a comment about a lack of compassion for self. To him it meant “*you will not have compassion for other people*”.

Chris spoke about the Christian concept that implies “*there is a value in yourself and that you need to be loved*”. He added that “*in the context of a relationship with God that's all about God loving you*”. Commenting that some people may be “*inclined to think that it's all about ones' self*”, Chris could see another side of the argument that “*if you say you're going to be utterly selfless then that's a denial of the reality as well*”. He commented that sometimes the concept of self-compassion could be regarded as relating to being “*self-indulgent versus complete selflessness*”. Talking about self-compassion Chris also highlighted his belief about the need to give to oneself in order to be able to give to others. Furthermore, when discussing the idea of living an authentic life, living true to oneself, Chris liked the concept of authenticity as being an integral part of self-compassion.

Garrett talked about the meaning of self-compassion. For him, being self-compassionate involved living an authentic life. The essence of his perspective was summed up in the following statement “*Self-compassion is ... I keep thinking almost ... true to myself in a way. That's probably what I keep coming back to ...*”. However, Garrett admitted that prior to the experience of his wife's BC, “*I would've seen that I had a job to do and it was my role to provide for the family, be a good husband, ah, you know, have a good career ... have some fun too*”.

The deeply personal journey of BC had generated some unexpected reflection and questioning of what it meant to walk alongside their life partner and to *“definitely (strong emphasis placed on the word definitely) ... feel all the emotions”*, but know *“you are going to have to support that other person”* (again said with emphasis). This ‘double-sensory state’ of feeling their own emotions, feeling for the other, and yet acknowledging that in practical terms that *“you’re not the one suffering”* activated a need and desire to remind themselves of the basics in life. For the three husbands this meant to focus on the fact that some aspects of life will need to be surrendered, and other aspects will be held close. One of Rob’s philosophies for living was that *“you’ve got to try and keep as many options open as possible so that they can then choose, as things unfold, what it is you’re going to keep and what it is you’ll let go”*.

Self-compassion was summed up by Rob who said that *“self-compassion ... important ... and we always swing between extremes, but I think recognising that trying to bring yourself to the balance point. We should come to a point of balance”*.

#### **6.4.11 Back to basics: *“Its letting go of projects, plans, activities and thinking more in terms of the people”*.**

Coping with illness such as BC catapults couples into an existential uncertainty in which life as it had been known is up for review. The crisis faced by Rob, Chris and Garrett had brought them to review their self-understanding, their relationships, their personal strength, and appreciation for life. The three men spoke of how they managed the demands of an extremely challenging event that caused anguish, fear, discomfort, and anxiety for their wives and for themselves. While the event was the same for each, their experience was different. At the time of interview, Chris, Rob, and Garrett reported positive effects for their lives in both psychologically and in relation to the practical aspects of life, the basics.

Speaking about how BC has eventually brought positive growth into his life, Chris commented *“well, for me its letting go of projects, plans, activities and thinking more in terms of the people and the values that will improve quality of relationships in your life”*. Overall Chris felt that the experience of BC had been positive because it helped him to re-focus and adjust the priorities in his life. From

over-involvement in work-related projects, the future for Chris and Terri was one where the basic foundations of human relationships mattered much more than they ever had done.

Part of Rob's personal experience of BC was a state of inertia in his sexual relationship with Jenny. *"For us as a couple, it ... it does seem as though things are in mothballs to some extent ... for the relationship... in this moment of stasis ... while we're working with these things [referring to BC]"*. Rob spoke about the strength of the commitment between himself and Jenny. He recalled that their attraction to each other when they were young was because they *"actually liked each other as people. There were similarities in our gifts and the way we would operate"*. He went on to say that the current *"stasis"* had brought him to *"go back to what are the fundamentals of the relationship"*.

Garrett highlighted that as a consequence of the loss of his wife to cancer he now had developed a more existentialist view to life. *"I don't think too much about the future. I'm not all that keen on living too long either, which is very unlike me before"*. He shared that in the months after Louise's death *"I used to think about death a lot. I still do. I've just about got my funeral planned out in my head. One day I should put it all down in writing or none of it will ever happen."*

Garrett said he never seriously entertained the option of suicide as a way of relieving his own suffering. He was clear that *"if I was really honest ... I was never ever gonna do anything like that to myself"*. Nevertheless, what was important to Garrett was that realising the additional pain withholding expression of feeling could cause, he no longer wanted to anaesthetise his feelings. BC had helped Garrett to reorganise his thinking about what was important in life. He compared the practical and careful person he felt he was prior to his wife's BC, with what he had come to regard as worthy of valuing about life. Life in the future now looked different to Garrett. This was highlighted when he commented on his reminiscences *"...because reality is death. Like losing my wife. That changed my identity, in the family, everything changed"*.

#### **6.4.12 The future: “It doesn’t stay dark forever”.**

The husband participants in this study were optimistic about the future. Rob and Chris had eventually arrived at a place of quiet acceptance of the presence of BC in their life that was an event over which they had no control. Rob in particular was confident his strong faith provided a solid base from which to continue to draw spiritual and emotional strength for himself to support his wife as she adapted to living with BC:

*I just think it’s a very real journey and I think that reality of that relationship with God is about sharing pain with Him and about drawing strength. And it’s not about me being a winner.*

Chris talked about a tendency he and Terri had to see the future as always a long way off. The future had always been a horizon to which they could look ahead. He highlighted that for them now, it was as if BC had meant they had ‘arrived’ at that horizon “*and suddenly the future is with us now, and, you ... there’s lots of philosophical approaches to that, but ... we’ve become aware of this through the stuff we were doing through [our time at] ‘B’ [names a cancer retreat centre]”*. Engagement with the cancer-care retreats had helped Chris and Terri become aware of, and employ “*that concept of mindfulness, and ... being in the present, in the moment ... that sort of thing”*.

Garrett also stated that he now had a different perspective on what mattered in his life. He felt more aware of, and positive about, how he and his sons had “*all gone through something that we can always use as a ... a bit of a reference point”*. After his wife’s death Garrett decided to enrol at university. This was something he had sometimes wondered about but had never followed through. Chris was very close to completing a Bachelor’s degree in counselling, and found that he enjoyed the fact that friends and colleagues felt safe to be able to open to him about their personal challenges. Garrett felt his formal study of professional helping had brought a sense of purpose for his life. Although he disclosed that he experienced some sense of guilt because of his enjoyment of a newly developing role as a professional counsellor, Garrett felt that he could accept that life can hold new purpose and meaning after a profound loss. He commented that he “*found it quite relieving ... to hear, and be able to help someone else ... so its a little bit of selfishness about it I*



*suppose*". It seemed as though Garrett's newly-found professional direction helped reduce any sense of being isolated in his grief. The most noticeable dimension of life for Garrett had become the search to find how he could live life in a personally "authentic" way with a focus on what really mattered, rather than on a socially acceptable construction of success. His stated perspective was "So I think that's probably the biggest [for me]. It's just that ... how we live... the less concern with the material sort of living that ... [be] more interested in the bigger stuff".

In the case of Jenny and Rob, although they were engaged in an ongoing struggle to help Jenny overcome depression, Rob remained confident they would emerge from the shadow of her despair. The teachings, and value they placed in their Christian faith, were something he and Jenny felt they could rely on without exception. For Rob it was not a matter of slavish devotion to practice, but what he felt was a deep personal knowing that his God was present and available. The strength of their faith had provided Jenny and Rob a source of assurance that "He's there ... He's been with us right from the word go ... in our relationship and in this journey ... we just have to keep trusting Him and keep walking the walk". Rob's faith did not blind him to the reality of the situation. It did not mean he ignored what needed to happen when Jenny was admitted to hospital for psychiatric care. He did not use faith to refuse the electro-convulsive therapy they felt had to happen. To highlight his ability to preserve balance between pure faith and acknowledgement of practical realities Rob said:

*We will get to a place where we will look back ... and I won't say 'Oh thank God for everything that's happened'. But maybe we will see things, and maybe we will be a help to somebody else, to other people and to say yeah I know how you feel cos we've walked that walk, but it doesn't stay dark forever. A new dawn comes ... you know ... and it does, it does.*

Chris and Garrett also spoke about the 'new dawn' in different ways. Garrett had found his new dawn in his training for the role of counsellor. Chris had found a new dawn by re-prioritising his life so that for however long they had together he could make every moment with Terri count. Rob's trust in his faith system was the 'glue' that was holding everything together while he and Jenny negotiated the mental health system.

#### **6.4.13 What might help: “*The medical side is needed but the psycho-oncology is really needed too*”**

The SOs had a mixed response to the question about what they thought might help the person whose partner is diagnosed with BC. Having a strong belief in a faith system was highlighted by two of the husbands, as was the need for attention to be paid to the ongoing mental health of BC survivors.

Rob felt that it was important to develop a capacity to know and understand the God you believe in. Balance and being able to find balance in life was another theme in Rob’s talk about what might be helpful in the face of a life-threatening illness. He felt an important personal capacity for humans was the ability to respond emotionally to others. His view was that without being able to feel compassionate toward others:

*You will lose your ability to respond emotionally because ... this is my theory anyway ... because you will have built walls that are so strong ... to protect... to stop yourself feeling the pain, you won’t be able to enjoy the colour of life you’ve created.*

For Rob, what would help was an anchor in life such that religion had provided for him. In addition, he felt it was important to know and understand the function of emotions as a prelude to offering compassion to others. Without being able to feel the painful times in life, Rob felt that enjoyment of life would also be inhibited.

Garrett’s experience had left him with the perception that there was more that could be done to provide emotional and psychological support for families in which one person has a diagnosis of cancer. In particular, he felt that more emphasis could be placed on helping couples understand the true nature of negative reactivity that might be exhibited by their children when under extreme stress because of uncertainty or fear about a parent’s cancer diagnosis:

*I think the big component that needs to come in is that psychology side ... helping people with families how do you deal with children. We had a fair bit of stress with our younger boy during ... when Louise had cancer. And we didn’t know how to handle it. We thought he was being an arse ... and how*

*could you be doing this while mum's got cancer. And a bit of knowledge would've gone a long way. So, I honestly believe ... the medical side is needed but the psycho-oncology is really needed too.*

Chris spoke about BC and survivorship as being like a “*sword of Damacles*” that the person diagnosed, and their family, will never know “*when it's gonna drop again*”. He felt that the fear of cancer recurrence was always going to be present in their life, no matter how well a person thinks they have processed that fear. Therefore, Chris believed that sensitivity needed to be observed by “*being careful about your speech and your language so that you are being affirmatory rather than negative*”. Another focus that Chris regarded as vital for wellbeing was to “*practice the activities that are replenishing to your energies*”. Chris also commented that a process of ‘holding’ painful emotions gives the opportunity to not only acknowledge those painful feelings, but to “*get perspective on them*”. The key ingredients for living in BC survivorship, for Chris, would involve acknowledgement of the fear that comes with survival, as well as acknowledgment of the fact that humans experience painful emotions and can come to terms with them. In addition, he spoke clearly about involvement in those things in life that are nourishing to the heart, soul and mind, and having the willing capacity to be compassionate to the BC survivor through mindful communication that was affirming and life-giving.

#### **6.4.14 Section summary**

In this section, thirteen themes identified from interviews with three significant others in the lives of three women who were diagnosed and treated for BC were discussed. The themes highlighted that, for the couples represented in this study, what was important was a need to keep things normal, make every moment count, as well as maintain a sense of balance about life. Discussion about self-compassion emphasised, for two of the group, how important they felt it was not to succumb to self-indulgent thinking and behaving. Balance in life was considered as a critical life skill. That balance however, was not one that denied the need, as humans, to express emotion or the need to receive care and love.

In terms of what would help survivors of BC the men talked about their perceptions of compassion, loving-kindness toward others (especially a cancer

survivor), in addition to engagement in the activities of life in all its shades and colour. What seemed apparent from the discussions with these significant others was the distinct differences in ways they had responded to distress in their wives during the adaptation to BC process. There was a general awareness in each of the significant others of the points of vulnerability in their wife. What was clear was the escalation in level of distress in each of the significant others when their partner was physically or emotionally unwell. Well-established patterns of relating as a couple could have, however, blinded them to discovering alternative ways of responding to distress. This appeared to be the case for two of the significant others. Seeking mental health care did not seem to feature as a critical or useful step in their thinking. In the interviews there was an expressed ambivalence about the usefulness of being self-compassionate as a way to facilitate relational change, whether that change was intra- or interpersonal in nature. Concern about selfishness presented as the stumbling block to consideration of the potential of self-compassion as an antidote to self-criticism. The speculation is that training in self-compassion, as a couple, may have raised their competency for resolution of intrapsychic conflict and consequently aid in strengthening a positive connection within their relationship.

## **6.5 Findings from counsellors' reflections**

Eleven major themes and six minor themes were identified from analysis of transcripts from interviews with three female counsellors who, as part of their professional work, had provided counselling support for women with BC. Pseudonyms have been used for all three participant counsellors. Names chosen were Mardi, Bridget and Alison. The counsellors expressed positive motivation to support women's optimistic adaptation to life post-treatment for BC. They each commented about how counselling support that could help access, and process, distressing emotions was something they regarded as productive and positive for women's mental health in BC survivorship. The counsellors offered emotional support, in addition to practical help such as organising fund-raising events and peer support groups, as a means of disabling potential negative after-effects of the women's experiences. According to the counsellors the principal negative after-effects that they recognised as most debilitating for women were guilt, self-blame, self-criticism, and shame.

Table 6 presents basic demographics for the counsellors who took part in the study. Each of the counsellors worked within different contexts that presented differing constraints and freedoms. Despite differences in the each counsellor's fundamental orientation towards the nature of counselling work, analysis of the three interviews presented observations that frequently reflected commonalities in the perceptions of challenges for women survivors of BC.

Mardi had completed a Master of Counselling degree and worked with a cancer care and support organisation for eighteen months prior to the interview. Describing her role as "*multi-variant in that it covers any scope that sort of ... that walks in the door*", Mardi had organised and facilitated BC support groups and provided individual counselling support to women with BC, whether newly diagnosed or living with BC for many years. Another part of her role was to arrange social events to raise research funds and heighten BC awareness within the broader community.

Bridget was a trained counsellor who had four years experience in a hospital setting. Her role involved offering counselling support to people with a chronic or terminal illness. In addition, her role with the pastoral care service at the hospital included working with women who were currently being treated for BC, or who had completed treatment for BC and were now an outpatient. Bridget's work covered both individual and family counselling combined with pastoral care duties.

Alison had over eleven years experience as a private practitioner since having completed a Master of Counselling degree. During her career Alison had spent twelve months as part of a cancer support team at a large public hospital. For seven of her years in professional practice Alison had worked as a contract counsellor with a cancer care organisation.

#	Name (pseudonym)	Years in practice	Practice location
1	Mardi	18 months with support group	BC care/support organisation Individual counselling
2	Bridget	4 years counselling experience	Private hospital setting Individual and family counselling
3	Alison	Over 11 years in practice	Private practice 7 years referral clients from a cancer care organisation

**Table 6: Counsellor participants**

The discussion with Mardi highlighted that during her time in the field of counselling she had awareness of the value of ‘doing’ as well as of ‘being with’ women. Mardi described her role as *“a lot of work with women that are dying ... and particularly then work with family members around that time”*.

Alison expressed a strong commitment to focus on providing counselling not just the women themselves, but for their family and extended family members. In contrast to both Mardi and Alison, Bridget indicated her focus was to help women through the initial trauma from hearing their diagnosis. She talked about *“journeying with”* patients and also mentioned feeling relieved to find a breast surgeon at the hospital who was *“very open to ... emotional and spiritual support”*. For Bridget, embracing a psycho-spiritual perspective had, she said, helped her understand emotional suffering as something that occurred both as a present moment experience as well as part of the ongoing larger picture of life.

Rather than regard the differing perceptions of their work with women with BC as a contradiction, or a purely personal preference, there was also the consideration that their practice perspective having been influenced by the needs, expectations and objectives of the organisations they were part of. For example, Mardi was part of a BC care organisation that had an holistic focus on provision of practical and emotional support for women with BC, as well as being part of the fund-raising initiatives for research. On the other hand, Bridget’s counselling was offered as an essential part of a counselling and pastoral care service provided within the context of a private hospital. Individuals and families encountering a harrowing journey through cancer diagnosis and treatment were referred to Alison by a cancer

care group. In her role as a private practitioner the referral process meant Alison could engage with as few or as many of the family members she felt necessary in order to support the emotional well-being of the person diagnosed.

Alison placed importance on restoration of healthy relationships for the woman. As a counsellor, in private practice, her perspective was:

*that relationships that people have not only with themselves, their self relationship, but with those that are their beloveds, that they may wish to communicate and speak in a way that is more intimate and more real and the changes might be made ... and they wish to speak of things they've never spoken of before...*

The eleven themes identified in the transcripts of interviews with the counsellors - listed in Table 7 - underlined their professional assessments and observations of women survivors of BC. Those assessments and observations formed the basis of counselling practice that supported enhancement of quality of life for women post-BC. The transition into survivorship was regarded as a major point of transformation and growth by the counsellors. This perspective is consistent with literature and help them manage the psychological side effects of medical treatment as they process. The major themes highlighted in the interviews pointed to the direction for counselling to help a woman with BC engage in a friendly, emotionally supportive and more flexible relationship with herself. Ultimately this process would mean a survivor would be able to better know and understand herself.

<b>MAJOR THEMES FROM COUNSELLORS</b>
1. Bearing witness: <i>"They're still part of the world"</i>
2. Not just putting bandaids all over the place
3. Personal challenge for counsellors: <i>"I don't want them to die"</i>
4. Being real: <i>"It's about how they actually see themselves as women - they're supposed to be all things to all people"</i>
5. Youth, sexuality, death and dying: <i>"For them - It's just one thing on top of another"</i>
6. The chaos inside: <i>"What if it doesn't work"</i>

7. I'm different, but what does that mean? <i>"A new sense of normal"</i>
8. Self-blame: <i>"I'm normally the cause of their happiness"</i>
9. Time to heal and grow: <i>"It's a long process"</i>
10. Self-compassion: <i>"Finding self as important as the other. It's like a blossoming"</i>
11. Survival and reconstructing life with a toolbox: <i>"I have evolved"</i>

**Table 7: Major themes from counsellor interviews**

Presentation of the major themes begins with the counsellor responses to the way in which they personally experienced their work with women with BC. The themes linked with each other and, similar to the findings from participation by women BCS, there was a 'space' of overlap in which themes overlapped with several points of interaction with each other.

The counsellors each held the same perspective on the therapeutic relationship. Their professional perspective was that it offered an open and safe context for supportive listening and therapeutic intervention as women told their life story. From the interviews it was clear that the counsellors allowed the women to relate their narrative in as much or as little detail as they were able. Furthermore, the counsellor reflections indicated they were of one mind in talking about the value of collaborative conversation and professional intimacy within counselling sessions. They acknowledged that the counselling relationship allowed time for women to be listened to, and time for women to reflect on what they heard themselves say. The sessions, from the counsellors' points of view, brought a 'legitimacy' to the unique way in which each client wanted to express her feelings about her BC experience. The counsellors reported they felt privileged in taking the role of a witnessing companion on the voyage of self-discovery.

#### **6.5.1 Bearing witness: *"They're still part of the world"*.**

A key function of survivorship is the reorganisation of a woman's sense of self. BC brings a crisis in the meanings to those aspects of life that had previously provided a sense of substance and structure to life. The three participant counsellors made statements that indicated they felt privileged to bear witness to the active and



deliberate attempts women with BC made to renew their sense of self-confidence, self-worth and self-identity and to bring new meaning to life.

At the start of our interview during a particularly busy day, Mardi expressed a willingness to make a contribution to this study, commenting that for her the field of BC was “... *great work; privileged work...*”. For Mardi, supporting women with BC gave her both a personal and a professional sense of living meaningfully. Although she felt her work with women with BC was “*very full on*”, she qualified that statement with the comment that “*I love this group of clients ... [there is ] so much you can do ... there’s so many different areas that it [BC] involves ... often its to do with issues they’ve had for many, many years ...*”. Her professional satisfaction and joy in counselling women with BC was reiterated when Mardi commented about her work “*its such rich work because it just involves everything really ... and ... I really love that sort of work ... it’s great*”. The intrinsic rewards for Mardi in her counselling women with BC became evident as she spoke about her involvement in her work. Mardi commented that “*its such a privilege to work with these girls and to get involved with their families ... and you can see that you make a difference ...*”.

Alison also pointed out that she was “*loving the work I do*”. For her, witnessing the telling of a life story, and being part of the person’s meaning re-making, was “*an honour*”. Alison regarded cancer as “*the catalyst ... quite frequently, for sometimes facing death and the journey towards death. It’s the catalyst for talking about matters that perhaps have been left to attend to one day, or preferred not ever to attend to*”. She felt that her nursing background was a positive factor in being able to assess and isolate aspects of life that are a client’s most immediate concerns. Alison also referred to “*beginning at the beginning*” with a client in order to establish trust and connection. Handing over, in a sense, the initial appointment to the immediate need to assess physical and emotional wellbeing, Alison alluded to being able to hold the space and witness the story the client wanted to give when they first meet. “*And, just the same with anyone that comes to see me, you know ... how are you sleeping? ... and just addressing the physical things first*”.

The process of witnessing a client begin talking about their BC was what Alison referred to as being “*the grenade in the water*”. The way Alison defined that

statement was *“You know... It wasn't there before, and you could just go along ... avoiding all the things you might talk about ...”*. Further explaining her comment, Alison's interpretation was that the grenade in the water meant that the focus on a client's BC brought a powerful imperative to the therapeutic relationship, because *“obviously when you're talking about death it changes the conversation”*.

What Alison reported as central in bearing witness was that she felt it important *“to understand the context of [a client's] world and what's important to [that client] ...”*. She would simply ask a client to *“... tell me a bit of this story”*. Alison had also witnessed the additional emotional and physical tension aroused in some clients by attending what may be their first ever series of counselling sessions. She commented *“you know, people are sitting there, like, oh, (mimics person sitting tensely on the edge of their chair)... and maybe by the end ... they may have ... aaah, it didn't kill me (Alison indicated a client's release of physical tension by settling back and relaxing), this woman didn't eat me; this is not so bad after all”*.

Bridget made the statement that *“counselling people with cancer – its not hard work”*. She also talked about the value of the counselling relationship and the need for counsellors to have the capacity to offer women a safe and protected psychological space because:

*for me, it's very ... soft ... (in a very soft voice) .. it's like there's a delicacy with it ... you have to get them to the stage of ... acceptance and, you know, the grief and the sorrow has to ... almost be at one. They just have to let it out ... however they can...”*.

By way of example, Bridget mentioned one client in particular whose life story she felt had never been fully heard and known. *“And I remember thinking about this with an elderly lady who came in for breast cancer, but totally related her story to miscarriages. She was 66 and her ... trigger ... was right back to her loss of three pregnancies...”*. The experience with this particular client was a reminder to Bridget that *“as a counsellor who's going to meet these women, that everybody is uniquely different in relation to how they perceive what breasts are about in their world ... who they are in the world”*.

Bearing witness to the uniquely lived experience of BC was regarded as a “*privilege*”, an opportunity to observe as women “*re-invent themselves*”, as they faced the professional challenge of being “*ready to let them fall, but also ready to lift them up*”. The participant counsellors each saw the support they provided as an important part of helping women with BC live more in the present, and to be alive and vital in a feeling, sensing way.

### **6.5.2 Passionate work: “*Not just putting bandaids all over the place*”.**

The idea that as counsellors each were bearing witness to stories of distress, emotional torment, or trauma, exposed a second major theme. That second theme was one of being useful, effective and making a difference for the women counselled. The responses from the participant counsellors indicated that they held a clear focus about the nature of their work. For them it was a case of not applying, to a woman, a therapeutic ‘disguise’ so that the women might appear more organised, more able to cope. BC was acknowledged by each of the counsellors as generating an inwardly chaotic emotional state.

In relation to this theme Mardi talked about how “*it’s nice to feel you make a difference and not just put bandaids all over the place*”. The ‘bandaid’ effect Mardi spoke of related to the value she felt emerged, for both client and counsellor, from the counselling process. For Mardi it was meaningful work “*being involved in people’s lives, making a significant difference ... helping people get through difficult times...*”.

Mardi talked about working through the fear that couples felt when confronted with BC and the common result of stress-related breakdown in communication within the partnership. She recollected that she had felt heartened when a BC client commented that their family had previously tried counselling to reduce negative communication, with no positive outcome. Their experience of the counselling process with Mardi brought the comment that their work with her had been “*really fantastic*” and they felt “*on track now*” and as a family “*we’re all happy now*”.

Alison stressed the importance of working compassionately with a survivor of BC. Her comments acknowledged the reality that a lot of BC survivors “*they’ve never been to counselling before*” and now a diagnosis that has the power to end their life has brought them to her therapy room. She referred to cancer as a catalyst for discussion about mortality. Alison said that the counselling sessions were a time when the survivor - and their family – could “*talk about matters that perhaps have been left to attend to one day, or preferred never to attend to*”. For Alison, counselling support for a BC survivor was time and space to listen to themselves, to find what it is they want to talk about, and have their experience honoured and respected in a trusting and compassionate relationship. “*They need to be able to trust me*” she said. This comment brought to attention the dramatic effect a BC diagnosis can have for a person who has never considered exploring their personal niche in their lived environments. Alison felt that if a survivor has had a previous negative experience with counselling, has limited understanding of what counselling is, or how it can help, or if they attend counselling as a conciliation to suggestions by medical or family support, then a trusting relationship with her would be important before they would feel safe enough to express the inexpressible. Alison felt that to work compassionately was to “*understand the context of [your] world and what’s important to [you]*”.

Bridget talked her observations of the importance of being aware and sensitive because “*there are fears and anxieties that they hadn’t even considered*”. Helping the BC survivor build awareness of their emotions was for Bridget “*the biggest thing*” in her work. She commented that cancer is a family experience for some people. Genetic counselling about the likelihood of BC was something Bridget observed as likely to generate anxious concern. In her statements about her work with survivors Bridget made a point of working with sensitivity to the fact that some people take the attitude ‘*Oh, I’m going to leave it [testing] until its necessary*’, and others had a mindset of ‘*I’m going to get every test under the sun and prevent it*’.

Each of the counsellors spoke about their work as offering challenge. Apart from the challenge of working in a ‘sea of stressful emotions’, they acknowledged the unique opportunity to step back from offering a cognitive map devised by another person and applying that framework in bandaid fashion over emotional wounds that

require a more agile, flexible approach to emotional support. That agility and flexibility was mentioned by the counsellors, not in those exact words, but commented on in their discourse as having the capacity to work with whatever comes through the door in ways that are helpful to the client's varied concerns.

### **6.5.3 Personal challenge for counsellors: “I don't want them to die”.**

Despite statements about the love they have for their work, Alison, Bridget and Mardi each referred also to the challenges inherent in daily involvement in a domain of distress, fear, loss and grief. The three counsellors referred to challenges in different areas of their work. For Mardi the challenging aspect of working with women with BC was the heightened awareness of her own personal values. Bridget referred to challenge in letting go of theory, of developing self-kindness and self-care in the process of caring for others. An overall concern for the future wellbeing of younger women diagnosed and treated for BC was a common theme amongst all three counsellors.

For Alison the challenge was primarily twofold and centred on the uncertainty of the person referred for counselling as well as the conversational exchange that can happen and individual needs that arise when family members come together to discuss a distressing event. A secondary challenge for Alison related to the fact that as a counsellor she is not always aware of a future prognosis or eventual health outcome for her clients. Her comment highlighted this challenge:

*but for me I think the most challenging thing is always ... I don't want them to die. (Very long pause) That's the most challenging thing, and you know that some people will [die], and that sometimes you won't know. You won't know... I don't have their six monthly report of you know, how they're going ... that is the most challenging thing ... I don't want them to die. I just don't.*

Alison felt that the not knowing whether the client with BC lives or dies was a significant landmark a counsellor in cancer care needed to come to terms with and accept.

Managing the individual expectations of family members of the person with BC can present in-session challenge for a counsellor. Alison pointed out that family

members have their own agenda about what needs to be addressed in a counselling session. The challenge in this scenario is, as Alison highlighted:

*The client says what they're wishing to speak of ... and should they be bringing other members of their family, which they may do in the progress of our time together, the family members may come in and expect to be part of it, and so often they will bring up things. And then they might go off, but something's been brought up ...*

To clarify her comment that a client “*might go off*” Alison said this referred to the challenge of working with a family where one or more of them expresses strong emotions about the situation. As an example Alison recalled a family of nine (all adults) who came to her for counselling after diagnosis. Her response was to help each person work with “*stuff that comes up*” in the sessions.

Alison's comments about what challenges a counsellor in the field of BC faces meshed neatly with the challenges spoken of by Bridget. The language of BC and the way of communicating with a woman with BC was a challenge Bridget spoke about. Her words accentuated the notion that sometimes there are no words, nothing that can be said that will make things better and the challenge of sitting with a woman's emotionally painful feelings and simply holding the space open for them to express in whatever way they can:

*So the challenge is ... the language often ... that you use .... so ... what is it like? ... what [do] you know? The challenge is just staying with that ... and it might be tears for weeks and weeks and weeks... before they can even say. It seems like a long time. It's quite challenging for me to be... to sit there and think there's any words that's going to come that's going to be of help.*

As an illustration of this point Bridget spoke about a client who was “*so beautiful to look at ... stunningly attractive*” but who, on reflection, Bridget said had “*no self-worth at all*” and was about to undergo a double mastectomy. Bridget was moved by the lengthy struggle this client had with “*grieving this sense of who she was*”.

Bridget commented further on her experience of professional challenge: “*I have to say to them ‘It’s challenging to begin with. It’s very difficult for me to even have an understanding of what this is going to be like for you so. Can you help me?’*”

The organisational setting in which Bridget counselled also presented a challenge for both counsellor and client. A busy hospital, in Bridget’s experience, limited the potential for a woman to have enough time and a space ideal for exploring feelings in a way that could help with overt expression of emotion, working toward greater self-understanding, and discovering self-compassion:

*You know it’s always in a place where there’s a lot of intrusions ... on the ward, and a lot of times you see them really just being very vulnerable and then ... sitting up ... somebody’s coming in ... so they move out of it.*

#### **6.5.4 Physical changes and being real: “*Its about how they actually see themselves as women – They’re supposed to be all things to all people*”.**

The place of self-compassionate relating in BC survivorship was accentuated when the counsellors spoke about their observations of how women managed physical change and their relationship with their body after treatment for BC. In regard to this, Mardi had observed that:

*It’s really about how they actually see themselves as women, as ... individuals, as mothers, as wives, as partners, or whatever it might be ... and that takes a while for them to really understand the significance of ...um... whatever the treatment might have on them.*

Mardi explained that some women “*really react really strongly to any of the physical changes that they go through – they really find it so confronting*”.

In a discussion about the impact of treatment on a woman’s relationship with the body post-BC Alison commented on her observation that many women found themselves significantly confronted by changes to their body from surgery and also the strenuous physicality of treatment regimes. Alison spoke about her way of inviting women to reflect on and talk about the reality of their body image prior to BC. She said this was not to deny the huge impact that surgery, radiation, chemotherapy, breast reconstruction, or scarring had on the women, however, she

saw the relationship with their body as a larger issue to be brought forward for discussion. Alison's comments were that each woman may have a different idea about what is important to them about their body, as well as what they feel is important about being a woman.

Speaking specifically about clients' sense of personal attractiveness, Alison felt that for most women "*Oh, everything goes .....*" and in this statement she was talking about changes such as those that take place in or to a woman's breasts, hair loss, and change in body functioning. However, Alison mentioned one exception, a woman who as a result of BC had engaged in counselling with Alison, and who was clearly able to exert her sense of personal agency in her own way:

*Except for the darling one who said I'm just going to get them nipped and tucked and they're going to be perfectly level and she said "I've even said to the surgeon ... 'Oh, what are those things... that you make the level... a ... spirit level...'" she said "Never had even nipples before. I'm gonna have them now". She was so funny. She wasn't grumpy. She wanted to survive and she wished to be light-hearted in a very constructive way.*

Bridget spoke of the post-treatment body with which a woman has to build a new relationship. She described some women's reactions to treatment for BC by recalling their comments such as "*it's like you're just a piece of meat*". Bridget talked about the effect on women's psychology from "*invasive*" but life-saving procedures that involve a woman's breasts. She made the point that burns and blisters as a result of radiation therapy turn a previously special area of the body into something that is painful and "*scorched*". Bridget also raised the issue that post-treatment women begin to change their style of clothing and prefer to choose "*very baggy clothes, very loose fitting*" to avoid irritation to the breast area. Women also seemed to need time, Bridget said, while they were "*in the process*" of treatment to experiment with clothing that will provide what is most nurturing for their body after treatment.

Bridget spoke further about the focus on physical wellbeing and the relief felt by a woman when each stage of treatment is successfully navigated. She also pointed out the initial experience of excitement as their body heals. However, she hinted at the temporary setback to that relationship when after-effects of treatment can



interfere with a woman's feeling of femininity. For Bridget one thing that stood out was the fear women experienced when first seeing themselves "*without that part of your anatomy*". This comment linked to comments from Mardi and Alison about BC taking women to the point where they include in their focus what it is that is 'real' for them.

Revisiting her comments about the non-negotiable task of relating to their post-BC body, Bridget stated that:

*It's very traumatic to go and look at yourself that first time with these stitches and...even to feel it ... So the initial trauma from hearing cancer, having an operation, and having to visually look at it.... It's a big challenge there for them. And not knowing how they're going to look - especially with a double mastectomy ...*

In relation to "being real", Mardi's work with BC survivors had given her the impression that personal values and revising a sense of what is important in life featured strongly in recovery. Personal values and personal empowerment were also emphasised when Alison referred to one woman in particular who struggled to stay with her own decision not to have breast reconstruction, despite her husband's expressed desire for his wife's body to be re-constructed in a way familiar to him. Commenting that not every woman felt as that particular client had, Alison emphasised the highly individualised nature of a woman's relationship with her body. Alison reiterated her interest in understanding the nature of the woman's pre-BC relationship with their body.

Both Alison and Bridget emphasised the effort they had observed in a woman's journey in her attempts to move beyond BC. Their conclusion was that on completion of treatment women sought to regain a state of personal integrity, a state of "*being real*", and of beginning to allow a kinder, more authentic self-relationship. Finding what was now 'real' was part of theme four; the theme about women with BC having to relate with themselves as different physically, emotionally, sexually, socially and spiritually.

The challenge to a woman's sense of femininity, the rebuilding of a relationship with a changed body, and being real connected to a further theme that was a focus for all three counsellors. The theme that emerged in their conversations was BC and younger women, particularly in relation to sexuality, death, and dying.

#### **6.5.5 Youth, sexuality, death and dying: “*For them - It's just one thing on top of another*”.**

In contrast to an emerging view in the field of BC care about the need to monitor, evaluate and meet the needs of the older BC survivor, older clients Bridget had counselled seemed to cope by doing what they may have always done, and just got on with life without expecting that their needs in survivorship would be something they could ask for help with.

Mardi, Alison and Bridget each made comment about the added dimension of distress for younger women going through treatment for BC. As counsellors they felt acutely aware of the un-lived life for a survivor who had children to raise post-treatment, or for whom treatment meant denial of giving birth to a child of her own. Bridget summed up her comments with the observation that “*the women in their 60's are very much more matter of fact ... stoic ... get on with it*”.

Bridget recalled two young women with BC each of whom had an image that she would be stoic about BC until she herself was diagnosed. She spoke about the change of mind that happened for both when they were diagnosed with BC. Prior to diagnosis both young women felt that BC was just a matter of fixing the disease with medical treatment and then getting on with life. One of the women commented that because BC is “not part of your life” she would have felt less empathy and compassion for women in survivorship.

For Mardi, diagnosis for younger women was as if life had become “*one thing on top of another*” for them. She commented that BC meant the “*whole notion of themselves changes entirely*”. Mardi's comments related to her understanding of the aggressive nature of premature menopause as well as her knowledge of the effects of “*long-term treatment of the drug that they're on*”. Her perspective was that the changes to both physiology and psychology were undeniably life-changing:

*I find the young girls ...lots of them really struggle with losing their hair. That's almost a bigger thing for them, and they really, really find that very, very confronting, and yeah and ...um... and then the decisions about what they might want for themselves as far as reconstruction goes.*

Alison also talked about feeling especially touched by the efforts younger women had to make to engage fully with BC as a long-term companion both in their life and in the life of their husband and children. She reflected that young women feel the shock, not just of the health implications of BC, but a reverberating shock that *“this is not how its meant to be”*. In that comment Alison was referring to the abrupt ending to assumptions about health and the future. She added that young BC survivors with school-aged children worry about how everyone in the household will cope with the demands BC places on a family.

The topics of sexuality and sensuality for a woman post-BC, and self-compassionate relating with oneself as a sexual being, drew substantial comment from Bridget, Mardi and Alison. All counsellors referred to changes to sexual functioning and a woman’s sense of being a sexual being for the younger BC survivor as *“life-changing”*. In terms of sexuality and sensuality, Bridget made the point that the age of diagnosis and treatment made for significant difference in the after-effect on a woman’s sexuality and sensuality. Her comment referred to the absence of one or both breasts and the difference this would make for a younger woman who is sexually active, or who desires to be available to an intimate relationship. This issue was highlighted by Bridget and Alison as significant when counselling the younger survivor.

When personal attractiveness was intimately linked to an acceptable physical form Alison stated that loss of a breast and the resultant scarring heavily influenced a woman’s notion of herself as a sexual being. She commented that many clients who have had a mastectomy feel embarrassed about seeing themselves naked. Further comment from Alison emphasised that *“there is something about femininity and womanliness, and I suppose the breast is part of being a woman, its her shape ... its such an obvious thing ...”*. On this same topic Bridget made reference to the high

visibility of both single or double mastectomy, stating “*it's a huge life-changing event because its so visual ... they can't hide it ...*”.

The change in sexual functioning was something Mardi felt particularly relevant for younger women with BC:

*Plus along with that [menopause and drug treatment] is the sexual difficulties they may have particularly related to loss of libido and perhaps vaginal dryness and those things. For some young women it's absolutely life changing and really distressing ... Because for the young women it really is very, very difficult ... they might have had both breasts taken off, perhaps reconstruction, but perhaps sometimes that's delayed ... as well as losing their hair because most young women would have chemotherapy, plus then thrown into menopause all on top of one another ... and often dealing with little children as well ... and so they're dead tired and fatigued, and it's just one thing on top of another.*

Sexuality and being able to make a decision about having a sex life were aspects of life Alison thought were usually put to one side while the more immediate question of physical survival and the demands of the BC treatment regime were addressed. For Alison the question of death and dying commanded greater attention in the time immediately after diagnosis. However, Alison also commented that she felt each woman had her own unique time for directing her focus towards reconsidering her sexuality.

On the topic of mortality, Bridget referred to a liminal space that becomes a feature of life after diagnosis. Although BC impolitely confronts a woman with her own mortality and activates the struggle for survival, Bridget reflected on another facet of BC for women who survive - fear of what the future might hold:

*Maybe its not so much the fear of dying, it's the fear of being different, or looking different, or “Can I still make love to my husband, or will he still find me attractive?” So there's a lot of fear going on, so if you can bring it out and say its ok, but lets see what you're really afraid of, we might, eventually, get to the fact that “I'm not intimate with my husband” ... and that's a big thing to say.*

Because of her understanding that BC is “so... curable”, Bridget commented that “*the cancer, per se, doesn’t come into it so much as it would with the diagnosis of [a different] cancer where existential issues come up*”. Despite that comment, the existential issue of fear of death, opening the conversation about death and dying and contemplation of their own mortality was regarded by all three counsellors as a strongly salient, and distinctively fear-inducing ingredient in the personal crisis initiated by BC diagnosis and treatment. Despite the fear, Mardi pointed out that her observations of women with BC was:

*Initially they'll be dealing with what they've got to do, how they can do that, and they keep themselves really busy. But ultimately it is the feelings and emotions that they're really grappling with that often takes them a long time to start to deal with ... things of the heart.*

Mardi spoke openly about a professional challenge for her in working with younger women diagnosed with recurrent BC. Her comments linked to those she made relevant to the third theme of challenge for the counsellor in working with a vulnerable population such as BC survivors:

*Women who have secondary breast cancer ... and perhaps ... when they're initially diagnosed and the ... the reality of their situation, but yet not lose hope, and not lose a sense of who they are in amongst it all when their treatment is so constant. Often they're having chemo weekly and that might go on for years ... and you know with all the issues of family life around them ...and the small children, often babies, and stuff like that ... it can really be quite stressful for them and really difficult for relationships ...*

Mardi continued to talk about the process of re-prioritising life that some women with BC embark upon:

*I think it all opens up. You go through a life-threatening illness and sometimes it will take their lives. I think that it helps them to re-evaluate where they are in their life and what they might want for themselves and their family that's perhaps lost along the line.*

Discussion about sexuality, death and dying and younger women with BC led to the major theme of some of the challenges women face when their sexuality is

impaired either in the short term or the longer term. The life-changing effect of BC for younger women at a time in their lives when they may be raising their children, and simultaneously may be coping with a recurrent cancer was commented on with empathy and compassion by each of the three counsellors.

#### **6.5.6 The chaos inside: “What if it doesn’t work”.**

Bridget talked of her observation of there being “*chaos inside*” for many survivors. She said her work with women had led her to conclude that many women felt a lack of certainty about who they were. Bridget felt that the many roles women fulfil tended to dilute their capacity to stand forward in one particular way. Her comments were that women’s thoughts turn to: “*I am... trying to be mum, trying to be wife... trying to be... whatever they’re trying to be ... (reflecting on her own words) ... professional*”. Fear born of the loss of control was also a focus for Bridget:

*But fear is there ... “what if it doesn’t work?”, “what if I’m one statistic that doesn’t survive?” ... and I think its about addressing the fear and saying its ok ... to be afraid... but “how can I live with that fear?”. And its still there, “but how can I live differently?”*

Her work with women with BC had led Mardi to form an impression that the treatment process absorbs women in an initial “*loss of control*” and a subsequent “*regaining control*”. Fatigue, premature menopause, and the impact of medication were acknowledged by Mardi as significant factors in generating feelings of loss of control and the surrender of a sense of personal autonomy. Mardi stated that loss of personal autonomy was something present from the outset of a woman’s journey with BC. She took time to comment on her witnessing of women who she said do not feel there is enough time to come to terms with what has to happen for their chances of survival to be maximised. Mardi also talked about the women feeling like they are “*on a treadmill*” and needing to make important decisions for the future. She talked about her observation that for some women it is only after treatment has happened that they have time to integrate and then cope with what has happened to them. Drawing on her experience of counselling women diagnosed with BC, Mardi commented that once women go through treatment then the psychological challenge is about their self-identity, “*how they’re feeling about themselves and what they*

*might like moving forward*". This time of trying to integrate BC into their life was a very "*confronting time*" said Mardi.

Alison highlighted the torment some women encounter when they find themselves wondering and worrying about "*How did I get it?*", "*Why did I get it?*", or "*What did I do wrong?*". This 'wondering' that Alison talked about was not spoken about by the women survivors in the findings for this study. In contrast, a significant number of the women participants said they made a firm decision not to ask themselves those questions. Alison also commented on reports from clients who, in their counselling sessions, felt distressed because their BC had not been "*picked up as early as it should have been*". Alison used the term "*rage*" to describe the emotion expressed by those of her clients who felt their BC had been missed or misdiagnosed.

On the whole Bridget and Mardi confirmed that the transition from diagnosis, to treatment, to survival (or not) was a chaotic time when a woman was presented with needing to make her way through the medical system in a way she had never needed to do until diagnosis. The comments from Mardi provide a link to another important theme – a theme of being different, but wondering what that would mean, and knowing that being different means there is a need to embrace a new sense of normal.

#### **6.5.7 I'm different, but what does that mean: "*A new sense of normal*".**

Diagnosis and treatment for BC, according to Bridget, means women "*certainly join the world of cancer ... which is a different world*". Encountering themselves in a different world and of relationships no longer being the way they were prior to BC, meant adjusting to what Mardi called "*a new sense of normal*". This encounter and adaptation to a new sense of normal was described at length by the counsellors. Referring to women's adjustment to a changed self, Alison's perspective was that "*They work out the people who are good for them and who are their friends, their real friends. Who could be real and comfortable and listen to them*".

Many of the women Bridget had met post-BC were able to frame the experience of entering that different world within themselves as opportunity. Bridget commented:

*The whole world opens up, where they have to start to really look at what has meaning and purpose. What is life really about? A lot of them turn it into an opportunity to say, "You know, well, here I am now, and how can I live life as well as I can".*

Conversely, in referring to other women who encountered significant change in worldview, lifestyle or way of relating, as a result of BC, Bridget said they struggled with trying to accommodate, or integrate, their post-BC different self into a life they had created pre-BC. Bridget pointed out that some women choose to reject the life alteration that BC offers. Her interpretation of their choice was that some survivors of BC find it easier to resume an existence in which they are the person *"that somebody [else] wants them to be"* and live in a way that others need them to live. Bridget stated, however, that the discomfort of others, who no longer recognise the woman who has survived BC, underpins the decision to try to fit back into the pre-BC life. But, their identity, values, and energies are changed *"without a doubt"* said Bridget.

In her comments about fear, difference, a new sense of normal, Bridget defined what she saw as a 'hunger' in women survivors of BC for a deeper level of connection with themselves and others in relating:

*Because often the people ... who go to the place of unwrapping and grieving ... go to a different relationship with themselves because they want 'real' ... they're always saying there's no time ... especially the person who changed totally ... she's [saying to herself] "Just get on with life" ... but it's really about "How do I live differently ... And ... It's not preparation for dying, it's "How does it teach me to live differently?"*

The search for a way to live differently seemed to involve conscious reflection about how a BC survivor relates with herself. To live in a way that means normal life activities can be experienced in a such a way that rumination, self-blame



and self-criticism do not overpower the capacity for self-kindness was a theme highlighted by each counsellor.

#### **6.5.8 Self-blame: “I’m normally the cause of their happiness”.**

Being the one who causes of sadness in those they love was a theme that underscored the complexity of self-criticism. One aspect of self-criticism that added complexity was the feeling of unwittingly imposing an additional emotional and financial burden to a family. For Bridget self-criticism wasn’t always about being overtly hard on self and driving self into being, for example, a workaholic, or self-destructive. During her interview, Bridget was able to bring our attention to subtle variations in the ways in which her clients had criticised themselves:

*This particular woman was so much the protector of her children. She was always providing for them. And she felt it was a responsibility of hers that she’d got this cancer and they were in sorrow. And often that comes up that they have a sense of responsibility ... it’s more the responsibility of the sadness that it brings to people. ‘I’ve got cancer and I’m the cause of their sadness, whereas I’m normally their mother who’s the cause of their happiness’. This is what they say ‘I don’t want to burden them with my... um... cancer’.*

The potential lifelong influence of early life modelling on self-relating was also mentioned by Mardi when she spoke about a tendency for self-criticism and for a woman with BC to feel like she had created a burden for her family and friends:

*I guess ... a lot of it is to do with family of origin ... and how they were brought up .... That’s why it’s so important to go back and to really look at all of that. A young woman who’s grown up in a very critical environment often ... really, really struggles with that critical self a lot more.*

The complex origins for a woman of feeling like she is a burden or of engaging in self-criticism was also mentioned as having its genesis in some adverse life event that had been held as secret, perhaps for a long time. In regard to this Alison referred to life events not spoken of, and of BC becoming a impetus for some women to finally talk about something they might regard as “some kind of sin”:

*Sometimes, before their marriage, some things within their marriage ... like ... an abortion, affairs, or things that had not been.... they wanted to talk about them. Its like saying ... its almost like some kind of sin that they've got ... giving them the 'whoops'. It [the issue] comes up, and its "I want to talk about this now". There's some kind of burden, this guilt, which I always say is ... one of the most negative non-constructive emotions that any of us can have ... to relieve themselves of this ...*

Alison then described her perspective of self-criticism as psychologically toxic, as well as being exhausting and corrosive for the person burdened by self-criticism. Her view was that *"It comes from a place of resentment, and 'martyring', and self sacrifice, and that is ... that is pure poison ... I think ... inside"*.

#### **6.5.9 Time to heal and grow: *"It's a long process"*.**

The need was identified for clients to allow time for the process of healing and making personal change. For example, Bridget likened the process to a particular stage in a person's mourning process, emphasising that building self-acceptance and allowing herself time to grieve was important for a woman. Bridget also made the point that recovery from treatment was not a quick fix, and to her this meant women survivors becoming cognisant of giving themselves permission to grieve:

*It's too early to re-set any ideas of .... if there's going to be a future or not, and how am I going to be. And because it's a long extended time... [emphasising] and it can be a long extended time ... you just open the door and ... it's very much an open door. It's not something where you say to the person "OK, seven sessions, you're going to come in and have at least . ." It doesn't happen that way. Not with cancer, breast cancer. It's very different.*

Bridget extended her commentary about clients' needs to give themselves permission and acceptance to do less and be *"not the sort of person who's at the helm all the time. And it might have taken them that length of time for them to get there. It's not a quick fix"*. Bridget's interpretation of the experience was that there has often been a lifelong process of living with, regarding, and relating with oneself in a particular way. Reversal, for some women, of the way they have lived up until diagnosis, is something that Bridget considered could not be turned around within a

short space of time. For her, an emotional healing process was something that was, for most women with BC, going to take time and also needed time.

Time to heal and grow was felt by each of the counsellors as a missing element in the recovery process. They felt that the physical body did not take so long to recover from treatment, but the emotional and spiritual being of a woman needed much more time. Their comments about emotional healing needing time and space pointed towards the next major theme of self-compassion.

#### **6.5.10 Self-compassion: “*Finding self as important as the other - It’s like a blossoming*”.**

The themes from interviews with three counsellors recorded their impression that life for a woman post-BC is, from the perspective of the counsellors, not so much about physical change, but more related to how the woman actually sees herself - as a woman. Bridget and Alison talked of the realisations some women come to that they had expected themselves to be “*all things to all people*”.

During the interviews self-compassion emerged as a topic that the counsellors felt was not well understood or integrated into the lifestyle of many women prior to diagnosis and treatment. Therefore it was a skill to be developed and added to a toolbox that a woman could take with them into survivorship.

Talking about their perception of self-compassion, Mardi, Alison and Bridget all recalled instances in which a woman had blamed herself for the diagnosis. They talked about how some women acquiesce to pressure – internal and external - to return to normal and so do not allow time to find out who they are and what they need now. Each of them also stressed their perception that women with BC needed to engage in more self-care. When she spoke about the harsh effect of self-criticism on a woman’s wellbeing, Alison added:

*... talking about breast cancer. It's a lot of learning about ... self care ... and I always think ... delete, delay, delegate in your diary ... the three d's ... in your diary ... and look at that ...and practice that ... do that like it's a meditation... notice that ... its part of that self care ...*

Self-blame and self-criticism were emphasised by Mardi as something she commonly observed in the women she had counselled:

*Well, most women will come in and say ... well, I know why I got this, or there's certain things going on. They're really tough on themselves a lot of the time. "I've been too stressed, I haven't looked after myself well enough, I haven't ... you know my diet's been terrible", whatever the reasons might be. And there'll be a multitude of different reasons, that they really attribute some sense of blame to themselves... While they're struggling with all that they really forget to just start to really be nice, and care, and be kind to themselves.*

Alison also pointed out the extent to which self-blame played a negative part in her clients' psychological well-being. Speaking of one client in particular, Alison repeated the client's comment about "[I] must have been a naughty child that's why I've got breast cancer".

Alison continued with her recollections of ways in which women blame themselves and are not self-compassionate:

*And there's this blame thing that if only I'd lived a different life, hadn't drunk so much, hadn't had sex with so many people, not been such a bitch to my mother, or whatever it might be... or didn't work so hard, I wouldn't have had breast cancer...*

Bridget too mentioned one particular client who was ready to blame herself for the diagnosis asking "... is it because I drank when I was a teenager?" A point of interest for Bridget was her perception that, prior to BC, women often had little awareness of the value or need for self-kindness, stating that "I'd say 80% of them don't have it [self-compassion] beforehand. They don't ... 'cause they're not aware of it so much". However, Bridget had noticed that post-BC a significant number of the women she worked with did begin to focus on self-discovery in a self-reassuring, kinder, and more self-valuing way:

*But going through the process, and having a different change in values and beliefs they do begin to do a lot of it ... a lot of work on themselves, they do allow themselves, and give permission, and start to see themselves*

*differently ... and ... not so much differently even ... its more finding themselves as important as the other.*

Mardi's professional reflection meant she was also aware of a sense of contentment she herself experienced when a woman's self-relationship began to change. She commented that "... it's really lovely to see, too, when they start to honour themselves a little bit more." However, Mardi made comments that also emphasised learning to value self was not always a straightforward path:

*Some people when I first start to do some work in this area of self-compassion, they worry that they're going to become selfish, or self-centred or whatever. And so gradually they start to see that it's about nurturing and looking after themselves, and they then have the capacity to look after others - their family and people that they love - in a completely different way.*

Mardi talked about her way of introducing the concept of self-compassion within counselling sessions. She said she invited women to breathe, place their hands on their body and "*feel the warmth that they can generate for themselves*". Mardi had observed how responsive her clients were to her invitation, saying they realised they could "*slow themselves down ... centre themselves ... and feel a sense of caring for self*". Her comment was that there was a lot of self-blame going on at times and so introducing self-compassion in a gentle, non-threatening way meant "*you can just move that a bit and start to be kind to yourself*".

Alison mentioned that she talks about self-compassion "*with all people, wherever its necessary*". She then reiterated a point that was recurrent in her interview. The point she wanted to make was of the importance of women coming to a place inside themselves where they can begin to move towards feeling empowered in their lives:

*Its like ... "this is my choice, I'm choosing to do this, this is something I can do" ... whether they're coming along to counselling, or whether they're choosing to do something ... doing some Reiki, some meditation, choosing to eat carrots all day or whatever, they're actively involved in their own ... and the more collaborative ... and I know they're all words like 'empowerment' ... but its like "I'm doing something ... I'm doing something for me, I'm*

*picking out the ones that are right for me, and don't tell me, but I'm having a go at these different ... and working out which ones work for me".*

Bridget felt that women tended to leave themselves out of the care 'equation'. She said that self-compassion meant "*giving ourselves permission to just be in the world*". Her observation from her work with BC was that "*self-soothing is our only way, really. And if we wait for other people to do it, it might never happen*". Bridget said she encouraged her clients to first give to themselves what they would give to others. She pointed out, however, that her perception was:

*80% of them don't have it [self-compassion] beforehand. They don't ... cos they're not aware of it so much. But ... having a change in values and beliefs they do begin to do a lot of work on themselves, they do allow themselves and start to see themselves differently ... not so much differently even, it's more finding themselves as important as the other. It's like a blossoming ... it's like all the nourishment ... and so the nourishment comes from themselves, from within, not from without.*

Bridget spoke with an optimistic voice about what she called a "blossoming" process. This process was something Bridget felt she had witnessed when women were able to include self-kindness in their internal self-orientation. Likewise, adopting a psychodynamic perspective, Mardi felt strongly that the first step in the process of life reconstruction begins with finding self-compassion. She felt this was necessary before being able to explore self-identity and the ways in which a woman had constructed or accepted life pre-BC. "*And it starts with compassion, with being kind themselves ... and then you may be able to look at all the other things later on down the track*".

The counsellors each commented that not all women were able to journey with ease from the self they had known, and cross a threshold into a new way of relating with themselves self-compassionately. Bridget talked, for example, of one client whose prognosis was terminal, and yet who needed to maintain persistent external denial in the face of an uncompromising reality. What Mardi, Bridget and Alison had noted as a beginning point to being more honest and open with a counsellor about fear or distress was when a woman survivor 'crossed' a

psychological threshold into a new realm of relating with themselves in a kinder, more self-honouring and more self-valuing way.

The counsellors talked about there being a capacity in women to initiate and drive substantial personal change. This they said was particularly so for women post-BC. All three counsellors talked about women's ability to bring awareness to the bigger questions of life, and to create values and beliefs congruent with a changed body, a different relationship with their body, and with clear knowledge of what motivated their desire to survive. Bridget called it "*reconstructing life*", however, she added that this time they could be supported with the help of a toolbox of emotional skills with which they could construct - or reconstruct - their life.

#### **6.5.11 Survival and reconstructing life with a toolbox: "*I have evolved*".**

Mardi's experience as a counsellor had convinced her that part of the process of helping a woman reconstruct life involved exploring with the client what it is that each woman valued and wanted to retain in her life post-BC. Mardi said she felt that this process aided a healthy embrace of what it was like to be empowered:

*So I think for most people the whole searching ... and even ... that discussion about what are your values and what would you stand for, can really be very empowering for many of the women.*

Alison spoke at length about the potential for positive life change that women with BC had identified in their counselling sessions. At the same time as acknowledging that "*I know they didn't want to have cancer, but all of them in all their different ways and all of their different ages say ... 'I am so different', and 'I don't want to go back to being that person'.*" To elaborate on her evaluation of the situation, Alison recalled a number of related statements she had heard from women with BC. Some of the comments included "*I am much more this person that is me. I've made changes*". Other women had commented that "*relationships are different ... they're more real*". Yet others had said to Alison "*I'm a better friend. As in ... I don't mean better, better, better ... I mean I am ... I have evolved*".

Bridget explained that she regarded BC as an opportunity, a catalyst for change that women might never have found. However, after commenting about BC being a challenging but growthful opportunity Bridget hastened to add *“not that anyone would choose to have cancer [in order to grow]”*. Her assessment of what happened for some women was that there was a type of ‘honeymoon phase’ in which there was a sense of excitement. The excitement was the feeling accompanying the discovery that the person has a sense they have what Bridget called a *“toolbox”* with which they can reconstruct life. The toolbox Bridget referred to was women being able to leave the world of cancer treatment with new-found awareness of self, new skills for ways to understand and regulate their emotions, and a sense of meaning and purpose to their experience.

Excitement was also generated, said Bridget, when post-BC women come to accept *“all we’ve got is now”*. This meant the women had developed an attitude that they can live in the world with a sense of immediacy and only thinking about the present, rather than, as Bridget reported, thinking ahead all the time and thinking of others’ needs. Bridget felt that women survivors lived with hope as an ever-present companion, and at the same time had to exist within a reality that embraced fear of recurrence. She was of the opinion that her role was to help women grow, while at the same time Bridget felt certain that her role was not to give advice or strategies for living. Extending her comments, Bridget stated that *“we [counsellors] give them a chance to practice, to play with [ideas]. And you know, intuitively that person will grow. But as the counsellor, you can’t do it, you can’t get them there, you have to give them the space to do it [grow] for themselves”*.

Comments were made by all three counsellors about reconstructing life, but doing so with what Bridget called a ‘toolbox’ that would include women having the skills to be able to make emotionally supportive responses to themselves as a way of self-soothing and self-calming.

#### **6.5.12 Section summary**

This section presented themes identified from interviews with three female counsellors who had provided professional emotional and psychological support for women with BC. The initial five themes related to impressions developed by the



counsellors from observations and experience in their work. The first theme “Bearing witness” related to the counsellors’ impression of themselves as being privileged witnesses to each woman’s efforts to survive and to make healing change in their life. The next theme “Not just putting bandaids all over the place” referred to the desire by each of the counsellors to support women in meaningful ways. A third theme involved comments about the personal challenge in working in a professional domain where there was a need to maintain optimism. A fourth theme opened the topic of how women “see themselves” as they experience life post-BC. The ways in which diagnosis and treatment for BC effected a younger woman, how it effected a woman’s sexuality, and the question of survival were all part of the fifth theme “It’s just one thing on top of another: youth, sexuality, death and dying”.

Themes six to eleven highlighted “The chaos inside”, along with the concern women have that “I’m different, but what does that mean? Sadness about the change from a position where “I’m normally the cause of their happiness”, led into the need for “Time to heal and grow”. “Finding self as important as the other”, and “Survival and reconstructing life with a toolbox” focused more specifically on the women’s experience of themselves and ways in which their self-relationship could be re-formed. These final six themes shifted the focus from the counsellor to their reflections on their work with BC survivors.

Overall, the themes spoke to the fact that life for a woman post-BC is, from the perspective of the counsellors, not so much about physical change but more related to how the woman actually sees herself - as a woman. Comment was made about the realisation that women can function from a mindset that they are supposed to be “*all things to all people*”. Additionally, other comments emerged, including a woman’s perspective of her illness being a “*burden*” to others, and of having to adjust to a “*new sense of normal*”. The outcome of the BC experience for some women was the development of a capacity to draw “*nourishment from within*” herself. The essence of what the counsellors spoke about was the process through which some women would re-evaluate their life and arrive at the point where they were more kind to themselves as a result of having BC.

In their efforts to understand the personal, psychosocial dimensions of a woman's BC experience, each counsellor became a benign receiver of difficult life narratives. Therefore, through the repeated act of listening to BC narratives, it is feasible the counsellors could be vulnerable to a negative skewing of their worldview. If that happened the result might be a negative influence on their sense of meaning and purpose. The evidence that emerged during the interviews was that listening to the suffering of others seemed to create in these counsellors greater compassion and capacity for tolerance of human distress. In terms of their practice with women survivors of BC, what stood out in their comments, was a highly professional commitment to their work, compassion for the enduring challenges BC presents, as well as a desire to search for a practice framework, rather than a theoretical frame of reference, that would embrace a sense of the importance and benefits of developing self-love in women post-BC. Their reflections on the way in which women related with themselves and how women related with the concept of self-compassion highlighted the need for models of emotional support to provide pathways for their clients to locate a renewed, yet sustainable, way of creating a nurturing personal niche in their inner and outer world.

## Chapter Seven

### Discussion

#### 7.1 Overview

A diagnosis of breast cancer captures women's attention in a way that few other challenging life events have the capacity to do. Fortunately the reality is that some forms of cancer, particularly BC, are no longer considered an inevitable death sentence. The hope held by society is that the medical profession can extend life and continue to find cures for diseases that once brought physical threat, eventual death, and for loved ones that most unwelcome sorrow of loss. Since the 1970's there has been an exponential increase in numbers of survivors amongst women diagnosed with BC (Fallowfield & Jenkins, 2015; Hewitt & Holland, 2006, p. 25). This means the outlook for physical survival has become unignorable optimistic (Alfano & Rowland, 2006; Burke et al., 2012; Fallowfield & Jenkins, 2015). At the same time, however, over one third of those who are classified as 'survivor' will be vulnerable to a cancer recurrence in the years of long-term survivorship (Butow et al., 2015; Hewitt & Holland, 2006). Women diagnosed with BC face challenges on many levels (Wimberly et al., 2005). The experiences of diagnosis, treatment and survival, generate a range of unwelcome and uncomfortable emotions that include depression, anxiety, helplessness, pain, isolation, sexual dysfunction, feelings of vulnerability, and fear of recurrence (Alfano & Rowland, 2006; Hopko et al., 2015; Lu, Man, You, & Leroy, 2015; Montgomery & McCrone, 2010; Pérez et al., 2014).

Not every woman 'meets' BC in a negative way and in this study a small number of participants reported managing their emotions or encountering elevated mood experiences in the immediate diagnosis and treatment phase of their illness (Büyükaşık-Çolak, Gündoğdu-Aktürk, & Bozo, 2012). Some of the terms used by those participants to describe how diagnosis felt included "*a feeling of being blessed*", "*excitement*", "*feeling special*" and "*on a huge high*". However, the long journey ahead meant that reserves of emotional stamina were not an infinite resource for many of the BCS participants in this study. In the process of this study it was

observed, during individual interviews and group sessions, that when the women felt less positive or under some emotional strain there was an increase in the use of self-critical language. Women's reactions to themselves oscillated between the relief of feeling well and coping, and the disappointment on days when they felt unwell. During their participation in the study indications were that positive emotional energy was particularly vulnerable and unavailable in instances when emotional suppression was adopted as a usual coping strategy. In those times, the flow of emotional stamina that seemed to accompany the relief of survival, became less of an exponential curve upwards and more of a roller coaster ride through processes of physical and psychological adjustment re-alignment.

To be the bearer of the label 'BC survivor' means a woman brings focused concentration to the effort of remaining vigilant about monitoring health progress. The focus for many women is to generate and maintain optimism about survival, and the future wellbeing, and at the same time re-establish identity, and reclaim life in its everyday 'ordinariness'. To do this the survivor is required to adhere to a prescribed course of treatment and engage in positive health behaviours to arrest evolution of the disease. However, compliance with treatment has been identified as susceptible to a survivor's psychological state (Manning & Bettencourt, 2011). The beliefs of many of the women in this study were consistent with findings in current literature that encouraged concentration on diet, exercise, and positive thinking as the keys to success in overcoming the hurdles faced in having to live with the legacy of BC (Greenlee et al., 2016; Hamer & Warner, 2017; Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Sabiston & Brunet, 2012).

Alteration to a woman's identity and psychological functioning can happen through physical alterations to her body, and the way her body responds to life-saving chemicals. Cognitive impairment in the form of memory loss, inability to concentrate, and feeling like their mind no longer works as rapidly or as astutely as it was able pre-BC was reported by the women in this study and was consistent with conclusions drawn in research studies (Von Ah, Habermann, Carpenter, & Schneider, 2013).

In addition to changes in the relationship with self, and in relationships with others, change can also take place in other domains such as not being able or willing to return to a pre-BC career. Additionally, advancing age brings with it the inevitability of additional health and psychosocial related factors that will call for closer attention to the way a woman lives into her cancer survivorship (Thavarajah et al., 2015). Physical and emotional resources may be taxed not only by living with the after-effects of cancer, but will be extended by loss of loved ones, changes in cognitive and physical functioning, and other occasions of significant change that come with the passage of time (Hanchate et al., 2010; Mandelblatt et al., 2016). As aging becomes personally more relevant for the woman living with BC, a deeper understanding of the psychological energy expended in the processes of hope, maintenance, and resilience may remain invisible to a social world that can interpret survival as a return to normality marked by the end of a medical emergency.

In contrast to concerns about the potential for ageing to bring with it changes to cognitive and physical functioning, it has been stated that “older women with breast cancer have more positive mental health than younger women with breast cancer” (Colby & Shifren, 2013, p.18). This argument would need to be tested not only against a survivor’s capacity for an optimistic perspective on BC, or their propensity for pessimism about their likely outcome, but the nature of power in relationships with significant others, in addition to their attitudes and beliefs about self. In general, the women in this study espoused optimism about their future health. They talked about the strategies they engaged in to avoid recurrence. During interviews and the OtSC and PRP sessions all but one of the women tended to frame their dialogues optimistically. The study by Colby and Shifren (2013) pointed to prior research by Carver et al., 2006, that argued that optimism positively affects quality of life and mental health for BCS, but not for their physical health. In reality, normality exists as a concept filled with assumptions, expectations, and illusion.

A BC survivor is called to live in an ‘in-between’ space that carries an existential challenge (Hvidt, 2017; Trusson et al., 2016). That challenge comes in the form of an opportunity to explore the limits and potentialities inherent in personal resources to uncover who they had been, reveal who they are and want to be, as well as how they want to ‘be’ for themselves and others. The collective wisdom of the

women participants for this study indicated however, that the most immediate existential issue was firstly a process of clarification of who they are not or who they no longer wanted to be.

A survivor's psychological response to BC has been referred to as co-determined by the event itself as well as a (vaguely or profoundly remembered) background narratives and emotional coping styles (Wendling, 2016). The 'back story' to life is one that can be subtly powerful and therefore implicitly accepted as the belief of 'that's just me'. A cautionary note is relevant here. A survivor's background life narrative is not something that can be pointed to as a direct causal factor in the genesis of BC. Although some research in the 1980's assessed personality factors in relation to BC (Hahn & Petitti, 1988; Thomas, 1988), the debate about any causal link between personality factors and development of cancer has continued for several decades without clear conclusion (Bleiker et al., 2008; Chida, Hamer, Wardle, & Steptoe, 2008; Kruk, 2012; Price et al., 2001).

While personality factors cannot be regarded as a convenient, salient, and therefore excusatory, reason for maladaptive psychological responses to BC (Kruk & Aboul-Enein, 2004), the themes extracted from review of the narratives given in a variety of ways by women participants revealed a psychological legacy from their past that suggested a history of emotional suppression. Suppression of emotional distress has been found to be associated with increased depression, anxiety and anger in women diagnosed and treated for BC (Ando et al., 2011). Learned behaviours and relational styles from their past appeared to have conferred on the women survivors in this study a less than clear idea of their place and purpose in the scheme of human relational interactions. What they had inherited related to beliefs about their role as a woman being one of able to care for others, and be the willing bearer, and repairer, of others distress. Personal value was derived from being of service to others, and this was reflected in the choice of occupation for many of the women. Fields such as nursing, education, and teaching dominated the study population. Their encounter with BC had, however, begun to raise awareness of an internal desire to separate themselves from a perception that being of service was the a primary way to feel good about themselves. To do so would mean inevitable alteration in their self-perception and self-description.

In this study, eleven themes were identified in the narratives of women who had survived BC. Collectively the themes created an overall sense of positive growth and development of a stronger sense of self in most of the women. On the face of it the collection of survivor's themes could be interpreted as demonstration of definite and positive emotional distance having been gained from the initial shock. Such an interpretation would not however tell the full story. There is no denying that the 'first layer' of the stories gives an impression that the women's dialogues were strongly indicative of new life perspectives and changed attitudes toward self. Their dialogues were replete with words of hope and optimism, courage and strength. To be among those who had survived BC yielded significant relief for all but two of the women.

The themes that emerged from those interviews revealed that most of the women who joined the study had not considered that a meaningful life could be specifically about them rather than about them in relation with others. The women in this study who suffered negative disruption to feelings of balance in the emotional physical spiritual and intellectual aspects of themselves as they adjusted to living with cancer, reported feelings of alienation from their authentic self and from others whose lives remained untouched by BC. Living life in an outward 'form' similar to what it was prior to BC can be perceived as convincingly comforting in a socially constructed environment that can carry a well-disguised fear of cancer contagion through conversation. Despite the visibility of being normal again, inwardly the women were no longer the same person and often no longer able or willing to attend to the demands of their previous life. After friends and family had been able to be present to the intensity that came with the medical treatment phase, the women reported that there came a point when the usual support networks were no longer available to invest as much energy and time into offering emotional strength and practical support.

The participant women who realised they wanted to change the dynamics of relating with significant others in their lives post-BC were making attempts to do so through re-arranging external realities such as career change or re-investment in personally enjoyable social activities such as dancing. Interpersonal relating was also amended. An example for one participant was accepting, finally, that there was no possibility of a reciprocal friendship with a close relative despite having provided,

during her own post-BC treatment time, extensive practical support to that person. This shift in acceptance had brought a sense of relief for the participant because she was able to arrest constant rumination about ways in which she might be able to please that person. What remained relatively unexplored was the intrapersonal relationship and the inner directive to keep helping that resulted in constant failure to actually ‘help’.

For many of the women who participated, their narratives presented an invitation into a private world that ‘embodied’ contradiction. Themes that highlighted the relationship with their body, their active concern for others, and their perception of what it meant to be self-compassionate, told a tale of the women having ‘thin’ descriptions of themselves. It was as if the women described themselves on a one-dimensional plane – the dimension of carer – either care-giver or care-taker. While they reported feeling stronger than they had previously experienced themselves, examples of life events given to amplify statements made during participation indicated some inability to disentangle themselves from pre-BC relational structures and patterns that maintained an identity status quo. This was particularly so in regard to their self-relationship. The implication was that long-held beliefs about value and worth coming from tending to others was a legacy learned from traditional social and familial interactional styles.

What this meant was that to embrace SC as a useful and psychologically healthy way to ‘be’ for themselves could stimulate a process of self-discovery and self-management. Three phases could be identified for such a process. The first phase would involve an openness to and engagement with what it means to live in a self-compassionate way. The next phase would be one of observation of one’s internal responses to the way SC guides inter- and intra-personal relating and will call for a willingness to feel inconvenient feelings and relational discomfort of not meeting usual expectations of self. The final process would be integration of self-compassion into the structure of the personality in a way that feels harmonious and congruent within the egoic structure.

The women who began with anticipatory feelings of their diagnosis bringing something “special” to their lives found at times the journey became an arduous one.



Many of the women had previously enjoyed a career in ‘high touch’ fields such as nursing, allied health, and education, in which the needs of others were considered paramount. The encounter with BC as an unwelcome and intrusive ‘agent’ of change had propelled an unanticipated movement to greater awareness of their own needs and wellbeing. Admitting that BC had invited them to a place where they had come, not to die, but, to live they were now motivated to be mindful to include themselves in the picture of life.

## **7.2 Relationship with self and after-effects of BC**

Reconsolidation of the ‘self’ as more than a survivor of BC but as a person who is disease-free, who no longer has BC, was a prime source of emotional and physical effort for participants in this study. In discussing their relationship with themselves and their physical body women openly confirmed that prior to diagnosis the connection with their body had been ignored or put aside for a very long time. The women’s comments established that prior to BC they would more often than not unfailingly surrender concerns about their body’s needs and always attend to the needs of those they loved or as often was the case the needs of relevant others.

The physicality of disease and survivorship had generated intense body awareness. Exercise, healthy eating, and management of weight were the key directions women focused on to redefine themselves as well and cancer free. To concentrate attention on actively doing something that offered outwardly observable results (eg weight management) provided positive feedback of positive physical recovery. Concentration on lifestyle factors such as diet seemed helpful in limiting contemplation on personal emotional challenges. Acceptance and awareness of increased psychological vulnerability was centred primarily on emotional recovery from distress caused by discovery of the disease and subsequent treatment. This meant a paradigm of self-understanding that would include a review of psychological development was not part of their current thinking. Attempts to avoid dwelling on painful emotions meant acknowledgment of BC as a persistent emotional health challenge was eschewed by most participants.

What stood out as significant was that a large proportion of participants did not want to carry a label or be identified as a ‘BC survivor’. The term ‘survivor’ or

‘victim’ was rejected by them. It appeared that these women did not want to be reminded of ever-present realities. The realities for them were twofold. On the one hand there was expressed reluctance to be linked to illness or physical or emotional vulnerability. A concomitant reality was that a recurrence of cancer meant a return to exacting treatment protocols, in addition to presenting a potent reminder of a potentially reduced life-span. Participants reminded me that despite ongoing reliance on pharmacological treatment they regarded themselves as being free of cancer. In discussions throughout the data gathering phase there was expression of cognitive endeavours to negate not just the possibility of recurrence, but any fear of recurrence. My terminology in the interviews initially referred to “women who have had breast cancer” or asking about “living with breast cancer”. The common response from most participants was clear and swift. They were keen to adjust my use of the terminology by saying “*but I don’t have breast cancer - not now*”. Overall, their evidence pointed to a robust resistance to any potential for a newly-located self-identity as a strong person to become subsumed under the label of ‘BC survivor’.

The theme of emotions and personal growth revealed unpleasant outcomes for some of the women who had initially navigated the passage through treatment in a stable emotional state only to suffer a decline in their psychological health in the time after connection with the medical care system had formally concluded. From their reports it was clear those women experienced negative rumination that had gathered strength and persisted intensely after the end of treatment. Feelings of abandonment, dejectedness, and personal rejection were exhibited in different ways. One woman voiced bitter, angry, reflections related to the perceived absence of physical help and emotional guidance that she felt was not forthcoming after completing treatment. This participant referred to BC as yet another injustice with which she had to deal. Outward expression of her anger was directed at her spouse (in my presence during the interview), her medical advisers, as well as directed toward a local government council that she said had not rectified what she considered to be a toxic environmental issue that she believed had caused her BC. To another woman removal of her breast meant loss of a significant aspect of her ‘value’ as a sexual partner. A secondary loss was the unexpected removal of the opportunity to resume the employment role she held prior to BC. The meaning she made of the change BC made in her life was that her most valued and valuable roles had been

unjustly taken from her. Yet another participant continued to experience unpleasant treatment-related complications in her mental wellbeing. This participant had presented at her interview with what could be interpreted as an ‘upbeat’ attitude toward ongoing, post-treatment care, that involved painful medical procedures. However, the ‘mask’ of being able to ‘laugh it off’ fell away, temporarily, when, she acknowledged to me, briefly but it appeared, knowingly, the fear that her medical prognosis meant survival was not yet an assured outcome.

A further three spoke openly of their fear that every body symptom now brought with it some form of ‘confirmation’ of a sinister revival of BC. Those women also spoke of trying to manage feelings of fear related to uncertainty about their future chances of long-term survival. Despite acute awareness of the power of cancer to redefine their future, what was noticeable during the interviews was a hesitancy when negative concerns about their future health was given voice. This happened with broken sentences, retraction of comments that might suggest powerlessness in the face of fear of recurrence, and ambiguity within talk about cancer, their self relationship, and self-compassion.

During conversations about their experience of BC and beyond, the BC survivor participants preferred to replace comments that could have been interpreted negativity with positively-gearred and self-affirming statements. It seemed that this was an important choice for them to uphold a belief that a positive attitude would be some type of safeguard against recurrence. Talking in positive terms about themselves post-BC supported their sense of being free of cancer and in control of life once again.

Instances where fear of recurrence was expressed through physical indicators such as teary-ness, or through occasional inclusion in the dialogue of fear-infused or hope-denying language were followed up with comments that restored a sense of power over emotional distress. What was reflected in the process of their dialogues was the strain of suppression of enduring concerns. The lingering, cumulative effect of unaddressed emotion from both the trauma of diagnosis and treatment as well as unavoidable fear of what the future, collided with pre-existing habits of avoidance of emotions such as fear anger powerlessness that had negative social and personal

connotations. Comments were also made that expressed habits of not thinking well of themselves. An example was when one woman said she did not think of herself as “smart”. In general the women spoke about how having BC had helped them realise they were “stronger” than they had thought. During review of the transcripts, and revision of extracted themes, the question was whether their perception of now being stronger would become captive to learned habits of ‘soldiering on and doing more’ or would it be applied to being strong about self-acceptance and initiating patterns of self-kindness in self and other relating.

Resistance to identification as a victim or a survivor of a life-threatening disease indicated a potential for growth into a self-relationship that would be characterised by feelings of emotional prosperity. The ‘strength’ in themselves that many of the women mentioned finding contrasted with feelings of emotional impoverishment that could be unfailingly generated by negative judgments of them through ‘external feedback’. Conversations with women in this study were characterised by a resistance to acknowledge any lack of ‘specialness’ in their life – they felt special through their service to others rather than ever considering what it might be like to be thought of as special for no other reason than they were who they were. Not every participant followed this pattern of situating themselves outside of BC once they had completed treatment.

In contrast to resistance to a survivor label, at least two participants presented with what might be considered a form of ‘attachment’ to BC as the ‘thing’ that made them feel special. This appeared to be so because having BC engendered close care and support from family, friends, and social networks. These two women also acknowledged feelings of importance - a sense of being admired by others because of their battle with cancer. One of the two participants spoke of her disappointment that she had not received the same level of love and practical support she perceived was given to her sister who had, after a long battle with BC had died from the disease. Another felt that the social and work environments she tried to re-enter post-BC demonstrated little appreciation for the enormity of her struggle and the courage she had to find in order to survive.

Re-locating themselves back in a world that had moved on while the women 'lived' in the BC world brought challenge in the form of trying to join again workplace and social structures. Some women talked of the strength of family support whereas others felt that friends and work colleagues had 'run away' from them because of their cancer and not knowing how to broach the topic. They felt as though people whom they expected they could count on for support had disappeared. Yet, other people who had not been considered close friends prior to their encounter with BC were the ones who appeared willing and able to offer strength at the times when the woman's own strength was tested to its limits.

For the majority of participants the illness had generated a to-be-expected depletion in physical and emotional stamina. For many of the women their self-perception was that they had been able to find the strength to survive unpleasant physical and cognitive effects that included fatigue, depression, lymphedema, and 'chemo-brain'. Any impairment in physical functioning was something the women expected to subside within the characteristic 5-year window of survival. 'Chemo-brain' allied to the negative effects of chemotherapy was a state they anticipated would resolve itself as their recovery progressed.

The findings suggested that understanding of psychological health in relationship was framed by previously-enculturated socially-endorsed norms for females. Those norms centred on the importance of caring, offering empathy, listening and attempting to understand as best they can what the 'other' needs or wants. The outcome from this way of relating was that the women tended to ignore - or were not able to hear - their own body-voice. This was especially apparent in regards to warning signs from their bodies. Subtle internal processes that may carry a template of learned experiences and emotional events have been said to have potential to become disguised in the 'language' of the body (Pert, 1997). The implication from Pert's theorising is that unprocessed emotional experiences remain stored in the body. Somatic psychotherapy theorises there is correspondence between physical and emotional dysfunction (Broom, 1997). Unresolved traumatic or emotionally wounding experiences are regarded as those that can negatively influence the physiological functioning of the human body (Rothschild, 2000; van der Kolk, 2014).

The relationship with self and with one's own emotional needs was regularly subsumed by a characteristic desire to maintain relationship with significant others through being able to anticipate what was needed by others. The process of considering and anticipating others need was accompanied by giving attention to others needs. The willingness to meet others needs was not, however, consistently provided from a position of love and care. An accepted – and unquestioned – sense of duty and fulfilment of the expected role of women in their social world was pervasive. The boundaries between the multiple roles the women fulfilled regularly became blurred, and it appeared that what was surrendered was attention to self-care (Mackenzie, 2014).

For some participants, being a woman meant they had absorbed a constructed expectation to feel responsible for helping people work through their feelings. Penny talked about her relationship with her husband as being characterised by his upset when Penny was not in a positive state herself. In response to Penny's concern for her partner on receiving a BC diagnosis she made reassuring comments to her husband that she would survive, everything would be OK. From comments Penny made this appeared to be done so as to rescue him from feeling any distress. Penny was not alone in that shift from having an awareness of her own feelings to the process of care-taking feelings of fear and alarm in significant other's. Several participants reported decisions not to cancel holiday plans because others would be disappointed or because the woman felt that if she announced her BC diagnosis this would spoil festive season enjoyment for other family members. When asked to recall a time when she had been self-compassionate one participant commented that she had indeed been self-compassionate in taking a rest which then meant she had energy to cook her husband a meal.

Shirley commented about times post-BC when she was feeling depressed, stating that her husband's standard response to times when she felt in a less-than-happy mood was to remind her to take some medication to restore a more congenial mood. Her husband's comments served to reinforce for Shirley that his perception of her was a stereotypical one of her as 'woman'. To Shirley this indicated he regarded women as emotionally fragile and irrational in their moods. His 'remedy' for this was medication as a way women could restore their sense of balance. It seemed that

being able to resort to medication also offered Shirley's husband inoculation against his own feelings of helplessness when witnessing her as emotionally distressed. In short, medication helped him rescue himself from the threat of unpleasant, uncomfortable emotions.

When first interviewed, a majority of participants subscribed, some more, some less, to an accepted societal belief that in general women automatically take on an expected role of loving care-takers of a family (Mackenzie, 2014). The comments from the women indicated that they never expected to put themselves first and never questioned when they were not. As their connection deepened with others in the OtSC sessions and PRP a more authentic exuberance for life was, temporarily, more freely available in a safe and trusted environment with other women. The result was that acceptance of 'conditions' to their living - conditions such as care-taking, being aware of others needs, putting their needs down the 'list' - began to move forward in their awareness. In conclusion, despite decades of liberation from stereotypical roles for women in general, what had persisted in women participants was benign acceptance of their role, as wife, mother and/or partner, as the one to offer assistance, care, kindness and generosity to others when need arises. Breast cancer had begun a process of these women enjoying who they are and releasing what they are not – or who they do not want to be.

Treatment to manage or arrest the physiological threat and relief from symptoms that persist as a result of treatment is one part of the health care process. The field of care for the person living with cancer is now much broader than it would have been half a century ago. Recognition of there being layers to personal meaning-making in addition to awareness of what it is that holds potential for healing for human beings has brought about changes in care for the cancer survivor. Banded together under the collective term of complementary and alternative therapies/medicine (CAT/CAM) a cancer survivor now has access to a suite of supportive activities such as counselling, yoga, mindfulness, art therapy, and music therapy. Each of these activities as well as an extended range of creative-arts-based approaches to healing have the potential to support proactive moves the person makes to move beyond an identity as survivor.

The labels of ‘BC survivor’ or ‘woman survivor of BC’ may become ones that can obscure the person’s larger reality. That reality is that a person with cancer – who may survive or who does not survive – is a multidimensional being with a range of physical emotional intellectual and spiritual needs and desires who exists in a range of differing contexts. This means as a multidimensional being a survivor of BC would likely respond well to a multidimensional empowering and growth-focused approach to emotional support. A multidimensional approach invites the person who has survived to be proactively engaged as an integral element in their own healing process.

### **7.2.1 Restoration of emotional functioning: The psychological self.**

Reports from some participants confirmed a revitalised interest in life had been catalysed by their close encounter with death. That encounter had brought an often unpleasant, unwelcome, but necessary surrender to an essential, but temporary, shift in their psychological structure. There were a number of participants however, who maintained a pre-BC model of relating with themselves, family and with others. For them, enjoyment of life remained heavily influenced through shaping and maintaining harmonious relationships with significant others in their family and social environments.

Therefore, a not-so-surprising realisation was that the post-BC ‘self’ continued to ‘house’ significant elements of the psychological structure that had been in place prior to diagnosis. In other words, persistent in the psychological self were the shadows of negative childhood injunctions such as driven-ness, need to excel, low self-worth, and insistent self-criticism. For participants, thoughts, actions and ways of relating with self and others, continued to subtly mirror, or repeat, remnants of an earlier imposed blueprint for responding to emotions. Therefore a psychosomatic ‘network’ of embodied remembrances of BC continued to be unattended to. Those embodied remembrances of BC were able to be masked by the relief that came with survival and the confirmation of their strength in enduring the treatment regime.

The perspectives of the women in this study gave credence to the assumption that if a woman speaks up about things they are not happy or not satisfied with, then



they risk being regarded as being a selfish person. This appeared to be particularly so in negotiating relationships. The result was self-imposed restriction to being self-loving or self-compassionate. From their reports and my observations in the OtSC and PRP, the women were very capable of experiencing 'bad moods', able to feel angry, to grieve, or to be upset and sad. In the group of participants in this study there seemed little restriction on their ability to feel, However the retraction on self-kindness that would pave the way for a regular, natural, flow to self-expression seemed inhibited specifically so as not to appear self-centred. This was a persistent finding in the life stories shared for this study.

The interview process supported a hypothesis of the enduring, and depleting, power of cultural expectations and the results of trivialisation (and self-trivialisation) of women's concerns about themselves. The perseverance of past habits of self-value and self-relating was especially reflected in the first two themes – "I never said why me" and "I don't have a Plan B". In both themes participants reported an optimistic stoicism from which they made a deliberate and conscious choice not to outwardly express feelings of shock or fear on hearing their diagnosis.

One outcome of a tendency for procedural memory to regulate the relationship with themselves was that women in this study continued to hold close an expectation that preserved their 'role' as responsible and loving caregiver in their family, and to continue to be so, even in the encounter with a life-threatening disease. This meant staying focused on finding the energy to be optimistic about survival while keeping a mind for the 'suffering' of significant others in their life. was one source of distraction from the workings of their interior world. For example, concern for others emerged in a strongly conveyed desire to support women diagnosed with BC in the future. Self-concern would mean taking time to reflect on a deeper purpose and meaning to their life and their experiences. Self-concern might also bring an invitation to review what it was a BC survivor would like to encourage and create in their life for the foreseeable future.

Commentaries from the women about their BC experiences were couched in an overall expressed hope that what they disclosed could potentially help ease the suffering of others. Their compassion for the suffering of women diagnosed with BC

was beyond question. The concerns and hopes for others wellbeing reflected concerns and hopes they also had for themselves. This meant that the complex construct that emerged with compassion toward others was that on another level what was given to others was the very thing the women would have enjoyed receiving. The complicating factor was that many of the women found it more acceptable to give than to receive.

During the most intense phase of their treatment they had been able to experience and receive the concern care and love of others. However what remained evident in their personal narratives was that once life returned to something that equated with pre-BC normality, unconscious habits of self-exploitation re-entered their daily living. It seemed there was a self-protective function in treating themselves harshly. Self-protection in the form of an inner critical ‘voice’ seemed to offer respite from the emotional strain of anticipated self- and other judgment. The women’s stories told of an internal dynamic tension between care and concern for others and care and concern for themselves. In giving to others they were in a way giving to themselves and protecting against judgment. Therefore, in being compassionate to others there was an accompanying sense of creating a sense of self-worth through positive and helpful contributions made to other people’s lives.

Gaining a positive sense of self from being concerned for others provided only temporary relief from the absence of an abiding sense of self-worth. The evidence for this came to light in comments from the women about self-compassion. Asked to recount a recent time when they had been self-compassionate their comments often related to putting in place boundaries about how they wanted to be treated. However, there was more often than not a lack of being able to direct kindness toward themselves without some form of external catalyst. At the same time as the women were able to push back against previously unconscious habits of concern for others what persisted was the lack of conscious expectations of ‘receiving’ in return for care and concern given to others. There was also limited conscious awareness that caring and supportive attention to their own emotional state by themselves or by others could be tolerated for any extended time.

For the most part there was subtle, active, but seemingly unaware, resistance to receiving kindness from self or others without giving or returning the ‘favour’. The need to return kindnesses shown seemed to emerge from fear of being found to be selfish, or their needs being regarded as an imposition or too dominant. Kindnesses extended to the women during their treatment and transition to ‘survivor’ had been accepted during the time in which they felt ill and were unable to attend to daily living in their usual way.

Evidence from the interviews and group sessions for this study indicated that the indelibly physical nature of treatment for cancer had forced greater awareness of the interrelationship between illness wellbeing and self-nurturance. It had taken a diagnosis of cancer for women’s self-awareness and self-acceptance to begin to ‘open’ their mind to a larger version of themselves. That larger version of self was one of being a valuable and worthy human being not because of what she could do for others. That larger version was one in which a sense of wholeness and joy about self could be experienced. Tender self-comfort and self-reassurance could become part of a normal way of relating with self in the everyday, not just when they felt sick, or in need of help.

The personal strength the women survivors summoned in order to survive had aided a post-BC shift to make changes in previous unconscious willingness to overlook the importance of their own needs so as to accommodate others’ needs. However, while positive changes had taken place, positive change had not been universally integrated through all ‘dimensions of the self’. What remained unobtrusively embedded in participant narratives were disclosures that indicated the psychological ‘self’ post-BC still contained a residue of aspects of the ‘self’ that had been in existence prior to diagnosis. Restoration of emotional functioning post-BC so they were able to include themselves as important and deserving of nurturance was often challenged by the absence of physical symptomology and a belief that medical treatment had ‘fixed’ the disease. This meant concern and care for their own bodies, their minds - and their destiny - was still being unavoidably and unconsciously prejudiced by the legacy of a past construal of self as being of value most when in the process of being helpful to others.

What remained was an internal psychological orientation that was still subject to societal rules, values and expectations even of themselves as BC survivors. Rather than the rules, values and expectations relating to ‘women’ in general, their life as a BC survivor now had rules, values and expectations about how to ‘be’ as a cancer survivor. For example, one already-discussed dominant narrative that remained intact was fear of being selfish or being judged as ‘emotional’. Emotional ‘strength’ to ‘soldier on’ as a survivor of cancer was considered valuable. Family members and co-workers encouraged a return to a non-ill self. Supportive as such encouragement may seem, vulnerability to emotions or emotional intimacy with themselves was therefore something regarded as a form of submission to negative psychological remnants of the disease – an indication of weakness – and something to be recovered from or put aside.

Contradiction was inherent in the BC-saturated stories related by the women – a contradiction that at some level seemed implicit although not expressed. The women’s interpretation of their journey through BC was of their tolerant acceptance of an inevitable process to enable survival with a specific focus on taking positive action to remedy the physiological problem. However fixing the most obvious immediate problem through effectively and efficiently removing BC had cured a disease for the women but had not in a larger sense brought ‘healing’ for their psyche.

BC had affected the women’s attitudes towards themselves and their bodies in a way that had challenged awareness of a tendency to put their own needs aside to cater for the needs of others. The evidence was that a process of psychological evolution was underway. Changes that were not so visible had occurred in their conscious psychological self. Their stories told of personal change that meant an openness and willingness to listen to themselves and evaluate situations in relation to how they wanted to live post-BC rather than what they believed was expected of them. They had begun to perceive life differently and had begun to re-imagine their future self in a way that would not have been possible pre-BC. BC had presented the women with a ‘refurbishment’ of the self they thought they were. There was also intangible, but explicit, demonstrations of a shift in valuing their capacity for

relationship-tending as opposed to that capacity being devalued because of the expectation that it is what women do by virtue of their ‘nature’.

More conscious self-guidance of the direction of that re-interpretation began to happen when, in a psychologically safe environment, with no cultural expectations of how to be as a survivor, they had the freedom to begin reconstruction of their life narrative. Through embarking on a process of deepening self-discovery the women began to feel free enough to experiment with re-shaping their psychological self in relation to others and the world around them.

### **7.3 Emotional and personal growth**

The theme of emotional and personal growth revealed, in general, that participants had not moved outside recommended conventional treatments for BC. The interpretation of BC most commonly held was of it as a disease harboured in the body. Therefore, fixing the body was considered to as a medical matter. What followed the completion of the medical process was a decision that positive thinking and an optimistic attitude along with development of coping strategies would create a ‘savings account’ of evidence of personal effectiveness at staying well. The belief was these strategies afforded greater potential of personally defeating BC.

The majority of women in this study had not participated in BC support group activities other than as a way to seek short-term, immediate post-treatment psychological support. While many of them had been involved as a participant in a research study, or had brief encounters with cancer care groups, comments made indicated that for the most part, prior to the BC experience they had not consciously thought of engaging in personal exploration of their inner world. None of the women participants, nor the significant others, had engaged in in-depth personal development processes such that compassion-focused therapeutic activities or psychotherapeutic techniques might employ.

What had not been sought prior to participation in this study was a regular contemplative practice or process that would seek to foster self-exploration and re-evaluation of their post-BC sense of themselves. A commonly held view amongst participants was that BC was one of two things: it was either incurable or, in the

case of this study's participants, able to be 'cured' by application of medical treatment. A small number had engaged in short-term conventional verbal counselling that had provided much needed emotional comfort. Emotional comfort had been used as a means to increase their sense of personal control and take care of the body through external means such as massage. This form of support had helped them regain mind over matter by using distractions, by placing a positive interpretation on what was happening to them now as well as maintaining a positive vision of the future. In general participants were not clear about what exact purpose would be served if they were to engage in additional emotional support.

In terms of their personal growth, at the end of their participation in this study two of the women who had completed all three phases of involvement remained unclear about how to reconcile a dynamic inner tension between the concept of being self-compassionate and the deep desire to avoid being thought of by others and by themselves as selfish. This was not to imply that they had not grown personally.

The consensus amongst participants that their life was very different as a result of BC. This led me to wonder whether self-compassionate communication could be a conduit through which women and their significant others could be supported to emotionally take a step back from their disease. A step backward supported by counselling that included the work of finding self-nurture and self-love in contrast to work that might focus on problem resolution could allow enough time to develop self-compassion. The focus would be to herald a shift to a refreshed relationship with themselves and the world. This could mean stepping aside from thinking primarily about treating psychological symptoms of the after-effects of BC to a position that prioritised assessment and inclusion of ways to develop a long-term self-harmonious balance in emotional functioning.

One significant other had taken this step backward after his wife's death when he reached a state of feeling his life without her was pointless and meaningless. His 'rock bottom' moment, when thinking of his children were no longer an anchor to his human life, led to a subsequent review of his potential. He talked about his decision not to continue existing in a colourless world, but to acknowledge and allow himself to feel his emotional pain and at the same time open to living life more fully.

This significant other chose to investigate aspects of himself that had been ignored until BC arrived as the unwanted intruder in his marriage.

In the process of getting to know themselves these particular participants encountered an internal struggle as they attempted to reconcile loving kindness for self and a more tender internal commentary with a deep imprint about the negative implication of being selfish. Self-love self-nurture as kindness toward themselves began to emerge through the process of participation. This happened as the women became more open and less concerned about others reactions to their talking about losses, fears and concerns in a forum that offered deep listening and silent compassion. This type of environment offered time for gestation and ‘birth’ of new insights about themselves and revised relationships with others.

As the times of meeting as a group continued for the 8 women, there was permission from within themselves to become absorbed in ‘experimentation’. Having time to experiment with ideas about relating with themselves and others in the PRP sessions, as well as experimentation with creative tools, created acceptance of compassionate silence as a valid response rather than automatic entrance into someone else’s world by way of offering a remedy. Spontaneity and their capacity to enjoy was clearly demonstrated as their experimentation in the group sessions lessened the control of their thinking by collective assumptions of what being woman, being middle-aged, and a BC survivor meant to them. What replaced the collective assumptions was collective wisdom.

### **7.3.1 Emotions and wellbeing.**

A significant number of the women in this study regarded their encounter with BC as a commonly experienced source of temporary, but profound, personal disempowerment. Collaboration with the biomedical system in their quest for survival brought compromise to emotional wellbeing (EWB). The women’s experience of the disruption to EWB is reflected in the literature on the effects of BC. Although eagerly anticipated, a return to EWB was not enjoyed as an automatic by-product of survivorship by all women who took part in this study.

EWB was something the women had found they needed to give effort to, just as their body had been the primary source of effort to join the medical system in accomplishing their physical healing. With increasing distance from being a cancer sufferer to adjustment to life as a survivor, there came the risk of easefully settling back into unaddressed and habitual routines of intra-personal and interpersonal communication, social exchange and social discourse. The women in this study demonstrated a growing awareness that the stress they reported to me as integral to the decline in their health was not something they wanted to have as a life ‘companion’.

Anecdotally, a significant number of women participants in the study reported in this thesis, held a personal belief that unaddressed, extraordinarily intense levels of unresolved stress in the year or two leading up to diagnosis had compromised their immune system and precipitated the generation of illness in their body. Another woman survivor of BC, consulted as part of personal-experience ‘reference’ sources for the study, was asked about her perception of whether there was any connection between stress and BC. Her response to me was emphatic. While this survivor believed stress was not the actual cause, she did regard stress as a highly significant contributor to her development of the disease.

The concern was that conditioned thinking about needing to care for others or about others would reclaim primacy in their emotional functioning. Those ways of thinking and behaving were ones that sadly reflected acceptance of socially constructed stereotypical ideals. Having faced a fear and shock of diagnosis and treatment, survivorship presented them with the challenge of finding emotional sustenance from within themselves. This meant stepping away from limits placed on their self-expression either by themselves so as not to appear powerful, dominant or selfish, or by others for the same reasons. In this regard, the women reported BC as the life event that brought with it a relaxation of their previous acceptance of ‘norms’ about women’s roles. They spoke about feeling less bound by nagging concerns that they should think and behave in ways expected of them by significant others.

Engagement in personal discovery became the important intermediary that initiated a re-fashioning of the women’s attitudes towards themselves and their



bodies. Time to engage in a mindful but relaxed and ‘playful’ growth-focused approach to fostering emotional awareness, wellbeing, and personal vitality, was one way the women encouraged in themselves gently-paced movement towards exploration of unfamiliar ways of being. After the trauma of diagnosis and treatment, BC had become the indisputable agent of change. Autonomy of choice to go with the change or to return to life as usual belonged to the women.

### **7.3.2 A different perspective.**

In an entirely different direction Myss (1997) has taken a position of there being a tendency in humans who have suffered adverse life events (excluding trauma), to steadfastly maintain a position of being in need of care and support. This author points out that a façade of needing to be taken care of is a coping strategy adopted to avoid active engagement in a personal change process that would ultimately lead to separation from unresolved emotional pain that feels familiar and has been an habitual way to get some needs met. The possibility of being their own agent of change would, according to Myss, be carefully but usually unconsciously, concealed beneath a belief of being unable to be psychologically stronger than they know themselves to be. The view of Myss is one that seems to sit in contradiction to the principles of being self-compassionate.

Contrary to the social commentary put forward by Myss (1997) participants in this study spoke of their newly tested strength as something they regarded as bringing enhanced personal coherency to their emotional landscape. The term ‘strength’ seemed to represent an opening of a door to discovery of a collection of previously untapped resourcefulness. The resources waiting to be fully discovered offered the capacity to evaluate choices from a broader and more authentic self-perception – a perception that provoked self-reflection increased self-knowledge and considered self-determination through their relevance to qualities of self-kindness, self-nurturance.

## **7.4 The desire for self-nurturance**

Self-nurturance is a desired by people and is sought in many forms. In this theme the women’s comments were a reminder about the caustic effect of judgment from self and others. They felt that having another person listen to them in a non-

judgmental way offered a way to speak their own 'truth'. It appeared as though there had been much unsaid about themselves, not just about their BC experience but their whole of life experience. The chance to speak openly without fear of judgment or correction meant that the women had not had opportunities to hear themselves. What had been missed then was time and space to listen to their innermost 'being' and in doing so become aware of their innermost potential.

In the Western social world women are often assumed to be and depicted as nurturers of others, care-givers for others, reproducers, and sexual partners of others. Since the latter part of the 20<sup>th</sup> Century half they have also been depicted as being able to do anything that a male person can do. A dominant social portrayal of the roles of women as carers and nurturers of others was confirmed by participants. Referred to by Beverley as the ones who are over-generous givers, participants talked of themselves as the ones in the family who maintained relationships and an overall sense of peace and calm.

Self-nurturance had been accepted pre-BC as being primarily derived from creating and maintaining connections with family members, guiding relationships between family, and taking responsibility to ensure enjoyment for others during special events for family. Part of that 'responsibility' included support for aging and emotionally unwell family members in addition to attending to handy-person jobs around the house. Women BCS in this study commented on the perception that without their intervention relational disharmony within the family may be likely to extend beyond a bearable point, and practical tasks around the home would be likely not to be completed in a timely fashion. Some of the women commented about feeling a general lack of appreciation for and an invisibility of the contributions they made to family harmony.

Post-BC the women felt they gained nurturance from their connection with other women survivors. The group connection was most effective in reducing feelings of emotional isolation and mediating contact and sharing experiences with other co-survivors (Cozaru, Papari & Sandu, 2014).

## **7.5 Unanticipated benefits: The gift of cancer**

A paradox for a large number of the women was that their cancer experience temporarily isolated and alienated them from those who were healthy - family, work colleagues and social contacts - and yet those women also had the experience of becoming acutely aware that BC offered an undeniable opportunity for change. The women's comments confirmed a heightened desire to live a meaningful life. New-found strength was cited as an emergent 'gift' from traversing BC. This 'gift' was manifest in the theme of appreciation for their own resilience and ability to be 'strong' throughout the trials of the life-saving medical treatment regime.

An outcome of having a serious illness has been found to be a greater appreciation for life as well as for close personal relationships (Sears, Stanton, & Danoff-Burg, 2003). One specific area of unanticipated benefit, reported in comments from a large number of participants in this study, was that they had come to appreciate how emotionally and physically strong they felt as a consequence of having had BC. Several went so far as to say that having the disease had saved their life. They reported that realisation of their inner strength came from successful endurance of the immensely potent rigours of treatment for BC. That strength appeared to have come, in part, from the lived experience of having been able to exert some personal power over the outcome of the disease. In part, the emotional disturbance wrought by BC seemed to act as incentive to catalyse dormant psychological processes that would, of necessity, override fear and distress, and privilege survival.

Participants felt that their survival was positively affected by their adherence to the initial treatment process, to medication regime, and loyalty to a healthy lifestyle. They were clear that they would not want to have a recurrence of cancer as a way to gain personal growth. However, their interpretation of having received a benefit for their life echoed findings from literature on Post-Traumatic Growth and BC (Casellas-Grau et al., 2016; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009). The feeling of having received 'benefit' from BC came from having received support from their medical team, from BC care professionals, from family, friends, and from others who may not have been part of their life up until the time of diagnosis. The majority of participant survivors in this study had children who were

teenaged, or early adulthood, rather than children who were infants. One important finding was that all the women who participated in this study would likely be assessed as being in a reasonably stable financial position. This was evidenced by the fact that most of the women were able not to return to paid employment unless they chose to do so for their own wellbeing.

Overall, participant interviews signalled that a significant number of the women had come to accept BC as a valuable opportunity to reinterpret their minds and their bodies in ways that felt more empowering for their life. To capitalise on that sense of empowerment, self-compassion-focussed psychosocial interventions could be routinely included in post-BC treatment care. To do so could bring a way to circumvent any tendency to return to pre-BC habits of self-relating.

#### **7.6 Personal Reflection Program sessions**

The PRP sessions offered the women a space in which a different relationship with themselves could be explored and entertained. In those sessions the disease was not afforded power to define who they were. Observations of their engagement in the PRP sessions indicated the women welcomed curiosity about who they were as a whole person. In particular they were able to recognise social pressure related to gendered appearance of the female body. Of the women in the PRP sessions whose BC resulted in a mastectomy, only one had made the decision to have reconstructive surgery.

There was an overall awareness about maintaining fitness and good health. BC had meant taking charge of their wellbeing and their lives. From the group discussions came growing awareness of ways in which they had not exerted their own authority before BC. Curiosity about what being a woman would mean from this moment in time forward was something they laughed about, discussed, pondered, and reflected on in the PRP. Curiosity that was related to their suspicions about precursors to their BC, the disease progression, and what external ‘add-ons’ would indicate power over BC was discussed. There was an expressed desire to step forward into a renewed self physically, emotionally and spiritually.

The expressive-creative arts activities which supported the PRP, helped women detach a cloak that may have previously covered any silent, inner identification of self as a cancer survivor. Therefore, the group quickly assumed an identity other than that of helping each other through the defining life event of BC (Husebo, Karlsen, Allan, Soreido, & Bru, 2015; Spira & Reed, 2003). In the small group context it seemed the eight women began to redefine themselves as lively and interesting women first and foremost. Additionally, meeting as a group that discussed a range of facets of life – other than illness - helped locate and contemplate future directions they wanted life to take. As a group they took time to experiment with ideas about how they wanted to design their future from this current point in time. This redefining of themselves as a person was a central topic rather than the discussion remaining recovery-oriented or problem-focused.

Research into creative psychological interventions such as Supportive-Expressive Group Therapy that included hypnosis had been used to explore pathways to relief from emotional distress and pain for women BCS (Butler et al., 2009). In addition, Art Therapy (Svensk et al., 2009), Mindfulness-Based Art Therapy (Jang, Kang, Lee, & Lee, 2016) as well as group exercise and supportive group psychotherapy (Martin, Bulsara, Battaglini, Hands, & Naumann, 2015), Music Therapy (Lesiuk, 2015), and Dance and Movement Therapy (DMT) had been found to provide relief from emotional distress. The PRP sessions devised for this study involved experiential creative-arts-based exercises as a way to cultivate and practice self-acceptance within a group setting where receptivity to the other was intentional and non-judgmental (Aguirre-Camacho et al., 2017). Experimentation with flexibility in their attitudes towards self, while experientially making close ‘contact’ with their innermost thoughts and feelings was met with intensive listening from the group. The support experienced in the group provided a path to integration of physical, psychosocial and spiritual needs. The group process facilitated opportunities to explore and revise ways to effectively cope with stress (Koraleski, Ryan, & Carlson, 2014).

What this meant for participants who completed the PRP was that they came to the initial group without prior understanding of how expression of their emotional state, or their hopes for the future could take place through an imaginative, creative

process. As could be expected, participants had not previously had any introduction to the concept that their personal artistic expression could so easefully produce information about an envisioned or hoped-for autobiography. Awareness was low that painting or drawing something, or creating an image with miniatures, could spark self-interest and nurture hope and encouragement. Over the course of the group interactions there appeared to be reduction in the avoidance of emotion-laden cancer-related content in their thoughts and feelings. Cancer did not dominate the conversation, nor was it avoided; the topic of cancer had a place in discussions but was not the topic that captured most of their emotional involvement during the group sessions.

The women who engaged in the PRP sessions seemed to be those participants who exhibited the strongest desire to be of help to other women diagnosed. Their motivation to be a help to other women connects to the theme of giving support and emerged from their own move to make their lives more meaningful in which needs of self and needs of others could be relativised. This meant that needs of self and others were weighed up from a place in which self-knowledge and awareness informed decision-making about any course of action. Reciprocal 'actions' for support received was a hallmark of their discussion about life in the immediate post-BC phase of life. The comments about helping others related to the theme of giving and receiving support. Once they no longer regarded themselves as having BC, the women continued to find comfort in being able to give back rather than to allow themselves to continue being the receiver of kindness. Allowing themselves to receive without an urge to repay a kindness was being cultivated, however, to completely re-position themselves as able to accept kindness, without feeling some guilt or fear, was not yet realised.

In those reflection sessions the expressive arts activities meant the women were able to be free to be with each other in a natural way and enjoy each other. They came to experience mutual trust and respect through the inevitability of being vulnerable as they talked about their hopes, dreams as well as short and long-term plans. Rather than critical self-judgment that might have resulted in a reluctance to openly discuss feelings and ideas for their life for fear of being considered irrational, over-emotional, or selfish, participants in the PR sessions expressed openness to

wanting to be more creative, to a desire to be more self-caring, and motivation to feel more empowered about their lives.

In the time spent together in the PRP sessions what became apparent was a mutual trust and respect that was obviously solidified by a shared history of surviving BC. Beyond that initial trust and respect their group sharing indicated the relationships that mattered most to the women were those in which there was a sense of emotional freedom and reciprocity, natural openness, and an easeful giving and receiving of loving care.

Interviews with the women participants, the OtSC sessions, PRP sessions, as well as interviews with the significant others, revealed aspects of themselves that had the potential to impair or interrupt a coming to terms with women's patterns of self-relating. Participants in the OtSC and PRP spoke in terms of lifelong habits of 'veiling' their needs. These themes were also characteristic of interviews with women participants who attended an interview only. Self-care strategies were often related to regaining a sense of external physical attractiveness along with reduction in the fear of recurrence rather than revising an intrinsic state of self-valuing.

One of the women in the group had attempted suicide post treatment as her only way to relieve desperation at no longer feeling as though she fitted into a world that seemed not only to have forgotten her but rejected her attempts to reclaim a place of value and meaning. Her expression was of very real and genuine emotional pain and suffering. Her depression was profound and was experienced almost viscerally by others in the group. In the final PRP session, while her depression appeared not to have lifted significantly since the first OtSC session, a drawing created during the final PRP session was interpreted by her as an indication of new growth and hope for the future. Many of the images this participant created as her response to the experiential activities could be interpreted as depicting growth, colour, optimism and courage. Yet, the descriptions used when she shared the meaning of her drawings seemed not to have reached a sustainable conscious awareness. Positive self-statements in her responses to expressive activities were short-lived and, as would be anticipated in a state of depression, any feelings of optimism were constantly overwhelmed by hopelessness and negative rumination. In

response, the group was caring and supportive, and offered a safe, listening space in which she could openly express intensely experienced feelings without fear of judgment, expectation, or invalidation.

Each of the women became able to nurture a greater sense of self-kindness by focusing attention on her unique response to the activity-based exercises. Group sharing following an activity meant each person could talk about their values, their attitudes, what mattered to them, and their beliefs about life and what life meant for them. Simultaneously, for those listening as each person's shared those personal insights, there was a modelling of being able to contain difficult feelings and be comfortable in the discomfort that engendered.

One participant who at the start of her involvement in the process for this study felt confident she would not be a person who would engage in or need emotional support gave a telling comment on the last day of the final PRP group. On that day she mentioned to me that if we had 'done' the groups and expressive therapies activities at the very start of the project more extensive and even deeper reflection would have been forthcoming. Unfortunately the limited number of times we were able to meet in a group context within the confines of this study meant the growth that had begun could have used more time to flourish. At the end of participation in this study five of the women continued to meet monthly to offer emotional support and nurturance to each other.

What the women were able to nurture in themselves was a greater sense of balance about the meaning and importance of things. They realised that they neither needed to conform with or rebel against the status quo they had been faced with as young adult women. The result of the shift was that rather than being the nurturers - the ones who gave nurturance to others and took on the role of providers of love and care for their families and significant others - BC brought with it an unanticipated impetus to relinquish that role.

### **7.7 Participant observation from the OtSC and PRP**

The role of participant observer was adopted for the OtSC group sessions in addition to the PRP group sessions. Participant observation as a methodological



framework for these two aspects of this study was chosen because of the insider-outsider role the researcher played as facilitator for both of these phases of participation. The 'insider' role allowed feelings of connectedness to develop between participants and myself as researcher. The assumption was that given the sensitive topics being discussed the feeling of connection, trust, and being emotionally 'held' would be critical for meaningful dialogues to be shared. My professional background is in counselling, and this meant relationships between the women, and between the women and myself could be managed without my becoming over-involved or over-identifying with feelings expressed. The outsider stance was maintained through non-participation in any of the experiential activities. My role as facilitator, and one of standing 'outside' of the women's in-the-moment experiences, allowed me to stay separate from emotional engagement generated by the experiential activities. During the group sessions my background in counselling was surrendered as much as was possible, and the role of naïve observer adopted, so as to facilitate from a flexible and reflexive space.

The method of gathering data involved observing and participating (as a facilitator) in the group sessions allowed access to more explicit insight into the lived experience of participants. Observation in this instance was not the major source of data generation but provided an otherwise unobtainable insight into the beliefs, attitudes and behaviours of the participant survivors. Facilitation and observation of the processes gave a sense of being able to 'stand in their shoes' for a brief time (Alase, 2017). While it had been anticipated that video-taping and audio-recording would be possible, survivor participants were explicit in their request that the sessions not be recorded in any form apart from some notes I could make along with photographs of the images they created in response to activities offered.

## **7.8 Relevance of self-compassion: Finding self, saying no**

The relevance and benefits of a kinder more nurturing relationship with oneself, in the face of the challenge of BC, becomes evident when considering the potential to be proactive in developing adaptive responses to living with this disease (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2014).

Shifting from placing others first to thinking of self did not mean that the women came to ignore or deny the needs of others. On the contrary, they reported continued care that nurtured family and friends in the ways they had always done. The only change was that their choice to actively give to others was one that was now a more conscious choice. This shift to conscious choice stood in contradiction to previous giving as a way not to be judged as selfish, unkind, or feel helpless in the face of someone else's stated needs.

The women talked about how they now felt more able to give voice to their particular needs and more often attend to their needs without grief or guilt. In essence, they had begun to put themselves 'in the picture'. BC had removed some of the fear that had previously influenced their relationships with self and others. One way in which the women had begun to relate differently was in acceptance of themselves no longer being the person who would repair relational disharmony for their loved ones. To achieve this many of the women found that they had begun to set limits on the extent to which they would advise, support, and extend themselves. From comments made during interviews it was understandable that, as with physical healing, it was taking time to live into a revised personal post-BC narrative with the vision of themselves as independent of pre-BC patterns of behaviour. To do so meant acceptance of the opportunity for change in self-awareness and self-love, as they embraced the new vision of themselves as a BC survivor.

While the challenges experienced in adaptation were spoken about by each of the women, it was helpful to remember they were situated within wider family, social and cultural contexts. This meant that some women talked about their experience and their understanding of SC through the filter of what being self-compassionate would mean for their family. Some needed time to think about and reflect on the implications of being self-compassionate before they felt ready to share their interpretation of the term. Others openly admitted to not knowing what the term meant. Mention of SC exposed acknowledgment of the interest and desire for change, that paradoxically for many of the women was mixed with a pervasive concern about being judged as selfish. To be labelled as 'selfish' was anathema for women survivors.

## **7.9 Significant others and the shared journey**

The men who participated in this study found that BC brought a state of psychological unrest to their lives. There is evidence to suggest that it is important for men affected by cancer to receive counselling support (Banks, Pearce, French, Lloyd, & Lewis, 2017; Chronopoulou, Sakkas, & Damigos, 2016; Love, Thompson, & Knapp, 2014). In order to be able to provide optimal assistance to couples it is helpful to understand the ways in which men react and adjust to women's BC (Baucom et al, 2012). To understand women's adjustment to BC it is also critical to understand the interactivity between their emotional state and the emotional response of their partner.

A range of themes extracted from interviews with 3 men indicated that a significant other (SO) in the life of a woman BC survivor faces an exponential rise in the complexity of their relationship with the survivor (Love et al., 2014). In the first instance the men in this study told of the shock absorbed by themselves and their wife with the diagnosis of BC. They experienced intense, sudden grief, but also felt as though they had to accept a role reversal when it was apparent they would become, temporarily, the primary caregiver in the relationship. It was clear from the men's stories that they too had experienced significant emotional disturbance with feelings of grief, fear, anger and anxiety. However, they each talked about their first focus being "getting my head around" what was happening and what practical aspects of life needed attention. The desire to keep family life as functioning normally was a key drive in two of the husbands and this was reflected in the theme of disorganisation and unrest.

Despite an acute awareness of the perilous situation confronting their partner, the SOs had not sought, or not thought to seek, counselling support for themselves as a way to alleviate the significant strain they were under as a couple. In line with the second theme of 'being the strong one', the SOs support-seeking beliefs and behaviours that they should be the strong one to offer help to their wife were heavily influenced by cultural expectations of what it means to be male. This finding was consistent with the results of a study by Love, Thompson and Knapp (2014) that found men whose lives are affected by cancer found it difficult to ask for help.

The eighth theme summarised the men's comments about emotions – theirs and their wives'. Consistent with the conviction about staying strong (Theme 1), keeping things normal (Theme 3), and paring life back to the basics post-BC (Theme 11), the absence of finding opportunities to openly express their emotions meant SOs felt the only remaining choice was to internally enclose their feelings and carry on. This meant the men in this study identified no acceptable avenue for them to speak about their experience as a way to facilitate their own adjustment to BC. The men's emotional reactions to their wives' BC also interacted with the way in which their wife responded emotionally to the diagnosis and treatment (Baucom et al., 2012). The wellbeing of the partnership was subsequently tested when their wives' physical symptoms were at their most intense.

Each of the men became hastily aware of the disorganisation BC would bring to their partnership and to family life. The specific tensions and worries the men did not reveal to others combined with fear of what the future might hold meant they experienced high levels of stress and anxiety. Comments about initially feeling chaotic and disorganised as the SOs tried to restore some sense of order in daily living is consistent with the findings in a study into Iranian men's adjustment process to their wives' BC (Nasiri, Taleghani, & Irajpour, 2012). However, despite elevated levels of stress the men opted to rely on their usual strategies for coping with stress. What stood out from data that emerged from interviews with SOs was the way in which each of them drew heavily on their professional training to help them navigate the complications that BC had brought. This was interpreted as their most available resource to regain a sense of control over life that their wife's diagnosis had temporarily denied them.

Women with BC generally have positive interpersonal relationships that help them cope with the effects of the disease (Kayser, Feldman, Borstelmann, & Daniels, 2010). Husbands talked about their fear that the cancer would return at some future point, about adapting their work life, doing a juggling act to meet and prioritise the needs of their wife, the family, work, and caregiver tasks with their own needs. Many of these tasks were familiar to their wives but highly unfamiliar to their husbands. The SOs talked about putting their particular emotional needs on hold in order to concentrate on maintaining a sense of normality.

In this study Theme 5 highlighted that the husbands were highly supportive of their wives. They had enjoyed a positive relationship with their partner. It was therefore understandable that BC was regarded by the SOs as a shared journey, not one person's journey. This experience of constancy and commitment in their relationship during the BC experience has previously been found to be a buffer against poor emotional adjustment in women BCS (Kayser et al., 2010). The men in this study wanted to be present to their wives' illness and wanted to be supportive. This attitude was in line with one of the findings in a study by Pearce (2001).

One challenge posed for the male partners in this study was how to 'stay with' the ambiguity and uncertainty they realised they were likely to face over many years of their wives' survivorship. Their comments reflected the absence of prior 'training' that would help them feel better prepared to provide emotional support to their wife and to themselves across the long term. Communication within families about BC was a new challenge for the SOs. They developed plans for action as a mechanism for coping with the pressure of the unfamiliar role they now fulfilled. In concert with the findings by Pearce (2001), two of the SOs in this study temporarily suspended maintaining their focus on the family as a way to keep going. Although they soon returned their 'gaze' to the family, the strain they felt during the first months of their wife's illness left them overwhelmed and unsure of how they would manage if the worst happened.

BC brought one couple closer together whereas for another husband and wife, the depth of her depression post-BC introduced unanswerable questions about how the future might unfold for them as a couple. The death of his wife - for the third couple - led one husband into acute contemplation of ending his own life and ultimately to a questioning of his construction of self-identity. Theme 10 discussed SC and what it meant for the men. Similar to the women in this study there was the suggestion of concern about SC because of the myth that to be self-compassionate was akin to selfishness. The male participant whose wife had died from BC was the one who seemed to have a clearer understanding of SC. He talked about SC as being "authentic" in his relationship with himself as well as in his connections with others.

Several questions confront a socially constructed Self when reflecting on living with authenticity. Those questions revolve around what it means to be authentic, and what, for each individual, would it mean to live an authentic life. The self the SO's 'knew' of themselves and their wives was deconstructed by BC. In the interviews they each talked of an inevitable confrontation with the question of who they would become as a result of changes to the self known up until this point. The turning point of a life-threatening illness had sowed the seed of doubt about whether the life lived up until that moment was in right order for them to flourish, or was it an egoic fabrication, or wasted time.

Fear of compassion from others, fear of self-compassion and fear of importance to others has been highlighted in research by Joeng, Turner and Tracey, (2015). These authors pointed out Gilbert's (2009) assertion that "people fear compassion because they are afraid they will relive painful childhood experiences wherein they did not feel the compassion they so desperately needed" (Joeng et al., 2015, p. 454). Fear of being self-compassionate has been linked to habits of self-criticism and a fear of diminished motivation to achieve (Joeng et al., 2015). The inner struggle between treating oneself with kindness as opposed to a stern and often contemptuous attitude toward one's own actions and feelings was an issue highlighted by two of the husbands. For both men there was a concern that echoed the perspective held by a significant number of the women interviewed. Their concern was that SC could become a useful pretence - a way to conceal selfishness. The fear of being judged as selfish presented the greatest roadblock to embracing the idea of self-kindness, or acknowledgment of the usefulness of bearing witness to unpleasant or difficult feelings.

Interviews with SO's indicated that their experience of BC meant each of them had unintentionally adopted a more compassionate stance towards themselves. Each of the SO's had initially felt challenged and confronted by the changes that came with BC. Their intimate contact with the disease and the domain of cancer survivorship led to eventual changes that each of them regarded as positive for their life post-BC. Without specifically focusing on the need or desire to be kinder to themselves, exposure to the emotional overload from that potentially traumatic event

had mediated a more moderate, mindful, and accepting relationship with themselves and others as they adapted to and met the challenge of BC.

Despite attempts to keep life normal they had each surrendered to the unanticipated power of BC to heighten their awareness of their unique interpretation of life. They began to question and release previous apprehension about emotionality being a sign of weakness. There was permission to surrender a certain amount of objectivity about relationships. Each of them had come to a turning point where a heightened awareness of their capacity to make informed choices became a strong guiding influence on their thoughts and actions. Any previously held fear that being authentic for themselves might result in lack of control over life, or separation from valued connections with people already in their lives, was able to be re-conceptualised. There was a re-evaluation of what had previously been prioritised, had held value, and been privileged. Qualities such as focus, control, and discipline had made way for their interactions to be equally informed by relational warmth and tending to self-nurturance. The conversations with the SOs pointed to previously unrecognised resources that could help them have greater tolerance for emotional distress. Rather than use busy-ness to avoid it, or alienate themselves from their own emotional responses to life events, the men came to a position of reshaping their relationship with their wife and therefore reshaping the way they related with themselves and others.

In summary, the reflections from the men on their experience of their wives' experiences pointed out the importance to include compassion-focused counselling interventions for couples who live with BC. The comments from the men also highlighted that in some partnered relationships there can be a deep but unspoken understanding of the suffering wrought in their partner through their partner's self-criticism. It appeared in the three men in this study that BC was the catalyst for them to accept their importance in their wives' lives. Importantly BC also brought an ability and willingness to re-prioritise life and to communicate to their life partner her contribution and importance in their lives.

### **7.10 Willing witnesses: Counsellors' perceptions**

Counselling for emotional distress has been found to be useful as a way to help dis-empower self-criticism and to improve psychological distress (Banks et al., 2017). The results from counsellors participating in this study supported the claims made by Banks and his colleagues that counselling was beneficial for the person affected by cancer. There was limited current research available that discussed the reflections of counsellors about the psychological needs of women post-BC or the perceptions BCSs held about self-compassion. A significant amount of research was devoted to counselling for risk factors such as genetic family history, or alternatively discussed the benefits derived from specific interventions, as well as discussing survivor's needs for counselling interventions.

The reflections revealed in discussions with the counsellors was consistent with research that found poor body image was more closely linked to mental distress and impairment in the quality of life for BCS (Falk Dahl et al., 2010). The counsellors' comments were also allied to findings in research from Crompton (2003) about the importance for women to be provided with a safe 'space' in which they can be supported to reconceptualise their relationship with their body. However, comment was made that with the older BCS body image was not observed as particularly significant for mental wellbeing. This could be taken to refer to the physical attractiveness that women survivors may surrender as they age. In relation to body image concerns, the counsellors perspective was not supported by ideas from current research that outlined a broad array of personal responses woven into the concept of 'body image' for BCS and the critical need to monitor, assess and evaluate body image concerns (Fingeret, Teo, & Epner, 2014). Working to help decrease a tendency to cope with BC through disengagement with their emotional life meant the counsellors paid attention to finding ways to manage intrusive negative thought patterns and ways to support the integration of head, heart and reason was observed in comments made in several of the themes. The process of reconstruction of life was highlighted in the final theme extracted from counsellor interview transcripts. Statements made in relation to finding what held significance for a survivor and how they rebuild a meaningful life post-BC were related mostly to the perceptions of challenges faced by younger BCS as they negotiated return to



work, family commitments, and life stressors (Pudrovska, Carr, McFarland, & Collins, 2013).

One of the most important themes to emerge from conversations with counsellors interviewed for this study was their positive sense of the intrinsic value of offering psychological support for women survivors of BC. In addition to voicing their concerns for women's wellbeing in survivorship, the quest to provide quality counselling for BCS meant that the counsellors sought to understand the deeper psychological effects of BC. The counsellors expressed an existential issue that was reflected in the first theme – that of their professional desire for survivors to find a way to openly express their cancer-related concerns without an overriding concern for others' reactions.

Related to that first theme was the significant finding that the counsellors considered their work a privilege in a profession that afforded them the opportunity to bear witness to another person's life-death struggle post-BC. The counsellors wanted their work to activate and inspire women survivors to re-examine long-held beliefs and attitudes towards themselves. For example, in the second theme one counsellor talked about not wanting to 'band-aid' the emotional difficulties breast cancer generates. The devotion to providing for the psychosocial wellbeing of BCS Although all three counsellors interviewed supported women BCS with differing foci, each reported motivation, enthusiasm, and passion for their work.

Themes overlapped and presented an overview of the interactivity between counsellors dedication to their work, their robust commitment to helping BCS, awareness of the existential issues facing BCS, and the work of self-care. Self-care was particularly pertinent for facing the varying dimensions of distress exhibited by BCS. The counsellors were tasked with being able to sit with a survivor and manage their own reaction to a narrative shared by a client. The counsellor herself may have had BC, or a close relative may have died from the disease. These possibilities could mean feelings of vulnerability in a counsellor would be heightened. Being with survivors who talked of repetitive cycles of fear, negative self-evaluation, and feelings of disempowerment was discussed by the counsellors who admitted to experiencing personal challenges to their values and beliefs. This was especially so

when confronted by a terminal diagnosis in one of their clients. In addition, balancing the different needs of family members who attend for counselling, as well as finding language to communicate with survivors and their families about cancer in ways that were appropriate, sensitive, but clear, were discussed as needing focused attention from the counsellor.

Counsellors perceptions of their clients understanding of the difference BC made to their body and their life was reflected in the theme about a process of emotional healing and physical recovery taking time. Reflecting on the impact of physical changes as a result of either surgical treatment and scarring, loss of hair, or other after-effects of BC, the counsellors spoke of the contradictions inherent in survival. The theme about 'being real' highlighted the psychological relief women felt, and the rapid movement to feeling physically well once again when treatment was completed. That same theme exposed the torment some women experience at the loss of their breast/s, and the trauma inherent in visually reviewing the surgical scars to a precious part of their body.

The counsellors comments about their reflection of BCS limited understanding, or integration into their personality, of self-compassion, echoed findings about the desire for, and fear of, SC (Pauley & McPherson, 2010). The counsellors reflections included wondering about whether the fact that the idea of SC may initially run contrary to pre-existing ideas a BCS has about the advantages such a 'construct' would have for emotional wellbeing and reclaiming of personal vitality, as well as the disadvantages from being thought of as selfish or self-centred. Reports from their conversations with BCS indicated that the difficulty lay, to some extent in the women's grief and guilt that having once been the source of happiness for their family, they were now the source of stress and [implied] unhappiness.

Overall, the counsellors reflections were able to provide significant insight into and reinforce findings from interviews with women participants in this study. While not referred to using the same linguistic terminology, both counsellors and women participants spoke in general and in specifics about the hopeful search for a personally meaningful life in survivorship, and the accompanying disturbing conflicts that come from living with BC.

## 7.11 Chapter summary

In this study each of the participants was the narrator of their experience of BC from the point of view of experiencer, significant other/observer, and supporter. As a researcher the opportunity to uncover their descriptions and peer into the interpretations given by each participant allowed me a sense of being able to enter into each of their worlds and experience it from what Carl Rogers (1951) referred to as an ‘as if’ experience. The themes identified in each of the three groups of participants lead firstly to an improved understanding of strategies that had been adopted as self-regulatory mechanisms. Secondly, deeper exploration of the themes provided insight into the potential for SC to be included as a therapeutic intervention to support survivors of BC to maintain awareness of, safely explore, and understand their emotions.

The ‘place’ of beginning this discussion was the intention to explore and identify the current situation regarding self-nurturance prior to BC and whether that resource had been activated in BC survivorship. The intention was not an attempt to identify personality factors as a significant factor in the development of BC. The ‘ending place’ has been to identify a) how participants related with themselves in the past, that is, the stage from which they are emerging, b) their present relationship with self, and c) the stage toward which they are moving. A review of all three stages was believed to help distinguish the style of self-communication and whether SC could be a relevant support for BCS. The influence of unresolved personal issues was reflected in comments made by all three groups of participants. Self-compassionate communication was identified as something desired because it carried personal ‘rewards’ that might foster gentle, mindful attention to physical sensations and psychological adjustment. However, that same resource was viewed cautiously, in part, because of implicit memories of rejection of individuality by self or another. SC was identified as a resource that would likely move forward with personal growth through the existential challenge for BCS of finding who I am and who I am not.

With the intention to explore what it meant to live as a survivor of BC, relevant research questions were posed to women survivors of BC, significant others and counsellors who worked with women with BC. The questions called for reflection and consideration of what clinical practice might contribute to enhanced

emotional wellbeing (EWB) for women survivors as they age. The experiences reported by all three groups of participants highlighted the relevancy and usefulness to continue to explore how the practice of, and training in, SC for the profession of counselling can reach out, and into, women's experiences of living with the after-effects of the disease. The discussion of the findings question whether integration of the aspects of SC such as noticing and staying present to difficult emotions, could help BCS enjoy feeling more contented and connected within themselves, and endow a positive, nurturing effect on the self-relationship. The findings bear out that effort and practice is needed to adopt a caring orientation toward self, to stay present to oneself, be accepting of self, and see life in a bigger picture.

This research has been one way of aiding evolution of current authoritative knowledge about a well-reported and well-researched public health issue that can define the identity of a survivor from initial diagnosis until the end of life. Between the beginning and ending points for this study the 'adventures' of philosophical discovery and psychological realities also promoted clarity about the ways therapeutic interventions can provide extended emotional support for people faced with the immensely potent rigours of treatment for BC that is followed, for many, by the perseverance required to navigate survival.

## Chapter Eight

### Relevance of self-compassion for counselling

#### 8.1 Overview

“Ribbon awareness”, especially the pink ribbon movement has brought hyper-visibility to BC (Bell, 2014; Sulik, 2011). However, benefits survivors might receive from this heightened public profile need to be measured against the potential for invisibility of struggles some BCS encounter in daily living (Koczwara & Ward, 2015; O’Keeffe, 2004). Those struggles relate to efforts to maintain both a healthy physical as well as a healthy psychological self. Maintenance of a positive self-relationship becomes paramount at a time when intense connection from medical support has diminished and a BCS seeks to re-establish themselves in a social world unaffected by cancer. Establishing restoration of a pre-cancer self, can be a challenge for women who experience pressure to comply with the performance expectations in socially dictated roles of wife, mother, caretaker, and nurturer (Hesse-Biber & Leavy, 2013; Sulik, 2011). In addition, the culture that surrounds BC in Australia means BCS carry mean women perceive they are responsible for taking steps to care for their health through diet and exercise, in the hope that this will limit the chances of recurrence. Survivors are may also feel responsible for finding the personal endurance to survive, regain their femininity through accepting and following examples modelled, and strive for a return to the ‘normality’ of their pre-BC life (Gibson et al., 2014).

Although an optimal approach to the care of psycho-social needs of BCS may not yet have been clearly formulated or universally accepted (Halpern et al., 2015; Howell et al., 2012), awareness of the extent of variables involved in health care for BCS means the spectrum of treatment and recovery currently reflects more of an holistic 21<sup>st</sup> Century perspective (Brennan & Houssami, 2011; Geffen, 2010; Rettger et al., 2015; Reyes, 2012; Rowland, 2008). In addition to improved clinical outcomes

to BC, emergence of a coordinated, and refreshed, care etiquette for BCS calls for consideration of support for the whole person (Geffen, 2010). Ideally a BC care approach to psychosocial needs and EWB would combine an interest in physical, psychological, social and spiritual wellbeing of BCS (Ben-Arye & Visser, 2012; Carlson, Speca, Patel, & Goodey, 2004; Dodds, 1999; Howell et al., 2012; Koithan, 2009).

Psychological factors that impinge on physical and psychological well-being have been well-researched in relation to BC and quality of life for a survivor (Fallowfield & Jenkins, 2015). In addition the genesis and incidence of post-BC depression and anxiety have been extensively documented (Burgess et al., 2005; Deshields et al., 2006; Enache, 2012; Hanchate et al., 2010; Hill et al., 2011; Hopko et al., 2015; Kvillemo & Bränström, 2014; Reich et al., 2008). What stands out from a variety of studies is an overall desire to positively support an uncomfortable transition and improve quality of life for BCS.

The data gathering process for this thesis involved collection of information about the experience of ensuing complexities of the self-relationship post-BC. Collection of the narratives of BCS involved personal interviews in addition to, for some participants, engagement in OtSC sessions and a Personal Reflection Program. The valuing of open-hearted self-care for their own emotional and physical well-being presented itself consistently as a quality to life that the women sought, or at very least, felt was highly desirable.

The actual dialogues with participants were interpreted as suggestive, however, of a 'return', after initial treatment, to less than healthy habits that could be viewed as reflection of learned inclinations toward less-than-compassionate self-relating. The emergent indications were that influences of past relational and attachment experiences continued to dominate the self-relational aspect of life. This return to habitual patterns of self-relating was something that seemed to call for particular attention. Each of the women spoke optimistically about the likelihood of a lengthy survivorship. None of the women had, prior to participation in this study, chosen to engage in any personal development. Their focus had definitely been on physical survival. The question this thesis sought to explore was, in part, the

contribution of counselling with a self-compassionate focus as a way to nurture self and improve overall survivorship experiences for BCS across the long term. It was hypothesised that in the evolving ‘landscape of survivorship’ SC could sustain emotional resources needed to contain negative feelings evoked by unwanted remembrances of the treatment regime. Similarly, there was a question about fear of cancer recurrence and whether training in SC could provide relief from what might have been a lifelong pattern of ruminative coping.

The public perception is that there is awareness and understanding of the ‘common-sense notions’ constituting the central concepts of both counselling and SC. The direction of SC is to be self-forgiving, to kindly acknowledge one’s humanity, as well as allow oneself (and others) not to be perfect (Neff, Kirkpatrick, & Rude, 2007), promotes a balanced attitude toward the self, and especially self in relation to others (Hall, Row, Wuensch, & Godley, 2013; Wegdan, 2012). Importantly, while large numbers of people may claim to be aware of the basic tenets of SC, the practice of being self-compassionate can slip away when adversity challenges emotional equilibrium. What this generalised ‘awareness’ and generalised ‘emotional amnesia’ highlights is that while the concept of self-compassion may be reasonably simple to explain, and the ‘doing’ of SC comfortable to embrace at a cognitive level, the ‘being’ aspect of SC takes time and practice (Desmond, 2016). SC calls for both practice and engagement and requires a willingness to become exquisitely aware of all aspects of ourselves without comment from a self-critical internal ‘voice’ (Desmond, 2016).

As a profession, counselling requires a practitioner to be able to understand a client’s suffering and their loss of control (because of BC), and at the same time convey nurturance and a deep sense of compassionate caring for personal and environmental stressors clients face (Corey, 2015). Significant benefits as a result of psychosocial interventions such as counselling means when confronted with intense emotional reactions to either past remembrances or future fears a woman does not find herself standing alone in the face of overwhelming emotions.

Of therapeutic endeavours it would be safe to say that “most therapists assume that compassion is an important part of psychotherapy” (Germer & Neff,

2013, p. 856). Importantly, research findings into the specific concept of self-compassion have unequivocally indicated that kindness to self, capacity to tolerate difficult feelings without over-identification with those feelings, and embracing a 'bigger picture' perspective of life challenges can be a predictor of mental health (Neff et al., 2007, p. 909).

Routine, ongoing care for BCS now requires that psychosocial care be well integrated into a perspective that shifts the focus from “how long to how well patients live” (Fallowfield & Jenkins, 2015). Part of the problem may be lack of a “generally accepted definition of what constitutes good-quality counselling” (Kaakinen, Kyngäs, & Kääriäinen, 2013, p. 2705) that is offered beyond crisis counselling, offered either at the time of diagnosis or in the time when medical treatment has been completed. In addition there is also a lack of acknowledged processes for assessment of the quality of counselling provided to chronically ill adults (Kaakinen et al., 2013, p. 2705). The presence of a person trained to be able to listen and provide emotional support is important for BCS. Post-treatment for BC a survivor may have used up all their available physical and psychological resources or may not have in place available social supports (Bohart & Tallman, 1999). The implication and relevance for counselling is a challenge to the notion that the process of re-educating a mind to think differently is the most effective way to have a person make clearer life choices and take action steps.

What this means is that provision of individualised client-focused care for emotional needs of a person with a chronic illness requires skills, knowledge and understanding of “when [patients] are psychologically ready to make changes and to encourage changes at a pace that suits the [‘patients’] needs” (Gambling & Long, 2010, p. 225). Even in its simplest version, however, good quality professional counselling, as a process for psychosocial wellbeing for BCS, would be expected to support a qualitative shift that offers a survivor the ability to carry their experience of BC less heavily.

Counselling with self-compassion as a key ‘resource’ means that a BCS can adopt the skills of giving affective nurturance to themselves through self-caring actions that become part of life. Bringing SC as the basis to help shift a woman’s



emotional proximity to her BC experience means that event can be safely explored in a way that will enhance rather than detract from her quality of life. Self-kindness and the skills of SC are then tools for living that can support the post-BC woman to psychologically create a place of “inner safety and refuge” (Germer & Neff, 2013, p. 866).

To be self-compassionate would stand in contrast to sporadic engagement in self-care or self-nurturance, isolated to a time when BCS regard themselves as ‘ill’. Cultivation of SC, over time and with the support of counselling that seeks to promote an increased desire for wellbeing and a capacity to proactively make changes in life, makes SC highly relevant for counselling BCS.

With regard to cultivation of a more self-compassionate way of relating with self and the world, engagement with counselling can support development of ‘inner life skills’ (ILS). Development of ILS has been hypothesised as a perspective or attitude towards oneself that can favourably influence restoration of a diminished, or lost, self-communication as well as foster a ‘self-connected’ mindset (Pearson & Wilson, 2009). In contrast to a technique-driven approach, connection with one’s ILS makes a therapeutic approach highly compatible with the core principles of SC.

The potentially active component of ILS is the notion that deeper awareness and understanding of our emotional state positively aids attempts to solve challenges that arise in social living (Keltner & Haidt, 2001). The notion of ILS supports regarding a client’s capacity for [emotional] self-healing and self-regulation as an integral part of a counselling process (Bohart & Tallman, 1999). Contact with emotions in a non-judgmental and self-reassuring way has been found to predict improved mood, develop authoritative self-knowledge and at the same time generate self-kindness and self-comfort (Odou & Brinker, 2014).

The idea behind development of ILS is not to find ways to avoid any unpleasant realities of life, but rather to create a mindset that is open to both the joys and pains of life without getting lost in, or overwhelmed by, either perspective (Pearson & Wilson, 2009). The corollary of self-connectedness has been found to be reduction in negative affect and improvements in coping with difficult emotions

(Oudou & Brinker, 2015). This makes SC critical for managing side effects of medical treatment as the BCS transitions from patient to survivor. More importantly is the encouragement being self-compassionate brings as BCS encounter late side effects associated with BC. Additionally connectedness with self has been argued to foster more harmonious relationship with external social and emotional environments (Kristeller & Johnson, 2005; Reyes, 2012). Associations between the disparate elements of positive self and other relationships are depicted in Diagram 8.



**Diagram 8: Associations between elements of healthy relating**

## **8.2 Relevance of counselling and self-compassion for breast cancer survivorship**

The relevance of counselling and SC for BCS is that the unfolding of a natural psychological healing process, through active participation in their therapy, can be extended with provision of a client-focused, pluralistic approach to counselling (Cooper & McLeod, 2011). In practice counselling sessions would be tailored to suit an individual survivor's readiness to engage, their current emotional needs and level of distress tolerance, and consideration of whether anticipated outcomes are compatible with their lifestyle (Pinto-Gouveia et al., 2014). Tailoring therapy so that it includes an intervention that can promote self-acceptance and self-forgiveness is likely to enhance the effectiveness of counselling for BCS.

One significant aim in counselling support for BCS would be to avoid 'difference blindness' (Smith & Shin, 2014). In the case of BC, difference blindness refers to assumptions that women survivors of BC would, in general, benefit from a

therapy that was identical in technical style, and created as a formulated, manualised approach. This means that while survivors will have commonalities in their psychosocial needs, the expression of that need may be different in each person. This may call for revision of how the psychosocial needs of women survivors of BC are interpreted and understood within clinically-driven environments.

SC as an important emotional regulation strategy is foundational to communication guided by a frame of mind that “enables one to clearly observe one’s experience of the present moment, whether positive or negative and to be mindfully aware of one’s maladaptive patterns of thought, feeling and behaviours” (Pinto-Gouveia et al., 2014, p. 312). This holds potentiality for times when BCS feel confronted by “painful life situations that may be outside [their] control” (Neff & Germer, 2013, p. 856). With SC as the ‘backbone’ of a therapeutic process, BCS can gain a sense of connection rather than isolation in their suffering. Understanding and practicing the concept of seeing life events in a ‘bigger picture’ along with the habit of self-nurturance when recalling difficult emotions can provide a ‘safety net’ for in-session exploration of intense emotional pain.

Being able to access a state of SC leads to a deeper sense of connectedness with self (Desmond, 2015; Neff & Germer, 2013). To be self-compassionate has also been found to be a “defense strategy from emotional pain through self-nourishment” (Gerber et al., 2015, p. 399). Gerber and colleagues (2015) suggest that counselling that significantly fosters self-kindness and an attitude of self-nourishment could offer BCS a corrective experience that would positively offset a sense of aloneness and isolation in their suffering.

### **8.3 Counselling for breast cancer survivors**

Cancer challenges a person with a ‘double-edged sword’. On the one hand the person is confronted with the fact that life is limited and at the same time the person has the opportunity to evaluate their life and to choose how to live their future (Vos, 2015, p. 886). Counselling for BCS requires a professional to locate or devise interventions that can help a woman integrate the experiences of facing mortality, being opened to the reality of their life, and the opportunity to re-build a life with new meanings (Keitel & Kopala, 2000).

There are two critical aspects of counselling that a BCS may not have in her everyday life. In the first instance counselling offers a supportive interpersonal relationship that provides the opportunity to think about past, present and future together with another human being. Essentially this means time spent with a supportive other can help mobilize hope and renewed optimism. Secondly the therapeutic context provides a beneficial ‘workspace’. In their daily lives BCS may not have a time, place, or emotionally safe space to focus productively on what has happened and how they want their future life to be (Duncan et al., 2010).

Relevant for counselling is the self-care story a woman may have woven for herself. This life narrative may be one created as a way to survive adverse earlier life circumstances, or to cope in the face of previous experiences of hardship, neglect, or abuse. Additionally, the social convention has traditionally regarded women as the ones who devote time and energy to caring for others. Time and energy can often be given, but this giving may be at the expense of a woman’s own physical and mental health.

A range of rational reasons may deny a woman access to, or ability to seek and maintain, a counselling process. Factors that impede accessing emotional support include illness, fatigue, cost, time, and/or a busy post-BC work/life schedule (Keitel & Kopala, 2000). The problem may also be that “many mental health professionals are not sensitive” to the “realistic obstacles” that impede a survivor’s engagement in a counselling process (Keitel & Kopala, 2000, p. 146).

As an adjunct to the idea that BCS may revert to previous, familiar patterns of coping to manage daily and existential demands, Vos (2015) has referred to the idea of there being periods of “heroic coping” (p. 898) in which a cancer survivor willingly faces the realities of life with courage. The dilemma is that coping ‘heroically’ does not always present the healthiest of ways to generate a self-beneficial reinterpretation of life after cancer. Optimistically, Vos (2015) also posited that there will be times of oscillation away from heroic coping. This would represent a time when a cancer survivor pulls back and would be able to relax a sense of their role as the ‘giver’ being vitally essential. The assumption is that there are times when BCS may be open to support for dissolution of self-denying efforts that no longer serve cogent purposes in daily living.

#### **8.4 Change and transformation**

Change and transformation for BCS carrying a burden of negative emotion can be aided through counselling support that works to functionally reverse residual trauma as well as practice adaptive patterns of relating for the future. Within the therapeutic relationship a client can do more than ventilate emotions. Foundational to the exchange is a sense of safety fostered by the human, caring, respectful presence of a therapist (McLeod, 2013; Welfel & Patterson, 2005). Reflective dialogue and emotional communication combined with experiential tools such as creative journaling (Pearson & Wilson, 2009), storytelling, or construction of a symbolic narrative of challenge and change create a restorative focus (Knight, 2002; Pearson & Wilson, 2009; Thompson, 2014). The outcome, ultimately, would be to open new avenues for relating with self and other.

Counselling can provide time and space for any existential concerns of the BC event story to be fully processed. That process takes place through collaborative co-construction of a refreshed self-dialogue; a dialogue that is healing without needing to be heroic. Evidence from research reveals that “existential discussions should be considered in any cancer-related supportive approach whether preventive, curative, or palliative, and not be deferred only until the advanced stages of cancer or at end of life” (Lee & Loiselle, 2012, p. 123).

The social world may harbour romantic notions of how a person should recover from BC (Sulik, 2011). Rather than supporting a survivor to struggle deeply with their experience the presumption may be that a survivor will reach a faster return to normality through suppression of the emotions of an affect-charged event such as BC. Finding themselves emerging from what had previously been a place of unknowing, some survivors endeavour to create new meaning and re-build a post-BC life with a new – and future – horizon: the new normal. Others make an alternative choice and seek a return to a remembered normality in life in all the colours and shapes it was pre-BC. From a self-compassionate stance neither choice would be considered right or wrong.

A participant in this study reported here spoke eloquently about finally arriving at a position of being able to acknowledge that a person with BC may die

“healed but not cured [of BC]”. ‘Healing’, in a psychological sense, has been theorised to involve a reinterpretation of life (Siegel, 2003). Referred to as something more than an outcome of successful therapy, healing is said to result from an active personal process that ultimately seeks a new beginning rather than bringing to an end something unwanted (Fosha, 2009).

## **8.5 The art of counselling**

Counselling practice that has at its heart a SC focus invites BCS to join a process that extends beyond normalisation of feelings and the offering of a confidential space in which emotional distress can be expressed. To support the practice of SC means a counsellor would take time with a client to discover and explore how reactivity could give way to healthy responsivity to self. Provision of a safe compassionate container for a survivor’s emotional distress, reduces stress and fosters self-awareness, and gentler openness to self-knowledge (Gilbert, 2007). Recent research has found that fostering a relational reconstruction of the self can increase the “ability to manage interpersonal struggles” and cope with long-term strains (Stang, 2016, p. 161). Integration of self-compassionate self-talk would seek to re-orient a BCS to gradual moderation of habits of self-criticism and self-blame (Pidgeon, Ford, & Klaassen, 2014). This means survivorship can take on the mantle of a transformative experience in which a person would be able to ‘hold’ the memories of their BC reality rather than surrendering to a tendency to pull away from emotion-laden memories of the events or to be overwhelmed by ruminative analysis of the experience (R. Neimeyer, personal communication, August 5, 2017).

Relationship has been recognised as a ‘vessel’ that can foster intense personal growth (Corey & Corey, 2014) as well as provide positive adjustment to a life stress such as BC (Manne et al., 2004). From a personal construct perspective, however, it is conceivable that relationship can be both a source of emotional healing as well as emotional harm (Baker & McNulty, 2011; Leitner & Faidley, 1999). Therefore an uncomfortable reality exists that the nature of the relationship with self or with others can add significantly to an individual’s psychological suffering (Bolger et al., 1996). The extent of intrusion from BC in interpersonal relating has been found to differ for BCS, and for some women that disruption to the relationship may not persist as highly intrusive beyond physical recovery (Sohl, Levine, Case, Danhauer, & Avis,

2014). However, for some women the intrapersonal relationship may continue to focus, for instance, on debilitating after-effects of BC, or on lessened personal attractiveness, or lack of support, could be expected to benefit if adaptive self-compassionate responses became embedded in interpersonal dialogue, especially when encountering other-relationship stress.

According to the established principles of SC, self-compassionate relating offers non-judgmental, kind, self-reassurance, not just when life offers less than pleasant circumstances, but as a way that would promote personal thriving and flourishing across the years of survivorship (Akin, 2014; Liss & Erchull, 2015; Satici, Uysal, & Akin, 2015). The result is hope and optimism of being able to reclaim mentally healthy participation in a productive and fulfilling life. The hypothetical stance is that SC promotes expanded openness to self that involves a willingness and capacity for self-comfort and a tender, self-comforting, heart-centred relationship with self (Akin, 2014; Desmond, 2016; Gilbert & Procter, 2006; Leary et al., 2007; Neff, 2003; Raque-Bogdan, Ericson, Jackson, Martin, & Bryan, 2011).

Self-compassionate counselling practice supports the BCS in learning to 'titrate' negative reactions to events (Neff & Germer, 2013, p. 857). Through self-compassion the reality of bittersweet emotions that can arise once medical treatment has ceased can be understood as both personally accessible and changing. The result could be expected to have a direct and positive influence on self-care and self-nurturance as well as reorganising relationships with significant others. This means that rather than counselling being regarded as offering self-care strategies that operate from a reparative basis, self-care support focused on SC training could function as a restorative aspect of life.

Traditionally, women have defined themselves in relation to and in connection with others, devoted to others, responsive to their needs, attentive to their voices (Gilligan, 2011). Therefore, for some women, the practice of SC may stand in opposition to a concentration on a pre-existing mindset that compassionate care is something offered to others first and foremost (Goldstein, 2003). SC focused counselling would aim, then, to empower survivors of BC to discover the ways they seek to define and express themselves in relationship with self and with others.

The research evidence of SC as a way to activate innate soothing and self-regulating functions (Gilbert, 2009) together with the exploration into the meaning of SC for participants in this study, has emphasised the considerable relevance of SC for the field of counselling. Neff's (2003) description of SC parallels one of those common-sense notions that large numbers of people may claim to have realised, but which is essentially a notion easily forgotten, or buried under the weight of emotional adversity.

What remains important and relevant for counselling is the prospect individual or group therapy offers BCS to access skilled support to explore the place of SC in both the traumatic and the transcendent aspects of their lives. In the therapeutic interaction a counsellor can provide positive guidance and strength when a woman may, temporarily, not be able to regain or locate her own sense of meaning and personal control. By virtue of their training and proactive approaches to explore deeper understanding of life events within the context of a client's lived experience, counsellors are in a unique position to help empower women BCS to use SC. An anticipated outcome from this process would be positive life change across a range of domains consistent with post-traumatic growth (Ruini, Offidani, & Vescovelli, 2013).

When a woman lives with a previously diseased or surgically-changed body, reliance on dictionary-type explanations of her psychological processes or rationally-focused solutions to emotional challenges may obscure the chance to become emotionally intimate with herself, either once again or perhaps for the first time. Before encouragement to rush to return the body and the self to a socially acceptable article, there is a need for women to tolerate and sustain self-permission, as well as being willing and open to accept their post-treatment body and mind (Crompvoets, 2003).

Importantly, not all women survivors of BC who experience distress initiate or accept an invitation to counselling (Riba, 2006). Nor is it ideal that women be coerced, no matter how gently or persuasively, to accept involvement in counselling or support group sessions. Given that freedom of choice remains non-negotiable, there is, nevertheless, evidence of the importance of ongoing research into training of counsellors that encourages development and implementation of ways to sensitively



and appropriately assist women survivors. A capacity for dual awareness of past and present events that have shaped the identity of a BC survivor enables a counsellor to understand what is happening in the current moment while simultaneously being aware of how responses to emotional reactivity may have their origins in the past (Ogden, 2015). Unchallenged, habitual patterns of relating, as well as customary interpretations of life events, can deny discovery and resolution of emotions related to adverse life events. Acceptance of this premise directs emphasis toward the training of professional counsellors who choose not to train in a conventional path of psychology.

The link between SC and attachment style has already been the subject of contemporary research (Raque-Bogdan et al., 2011). The evidence is that the self-relationship is not the only aspect of life that benefits from being self-compassionate. Found to engender emotional resilience (Gilbert & Procter, 2006), SC actively neutralises a sense of threat (associated with feelings of insecure attachment, and defensiveness). In addition to its threat-deactivating capacity, SC generates feelings of self-soothing, self-reassurance and promote 'caregiving' to oneself (associated with feelings of secure attachment and safety) (Gilbert & Procter, 2006).

The giving of compassion to clients as they begin to develop compassion, acceptance, and understanding toward themselves is considered a core skill and requirement of the counselling relationship (Cooper & McLeod, 2011; Neukrug & Schwitzer, 2006; Teyber & McClure, 2011). The therapeutic alliance provides a client with an experience of a secure attachment that echoes theoretical frameworks Bowlby (1982) developed as a way to identify varying patterns in human relating. It follows that counselling professionals most likely will feel charged with the task of cultivating a felt sense of goodwill between themselves and their clients. That sense of goodwill is gained as the counsellor works to develop a positive therapeutic alliance (Ivey et al., 2016; McLeod, 2013; Neukrug & Schwitzer, 2006).

For women living with physical and emotional consequences of the after-effects of BC the anticipated consequences from a counselling process that has at its core the practice of SC would be a stronger sense of self-awareness, self-understanding and connection with their ongoing and changing needs throughout

survivorship. The development of a more accepting, less critical, self-relationship will facilitate an enhanced ability to discern how to relate with oneself in ways sensitive to one's uniquely individual emotional, physical and spiritual needs.

## **8.6 Self-compassion and the professional counsellor**

As the Australian population ages and BC survival rates remain optimistic, it is expected that more women survivors will seek the support of counselling services. Psychosocial services can be regarded as an integral part of a comprehensive treatment program for BC. To work effectively and be able to encourage and empower survivors to formulate a revitalised personal narrative, counsellors would ideally have undergone training in self-compassion principles and practices.

The need for counsellors to attend to self-care is not a new idea. Because of awareness of vicarious traumatisation, burnout or compassion fatigue, the psychological well-being of the person of the counsellor is a critical preventative health measure within the profession (Skovholt & Trotter-Mathison, 2014). This means that SC has relevance in counselling for both a client as well as for the counsellor. While professionally counsellors take the part of benign receivers of narratives of distress and disturbance, neither the 'servant' nor the 'served' is exempt from a human need to feel that we matter or that we have significance. Sustainable PWB is just as important for the helper as it is for those who are helped. A connection between counsellor health and SC can be found in research that identified SC as a positive mediator of PWB (Hollis-Walker & Colosimo, 2010). The indications are that while other self-care measures may be normal practice for counsellors, development of SC during their process of 'formation' as a counselling professional could form an integral aspect of PWB – an aspect of training that may have been overlooked by counsellor training programs (Patsiopolous & Buchanan, 2011). Reflecting recent research, interviews for this study highlighted that a new-found appreciation of self and life, improved self-management, and opportunity for relational reconstruction presented as key areas in which emotional growth was experienced as a result of having faced BC (Schulman-Green & Jeon, 2014).

## **8.7 Chapter summary**

BC is a choice-less event but one that, paradoxically, is also rich with choice. What emerged from the exploration for this study was that an important component of a BC ‘survival pathway’ involved receipt of appropriate, sensitive and yet active, therapeutic responses that could enhance emotional prosperity for women in their personal experience of survivorship.

In this study with its interest in particular elements of psychological support that provide a ‘model’ for BCS of a renewed yet sustainable way of being, the hypothetical stance taken was that counselling practice with SC at its core could likely offer a persuasively positive, growth and health-focused process. Personal counselling attended to with a qualified professional, trained in SC, offers the potential to address the potential for self-nurturing amendment to a woman’s understanding of her attitude to self-care. The strength and relevance of SC for counselling practice for survivors of BC becomes evident when the focus shifts to develop a life practice of SC through short-term support from a professional counsellor.

In conclusion, the elegance of a particular form of therapy or the efficacy of it is not the critical factor. What is important is whether for a particular client the exploration of SC within the therapeutic relationship has encouraged positive self-regulation, greater understanding of a BCS mental wellbeing, and fostered a caring and kindness for self within the client.

## **Chapter Nine**

### **Implications for counselling practice and training**

#### **9.1 Overview**

Cancer is a disease that, metaphorically, can be represented as an ongoing war on a constantly changing battlefield. Contributing to this concept, medical science has encouraged optimism through research that ignites an ever-present hope of new ‘weapons’ to vanquish the threat of the disease. While improved cancer treatments have led to undeniably improved patient outcomes in the form of extended life expectancy (Riba, 2006), a sense of isolation from life as it was previously known and unreality about their situation continues to characterise the post-BC experience for some women (Little et al., 1998).

There is now a socially-anticipated, and statistically growing improvement in BC survival rates through a combined process of “public awareness and education, early detection and diagnosis and research into improved therapies” (Jacobs & Finlayson, 2010, p. 363). Despite these gains the pervasive and practical dilemma of emotional distress that can interfere with positive movement forward in survivorship means there exists a need to strike a balance in the domain of care. That balance will entail managing a vital focus on maintenance of physical wellbeing alongside simultaneous engagement by a survivor in the task of self-enquiry, self-care and emotional wellbeing. Positive health outcomes can depend, in part, on identification of ways to facilitate development of a woman’s psychological resources as well as determine and respect her motivation in regards to meeting personal bio-psycho-social needs.

In this study what was found was that participants who were a) survivors of BC, b) counsellors working with women with BC, and c) husbands of women who

had BC, all had an acute awareness of the way in which the journey through BC involved not just physical repair, but one that involved a 'liminal' psychological experience for women diagnosed. The uniqueness of the experience meant each, in their own way, entered an unfamiliar terrain in which previously taken-for-granted assumptions were challenged, discarded, or hoped-to-be-maintained. When reflecting upon their experience from diagnosis through until the time of interview, the majority of women participants spoke of the journey being a transformative one. They gave examples of how post-treatment they had moved across perceived boundaries about expression of who they were and who they wanted to be. In particular those 'boundaries' were ones that seemed to reflect accepted imperatives about their role within the family. The participant husbands also reported experiences of transformation within themselves in terms of life priorities and life directions. Participant counsellors spoke about the sadness and the joy they experienced in helping women integrate the experience of a life-threatening illness and subsequent treatment into life. Those counsellors also spoke about the shock, disruption, fear, and stress experienced by all the women they supported as the familiar world was deconstructed in a short timeframe. Important perspectives held by the participant counsellors was that the abrupt move from one life state to another needed to be met, above all, with sensitivity and compassion for the woman and her family.

In its most simplistic definition, counselling involves a therapeutic intervention and the communication of that intervention. Ideally counsellor and client form a collaborative relationship to work together in the process of structuring sessions, identifying the focus, as well as the pacing and progress of the therapeutic work. That process would require acceptance of the psychological effect BC has on identity, perceived sense of self, and attitude to life demands continual revision and extension of counsellor knowledge and understanding (as discussed by Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010; Han et al., 2010).

With BC as the most commonly diagnosed cancer in women (Malek & Silliman, 2007; Riba, 2006), it would appear that professional counselling can invite people affected by BC to participate in the process of mutual involvement in creation of a new self-vision for the woman treated and for family adjustment to BC. Additionally counselling would provide support for partners and family members to

explore the complexities of thoughts and feelings they have about BC and its impact on their lives (Moestrup & Hansen, 2015).

## **9.2 Counselling with BC survivors**

To assist women in their post-BC quest towards construction of an intended or preferred ‘future’ a trained, professional counsellor can engage in a collaborative dialogue that has as its central characteristic a mutual involvement in creation of a vision of the woman as well, not ill. In this study the participant counsellors regarded a key ingredient of their work was the encouragement for women with BC to develop a flexible and optimistic view of themselves, and others, as well as the summoning up the courage to be imperfect in a society that appears to prize perfection.

The adjustment to living with the legacy of BC needs to be considered as a process that unfolds over time; adjustment is not something that happens in the immediate months post-treatment. Revision of counsellor knowledge and understanding would mean the counselling process could better assist women in this adjustment in a number of ways. Counsellors’ enhanced understanding of the impact on women of living with BC could help their clients relate with their post-treatment mind, feelings, and body through a multi-dimensional lens. Using that lens counsellors can assist women to nurture the multi-dimensional psychological self. A multi-dimensional lens includes their identity as a woman, their identity as a survivor of BC, their perspectives on power and powerlessness, as well as developing recognition of their individual unique abilities, supported by enhanced self-compassion.

Certain characteristics have been said to be particularly important “in dealing sensitively with the life-and-death issues” presented by the BC survivor (Keitel & Kopala, 2000). Tolerance for the physical and emotional suffering of a client is an essential ingredient in counselling and this was referred to by the participant counsellors in this study who talked about “bearing witness” to the suffering of the women and their families who struggled with adjustment to BC. Similarly, a counsellor can be effective in working with the psychological ‘fallout’ from BC if they are comfortable to talk about death and dying. The BC survivors as well as the significant others who took part in this study gave mixed responses about the topic of

mortality. One woman who seemed to struggle to make sense of what had happened, expressed intense anger at knowing her diagnosis was terminal. Others spoke only about working to ensure they were in the population of women who survived BC. Overall it seemed as though most of the participant women were either not anxious about the thought of death, or they had expressly avoided thinking about their own mortality. The participant counsellors expressed sorrow at the thought of any of their clients succumbing to the disease. One of the significant others whose wife had died from BC recounted that they had tried to ignore the fact that her diagnosis was terminal until such time as it was an unavoidable reality.

The counsellor whom a client experiences as trustworthy, genuinely caring, and keen to understand a client's own worldview and experiences is more likely to be effective in terms of creating a sense of connectedness between themselves and a client (Knox & Cooper, 2010). Counselling is a process that offers the client an opportunity to explore, discover and clarify ways of living more satisfyingly and more resourcefully. As such, counselling can resist being a service used to create distressed and vulnerable people as socially acceptable commodities who then 'fit' more appropriately with societal norms.

Working to encourage positive life change is one of the key ingredients of professional counselling. In that process of fostering positive change, counselling must be able to provide the opportunity for a client to feel deeply heard in a way that they may rarely have previously experienced (Crago, 2012). This would include being able to hear and understand the client's relationship to concerns about aloneness, making sense of life, death, and choice (Moestrup & Hansen, 2015). Counselling also involves as an interpersonal process in which each person communicates to the other that they feel heard, understood, and for the client, respected.

Counsellors working with post-BC women are effective when able to adopt a therapeutic approach that inherently has a positive view of women. Many of the intrinsic deficiencies with regard to counselling women using traditional approaches have, in recent decades, been addressed (Enns, 2003). Despite greater acceptance of a wide range of social roles for women gender bias and stereotypical labelling of

women remains a reality. When compared to views held in past decades it would appear that tendencies for bias and stereotypical labelling of women have undergone major alterations (Enns, 2003). With 21<sup>st</sup> Century constructions of BC women are now more able to speak openly about their experience of the illness

The potential for countertransference needs to be understood by a counsellor. Facing the person who has had BC means, to some extent, facing oneself and facing the question of whether, given the prevalence of BC, they too may one day be diagnosed with the same disease. Similarly it is important for the counsellor to be aware of their own orientation to life and death (Keitel & Kopala, 2000).

The therapeutic relationship presents the prospect for both counsellor and client to grow personally, and professionally, through the encounter with the other. Counselling is a setting in which a client affected by BC needs to feel safe to talk about issues such as fear of cancer recurrence, fear of the aging process, as well as decision that need to be made about their own life. Sharpley, Bond and Agnew (2004) conducted a survey in Australia into attitudes toward counselling and found that a majority of respondents listed “fear of confronting, expressing and reliving unpleasant experiences” as the most “frequently mentioned personal drawback” to attending counselling (p. 101). Feeling embarrassed, the dilemma of trusting another person with one’s deeply personal perspective on life experiences, and the social stigma of attending counselling were also viewed by respondents as potentially unhelpful for a person seeking emotional support (Sharpley et al, 2004, p. 101). The indication from this study could be that the perceptions about, and disposition a person holds toward, counselling may offer either a way through emotional suffering, or conversely a cognitive state that constrains expression.

### **9.3 What has already been offered: What can be offered**

No single model of counselling can claim authority over positive outcomes for clients. Some interventions have been offered face-to-face and some in an online context. The participant counsellors in this study held a fundamentally similar approach to counselling that had as its basic premise psychodynamic theory. All three participant counsellors worked in a face-to-face context with clients and/or their families. The literature reviewed for this study has indicated that psychosocial



interventions include both individual and group therapies from a range of theoretical frameworks explored in a range of different approaches such as Cognitive-Behavioural Therapy psycho-education (Ye et al., 2018), mindfulness practice (Niazi & Niazi, 2011), meditative practice (Yun, Song, Jung & Yu, 2017), as well as using creative arts such as writing (Jensen-Johansen et al., 2013).

For people living with cancer a range of therapeutic initiatives have been trialled and found to be helpful to alleviate a range of BC after-effects. Those initiatives have included a Behavioural Activation Treatment (BAT) and problem-solving intervention (Hopko et al., 2011; Hopko et al., 2015), cognitive-existential group therapy (Kissane et al., 2003), education and peer support groups (Mens, Helgeson, Lembersky, Baum & Scheier, 2016), supportive-expressive group therapy (O'Brien et al., 2008), dance/movement therapy (Ho, Lo, & Luk, 2016), mindful exercise (Tacón & McComb, 2009), Mindfulness-Based Stress Reduction (MBSR) (Birnie et al., 2010), meditation (Dodds, 1999), as well as peer support groups offered by organisations such as the Cancer Council in Australia. Peer support groups for BC survivors offer social support, can improve coping skills, and help reduce a sense of isolation and distress. Each of these aspects of meeting in a group can be regarded as potential protective factors for mental health and have been shown to improve survivors' wellbeing across the short-term (Mens, Helgeson, Lembersky, Baum, & Scheier, 2016). However, authors of the Mens et al study (2016) found that gains made in their exploration of an education and peer support program were positive in the short-term but with clear indication of the tendency for gains to dissipate over the longer term.

A study into individual versus group exercise and counselling program for BC survivors found higher compliance among women participants attending individual exercise and counselling sessions than those assigned to group sessions (Naumann et al., 2012). The exercise and counselling program was conducted over a 9-week period, however, to date no follow-up data appears available to consider whether personal gains made in the individual or the group sessions were sustainable across the longer term.

Ideally, the implications for long-term survival with BC, and potentially co-morbid conditions, would encourage alertness by health care providers to the contribution to BC care that can be made by counselling from a stance underpinned by a female-focused, self-compassionate model of therapy. In essence, the counselling practitioner is able to assist a BC survivor by exploring ways in which she is able and willing to make positive transformations. The starting place for positive transformation would appear to be to locate and foster self-acceptance. To engage in this process the counsellor and client would be encouraged to collaboratively review not only strengths and intrapersonal resources, but also any practical difficulties that might emerge as a hindrance to her development and ensuing empowerment process. This latter step would entail some vigilance about subtle privileging of aspects of identity and gender over other dimensions (Keitel & Kopala, 2000).

From a feminist perspective the argument would be that counselling is, and counsellors are, able to be aware of cultural perceptions of “how breast cancer is constructed and how breast cancer is positioned” (Gibson et al., 2014, p. 523). Gibson et al have discussed the perception that women are in control of their illness trajectory by virtue of information provided and support offered, through “practices that maintain their femininity” and self-surveillance (p. 524). Women are encouraged to feel empowered in Australian society also by sharing the narrative of their experience with others. Representations of women survivors usually depict a person who is youthful, without any visible signs of the struggle that has taken place (Sulik, 2011). The challenge for women survivors of BC is not to ‘believe the advertising’, but to discover their post-BC identity for themselves. As the period of time of survivorship extends a second challenge is not to revert to pre-BC automatic patterns of nurturing and caring for others without including herself in that equation. Awareness in counsellors that some women may not see their giving to others as self-sacrifice or denying themselves, but may feel happiest and most valued when giving, would shed light on a woman’s perception of her role. The participant survivors in this study talked about how they valued the role of being the one who could help others; they did not regard that as self-sacrificing.

Counselling can support people through the fear, isolation and distress that attends BC through co-creation of an individualised model for positive change. Through counselling that can be tailored to meet the values, beliefs and lifeworld of the client, positive change in BC survivorship comes to be regarded as a position that also accepts the negative changes and what a 'new normal' means for them. O'Hara (2013) has referred to hope, in part, as the practice of patience. Living into a 'new normal' means patience and hope is required. Hope and self-efficacy for women with BC has also been found to be linked to the quality of life of their male spouse (Duggleby, Wendy, Heather, Dan, & Roanne, 2014). These authors found that the quality of life of male spouses of women with BC influenced the degree of support they were able to give their wives. Therefore, the degree of hope and self-efficacy a BC survivor perceives herself to have post-treatment, and the sources of hope and would be an important resource for a counsellor to assess and understand to be cognisant of any challenges in helping a couple living with BC find and foster hope.

Within the therapeutic setting contact with strong emotion has been described by Fosha (2000) as a pivotal contributor to metamorphoses of the self. Fosha (2000) argued that it was this paradoxical contact and expression of the previously inexpressible that figures as the central agent responsible for therapeutic change. In short, the psychological experience of BC can typically be deeply emotional, constructed within the rules, values and social world of not only the survivor but her family, and yet that emotional response may not fit with the cultural context of the survivor. Additionally, sensitivity to the pacing as well as the development of narrative processes within counselling sessions is a useful consideration for counsellors as a survivor processes and (re)constructs viable meaning systems (Neimeyer, Klass, & Dennis, 2014).

There is respect for emotions as complex, multi-layered experiences that elicit multiple concerns and generate a range of responses (Mesquita & Frijda, 2011). For example, the experience of emotional distress that can companion BC survivorship may have as its antecedent in pre-BC unresolved psychological distress, as suggested by Burgess and colleagues (2005), and corroborated in a 2012 study exploring the trajectory of emotional distress from first year post diagnosis to 6-year survivorship (Lam, Shing, Bonanno, Mancini, & Fielding, 2012).

#### **9.4 Survival and readiness to explore self-compassion**

The work of Eugene Gendlin (Madison, 2014) has long promoted the idea of being mindful of discovering and understanding the need for a workable distance from emotion. Drawing on Vygotsky's socio-cultural theory of learning in addition to the foundational tenets of counselling theory, the notion of there being a 'zone of proximal development' (ZPD) and a 'more knowledgeable other' (MKO) (John-Steiner & Mahn, 1996; Poehner, 2012), supports the potential for SC to become a transformative intervention in counselling's repertoire for emotional healing. Therefore, understanding both the ZPD and MKO would mean a step by step process to integrate SC into life after the experience of BC. The key construct Vygotsky proposed was that ZPD and MKO significantly influence developmental and learning processes (John-Steiner & Mahn, 1996; Poehner, 2012). This means that appropriation of the practice of SC would involve a steadily-paced, sensitive revisioning of previously developed self-constructions, carried out as a collaborative 'development' between counsellor and client.

The process of collaborative development would require the counsellor to mediate between difficulties encountered in learning to be more SC with the task of learning to meaningfully assess the survivor's process of change (John-Steiner & Mahn, 1996; Kees et al., 2005; Poehner, 2012) as a way to advance self-compassionate communication. In simple terms, in the light of the concepts of ZPD and MKO, through dialectical processes, a counsellor, using guidance and encouragement, can interact supportively with a survivor to extend and enhance self-discovery and self-knowledge. This may best be achieved at a pace and in a way that is able to be tolerated, integrated and sustained by BCS. When asked about the meaning, for them, of the term self-compassion, women participants, as well as significant other participants, in this study the response was often that it was about kindness to yourself. Responses from those two groups of participants also highlighted the fear of self-compassion. The most reported fear, in both survivors and significant others was the fear of being self-centred or selfish. Commonly held beliefs about SC, that it is more akin to selfishness, complacency, weakness, self-pity, and narcissism have been acknowledged and reported in the literature on SC (Neff, 2015). In responding to concerns about SC being selfish, Neff points out that self-kindness and self-attentiveness in meeting one's own emotional needs means a greater capacity to focus on the needs of others. Counsellors have an

understanding that for a client to embrace being kinder to themselves is one of the positive steps forward in a counselling process. Student counsellors could be introduced to the concept of SC and over the course of their study could explore their perspectives on SC and its impact on the therapeutic relationship and place within a counselling process.

### **9.5 Implications for counsellor training programs**

The counselling profession's deep appreciation of the interconnectedness of language, thought, and feeling along with the benefits from time for evaluative self-reflection, create an environment ideal to support BCS engagement in a transitional process. Curiously, however, language can also be reductionist and can limit proximity to the feelings of an emotional experience (Wilberg, 2004). Additionally, not all illnesses have a mind-body element (Broom, 1997). Counselling processes underpinned by understanding of the relationship between body, mind and feelings takes into consideration bio-psychosocial symptomology, the mind-body relationship, and interactions between these systems and their capacity to influence health and pathology (Broom, 1997; Broom, Booth, & Schubert, 2012; Cohen, 2011). Important skills for counsellors are to attend to the body's way of communicating so as to avoid unwittingly re-traumatising a client (Helsel, 2015). This would mean being able to encourage a client to actively notice and become aware of, in a carefully graded way, physical sensations in the body, and to acknowledge the recording, at a physiological level, of bodily responses to the trauma of BC.

Counsellors and professional helpers who provide psychological support for women with BC will find themselves faced with significant numbers of clients who enter their therapeutic process with the legacy of BC as a chronic illness (Schaefer-Schiumo & Atwood, 2009). For some of these clients, their illness will have an uncertain outcome and, in a number of instances, may have a progressively downward-oriented life direction. To work with BC survivors, skills and strategies are needed that can rapidly distinguish between a woman's illness experience, the emotional impact of the likely trajectory of her illness, and the meaning she makes of that illness (Schaefer-Schiumo & Atwood, 2009).

Participant survivors in this study wanted not to have their identity defined or classified by the fact that they had survived BC (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). The women survivors reported that what they wanted was to gain control over their lives once again, and did not want to feel controlled by the need to consider BC. The participant significant others also remarked that regaining control over BC had been important to them. Observations by this researcher, of both the survivors and significant others was that the majority preferred to adopt a positive thinking model for living. While it seemed from their reports that the choice to do so was applauded by family and friends, this ‘model’ may also be the very thing that supported a desire not to think about death and dying.

BC survivorship will impinge, in both overt and covert ways, on a woman’s attitudes and perceptions of self-identity, her self-concept, and her self-relationship. This means counsellors can be most helpful and facilitate change when equipped with enhanced knowledge and understanding of the complexity of personal issues BC forces upon the individual (Fossey et al., 2002). Women, husbands and counsellors in the three different participant groups in this study may, at times, have experienced feeling demoralised about the future for the persons affected by BC (Kissane, 2014). In contrast, all but three of the participant survivors in this study did not speak about feeling demoralised. In contrast their dialogues highlighted a focus on significant relief at having navigated their way through diagnosis and treatment. They reported feeling a new strength in themselves for managing rigours of that process. Post-BC a survivor may not give voice to, or find words for, a new awareness of themselves as physically and psychologically vulnerable - and finite (Vos, 2015). Counsellors trained to understand that the legacy of chronic illness generates emotional complexity can offer psychological security to explore and find meaning, encourage and support autonomy in decisions to be made, and help discover insight into the richness of living.

What counsellor training can address is more subtle forms of bias that may persist unchallenged and undetected in a therapist’s conceptualisation of a case. Counsellor training courses in Australia are, by and large, populated by female students, and counselling professionals are also primarily female led, with 78.8% of counsellors being female (Department of Employment, n.d.). These facts do not

automatically mitigate against outdated, genderised attitudes toward a female client. Therefore, the implication for counsellor training programs is a commitment to training in non-sexist frameworks that embrace feminist, constructivist, postmodern ideology.

To effectively support well-being in a client without assuming that a client's worldview and values will automatically parallel their own, a student of counselling would ideally develop awareness of their particular worldview and the culture that created or influenced that view (Duncan et al., 2010; Ivey et al., 2016). There is less likelihood then of the BC survivor's views being overlooked or 'missed'. The other implication for training of the counselling student is an awareness of inherent bias in therapeutic approaches that may privilege an individualistic perspective. Through experimenting with being self-compassionate, a counsellor will likely experience the challenge to move from prioritising other responsibilities over nourishing their own wellbeing (Desmond, 2016).

There is an onus on providers in the helping industry to continue to seek out, qualify, and follow best practice (Fossey et al., 2002). One stand-out aspect of best practice would involve the capacity for reflection by counsellors about potential counter-transference and transference that may occur during the therapeutic process (Riba, 2006). A counsellor may have had a close relative, friend or colleague, or previous client, with BC and such an occurrence requires mindful awareness of feelings, perceptions, grief processes while offering support to a client. Therefore, self-awareness, an understanding of one's personal values, views and the meaning made of life experiences, could be assumed to be an automatic adjunct gained through the process of studying counselling. Without some insight into self-awareness the risk is that the counsellor who is not self-aware is less likely to be effective within the professional interpersonal relationship that is so crucial to the intimate emotional process that occurs within counselling. Attention paid to the interpersonal relationship in therapy requires awareness of issues of power and values as well as awareness of one's orientation to any variations in traditional gender roles and behaviours (Enns, 2003). The counselling skill to develop is the capacity to hear an as-yet unheard voice of the client – a voice that heralds the change desired by the client.

Listening as a skill can be taught, or misconstrued by students, merely as something of a prelude to giving a response that demonstrates a therapist's ability to empathise or offer an insightful response to what a client says. If regarded as 'waiting time' until it seems appropriate for the counsellor to speak then an opportunity is missed and listening becomes more of a mental activity than a state of embodied resonance with a client (Wilberg, 2004). In contrast, the capacity and skill for a counsellor to 'stay' in the 'pregnant pause' with a client, giving time for the client to reflect, allowing emotional and auditory space so they can listen to themselves and their body deeply, offers an opportunity for transformational experiences for the client.

Wilberg (2004) has referred to "maieutic listening" as the skill of being able to be with and bear a client's feelings. This approach stands in opposition to a more conventional therapeutic approach in which a client is encouraged to translate bodily felt experiences into language understandable by the 'other'. Wilberg's approach (2004) has argued that the therapeutic alliance therefore has the potential to offer something different to the usual work of amelioration of distress. The participant counsellors in this study may not have used the term "maieutic listening", however, their reports of their work with survivors of BC indicated that in response to the emotional state of their client population they intuitively moved to the space that allowed them to be with and bear the feelings being expressed in counselling sessions.

While reports from the participant survivors implied that extended counselling support had not been considered necessary beyond the initial first year after treatment, it is possible that this reflected a national (Australian) lack of clarity about what professional counselling has to offer, what it involves, or the life benefits to be derived. It is clear from the major themes that emerged from interviews that there were a number of psychological, emotional and existential issues or questions that were of high interest to the survivors. The participant survivors concerns about self-worth, guilt, and self-blame and their recognition of a tendency to put their needs second to those of family and friends suggested that their own existential questions may not have been addressed until they were diagnosed with BC.

Indications are that a rudimentary understanding and factual knowledge of the processes involved and the milestones of the psychological and psychosocial



process from diagnosis, through recovery and on to survivorship would be a prerequisite in supporting the psychological needs of BCS across the life span. This would also encompass understanding the particular needs of the aging BC survivor and how it might differ from the emotional experience and needs of the younger BC survivor. Therefore, knowledge of a developmental perspective, in addition to awareness of the changing somatic resources of the older survivor would be fundamental to supporting the aging-with-BC process. One way this could happen would be for counsellors to have an understanding of the body-mind relationship and to support a BCS to draw on that relationship to achieve a sense of overall wellbeing. In this study, the researcher's experience of 'sharing' in a world of vulnerability and challenge through the process of gathering data has suggested that preparation of counsellors to support this particular population would benefit from developing a high level of self-awareness in trainee counsellors. Experiential training would ideally support trainee counsellors to bring awareness of habitual reactions they may have when emotionally reactive, or tendencies towards lack of self-compassion toward themselves.

Overwhelmingly, the women participants in this study highly valued the opportunity to share their personal narratives of their experience. An implication for preparation of counsellors, and not just those who plan to work with this population, might focus on the value of person-centred active listening as opposed to a counselling approach that might encourage moving to 'do' something, or provide coping strategies in the short term. In other words this would mean counselling, first from a perspective to encourage the emerging narrative.

The art of listening is lauded in conventional teaching texts currently in use within counsellor training programs (Ivey et al., 2016; Neukrug & Schwitzer, 2006). It is highly appropriate for a trainee counsellor to demonstrate the skill to offer professional responses in line with their chosen theoretical and practice framework in a way that is sensitive to the emotional state and needs of a client. Over the course of their training, student counsellors develop skills that encourage the ability to activate in a client a feeling of being listened to. Feeling listened to is, however, a different experience to the experience of being heard (Wilberg, 2004). What appeared to be of value to the survivors and the significant others in this study was the experience of being heard, in a

psychologically safe context, that offered a sense of their being time and space in both the interview and group processes, for each participant to hear and reflect on the comments they had made before needing to give time to another person. To influence the extent to which a chronic condition affects a woman's adjustment to that illness, a counsellor needs to be skilled at giving space, time and support for a client to speak *with* feeling rather than simply speaking *about* feelings (Wilberg, 2004).

Participant survivors in this study welcomed the opportunity to have a safe and private context proceeded tentatively and only revealed their narratives once they had arrived at a place of psychological safety. Given that each journey of the participant survivors was highly individual, counselling educators would need to emphasise a flexible, integrative and pluralistic perspective to meet the needs of the survivor and their significant others (Cooper & McLeod, 2011). Additionally, the themes from the participant counsellors suggested that "bearing witness" and not "putting band-aids all over the place" ie attentive listening was what was most helpful to their client population. Furthermore, different stages of the cancer 'journey' evoked different psychological and emotional needs in the participant survivors in this study. This means that counselling for BC survivors and their significant others will not be a 'one size fits all' approach. Respecting the needs and interests of each individual BCS is paramount to effective counselling. Just as the findings in this study cannot be generalised because of the individual differences reported, so there is no overall guiding template that can be applied to counselling a vulnerable population such as BCS. The recommendation for counsellor training is to establish the skills of critical enquiry, sensitivity to pacing, and awareness and recognition of the application of a variety of practical resources for working with survivors and their significant others.

## **9.6 The place of self-compassion training**

Whether a woman's post-treatment body is a one, two, or no-breasted form, the sense of personal safety and certainty in life has been temporarily dismantled. Their training may not automatically have prepared a counsellor well to take on the role of offering emotional support for women living with BC. Counselling women relies on a capacity to offer support through clinical application of approaches that are free of bias (Enns, 2003). Counsellor training programs in the 21<sup>st</sup> century aim to

provide solid research bases for course constituents and recognition is given to assisting the student counsellor. There is also recognition that ideally the student be exposed to knowledge to understand and be able to adequately address issues for women “related to power differences, gendered family roles” and the emotional legacy associated with “physical, sexual and emotional abuse” (Enns, 2003, p. 13).

Self-compassion is not easy. Desmond (2016) claimed that “our tendency as humans is to judge and criticise ourselves for any way that we fail to measure up to our idealized standards” (p. 3). From this study’s exploration into SC with a group of women who survived primary BC, it seems critical that student counsellors be supported to develop a capacity and willingness to ‘be’ and ‘bear’ with another person’s emotional suffering (Keitel & Kopala, 2003; Wilberg, 2004).

Professional counselling with a self-compassionate focus can offer support for women to move closer to their illness experience in a mindful way in order to move away from the more stressful aspects of it. Given that the principles of SC offer the potential to experience emotional pain without an accompanying and sometimes unbearable sense of aloneness, SC could be regarded as something of an antidote to the traumatic aspects of the experience (Przedziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-Bilinski, 2013). The indication from the literature reviewed and from the reports of participants in this study, is that the counselling process is well-placed to offer a woman the string of emotionally supported experiences that will aid secure strengthening of her self-compassion. At very least SC provides a significant mediator between beneficial life adaptation for the BC survivor, and depression and anxiety. Using SC as the basis to help shift a woman’s emotional proximity to her BC experience means it can be safely explored in a way that will enhance rather than detract from her quality of life. What is important is that when confronted with intense emotional reactions, the healthier path is for a woman to find herself not standing alone in the face of overwhelming emotions (Fosha, 2006).

## **9.7 Chapter summary**

There is acknowledgment of extensive research on a broad range of personal issues that emerge from diagnosis and treatment for BC (Cappiello et al., 2007; Razavi et al., 2002). Unfortunately, data has indicated that “barriers exist to receipt

of mental health care in comparison to physical health care” (Henderson, Evans-Lacko, & Thornicroft, 2013). Perceptions of social or family stigma about the implications of seeking counselling support in the aftermath of BC treatment can result in avoidance of or delay to care. The implications for the counselling profession would appear to bring forward a case for education programs to offer students of counselling active engagement in training in self-compassion. At very least, counselling educators with a workable understanding of the concept of self-compassion and its potential to positively influence the outcomes of counselling for some clients can help de-mystify cultural or socially constructed myths around selfishness, self-centredness, self-esteem and self-compassion. Exploration of self-compassion need not necessarily mean a confrontation with unpleasant emotional experiences that have been repressed. What is understood from research into SC is that future suffering can be transformed when a person is self-compassionate (Reyes, 2012).

Self-kindness need not entail uncovering intrapersonal or interpersonal wounds from the past, although this may happen in the process of any historical review of a lack of self-compassion. What counselling educators can bring forward is the findings from research that SC can help both the professional, and their clients, bring wisdom and insight to themselves in their practice. This firstly requires active acknowledgment of any internal experience of suffering (Reyes, 2012). The counsellor who can embrace self-compassionate relating for themselves can then be guided by the three core principles mentioned in Chapter 4 (pp. 134) in relation to awareness of their client’s perspective on isolation and aloneness in suffering, as well as hope for recovery from debilitating emotion-laden experiences and negative self-talk.

## **Chapter Ten**

### **Limitations and Future Research**

#### **10.1 Limitations**

While this study has provided a glimpse into the experience of SC in women who have BC, a number of limitations were identified that, in a future study where differing populations of people with BC were to participate, greater variety in narratives may be harvested.

In this study one such limitation was related to levels of participation. Women with high motivation to support other women would possibly be more likely to have volunteered to participate in the study. Similarly, women who were open to sharing the narrative of their BC experience could be said to be more willing to take part in a study that was qualitatively driven. It could also be expected that women whose preference was to put the experience behind them and move on with life would not be prompted to participate.

A desire to avoid going back over their BC experience combined with a study that asks women to do just that creates the potential for a mutually exclusive response to an invitation to participate. As a result the experiences of self-compassion in women who a) prefer to be future-focused and not revisit their BC experience along with b) women with strong resistance to openly discuss issues such as personal growth, sexuality, body image and breast surgery, do not form part of the constructed narrative on the topic.

Age of participants was another limiting factor. For this study women from 35 – 70 were invited to participate. The overwhelming majority of women who responded were in the 45 years to 70 years age range. What this means is that the

experience of younger women who may not yet have had children, or those who have young children to care for, is not represented in the results. Neither is the experience of very old women survivors of BC able to be reported. It could be anticipated that further research with a younger population of women with BC may highlight narratives that reveal a leaning toward more personal awareness of the need for self-nurturance.

Research into the lived experience of very old women survivors of BC may point to a different process of adjustment to the disease. Exploration of women with BC who are under 50 years of age may also highlight increased levels of psychological distress. The same may be found to be true for women who are single parents. Only a small number ( $n = <5$ ) of participants in this study were single parents. Those who were single parents took part in the interview process but did not join the focus groups or personal reflection program.

Importantly, Aboriginal women are reported to have less optimistic outcomes from BC than their non-indigenous counterparts (Reath & Carey, 2008). A significant limitation in the study was the absence of Aboriginal women from the participant groups. Aboriginal women did not participate, nor did a significant other in the life of an Aboriginal woman diagnosed and treated for BC. Several issues come to light immediately when considering the vulnerability of Aboriginal women to a decreased opportunity or likelihood of taking part in an exploration of the experience of self-compassion. In the first instance, the term 'self-compassion' may not have meaning; it may not be a linguistically or culturally relevant term. However, it is hypothesised that using a different terminology and talking about self-kindness and treating oneself well would be likely to have relevancy for Aboriginal women who survive BC.

Some of the challenges facing participation in this type of study relate to issues such as (i) the need for diverse approaches because Aboriginal women per se are not able to be viewed as an homogenous whole; (ii) the influence on health-care decision-making of diversity within Aboriginal identity and traditional beliefs; (iii) issues of power, racism and socio-economic inequality; (iv) lack of access to hospitals and medical care for Aboriginal women living in community; and (v)

Aboriginal women's cultural perceptions of counselling. Each of these factors would present a barrier to participation and would need to be addressed in a broader exploration of the experience of SC in Australian women who have BC.

An overall limitation was the lack of diversity in the demographic of participants. This limitation related to socio-economic status, cultural diversity, and marital status. The same disease can be experienced very differently in different culture and this points emphasises that varying explanations may exist across cultures for the cause of disease. Similarly, treatment preference in addition to sources for support and advice may vary according to belief systems and cultural mores. Participants in the exploration central to this thesis were an homogenous group keen to engage in a process of self-discovery and personal growth. However it is acknowledged that different ethnic groups may have negative experiences of mental health care (Henderson, Evans-Lacko & Thornicroft, 2013).

The importance of social support and stable partnerships was a hallmark of the group of women who took part in this study. All participants, except one were in long-term marriages with spouses still living. The one exception was a participant who was in a long-term marriage but during the early part of her treatment separated from her husband. None of the participants was non-English speaking, although the parents of one woman had originally come to Australia as refugees from eastern Europe when their daughter (participant) was a small child. Absence of representation from women of Asian or middle-eastern origin presented a limitation in understanding the nature of self-compassion in the context of cultural expectations and culturally-defined health behaviours. BC in women defined as low socio-economic status was not able to be explored in this study since participation was confined to women who worked largely as professionals in the fields of teaching, nursing, or administration.

All women who participated lived within a relatively small geographic area bounded by the metropolitan area of the city of Perth, Western Australia. Women living in rural and remote areas did not participate. One way to address this limitation would be to set up a matched cohort from rural and remote women alongside their city counterparts. The use of technology such as Skype to conduct initial interviews

would address the challenge of distance. Access to medical treatment for BC could be compromised for women from small rural communities because of distances required to travel for regular treatment. Alternatively, women may need to leave their community and make a temporary move to the city in order to complete a treatment regime. The notion of SC for these women may be completely different to women who are city-based.

## **10.2 Suggestions for further research**

All facets of experience of cancer hold potential for exploration of the concept of self-compassion for moving through the experience of existential suffering, and for locating reasons to move into a new life and create meaning in life. In addition to the implications for coping with the emotional, cognitive and physiological consequences of all forms of cancer SC offers a broad range of areas of further research.

Specific to exploration of the experience of surviving BC, this study investigated the experience of self-compassion in female only breast cancer survivors. Breast cancer is most commonly portrayed as a disease of women, however, it is acknowledged that while relatively uncommon, this disease also affects males. Though the risk for males to be diagnosed and treated for BC in Australia has, in 2010, been calculated at 1 in 688 male persons (140 individuals in total) (Cancer Council Australia, 2014), it would be important to consider the experience of self-compassion in those men diagnosed. In cases where BC in males is diagnosed at a later stage, the mortality rate is correspondingly higher (Klein, 2010). The diversity in survival gap may mean men's experiences of BC would be different from that of women survivors (Forti, 2011). To explore the concept of the experience of self-compassion in men with BC could advance the understanding of male breast cancer, and direct efforts into BC-related issues that tend to become genderised.

A qualitatively-driven study to explore whether the construct of self-compassion holds value and significance for bio-psycho-social adjustment for males diagnosed with BC would have importance for development of interventions to support self-care and positive self-talk for Australian males at risk of depression.



Research into ways in which men who have made significant intentional change in their lives have been able to find their own way to self-compassion would provide significant data to develop greater understanding of enhancement of psycho-social interventions that inform cancer survivorship care for men.

Prostate cancer (PC) is a cancer that strikes at the very heart of what it means to be male. Further research into SC post-treatment cancer care conducted with individuals and groups of men treated for prostate cancer. Constructive group therapy with a focus on the exploration and development of self-compassion could be researched for the potential to bring additive influence on psychosocial gains for men diagnosed and treated for PC. For men with prostate cancer, research that can provide recommendations for self-compassion to improve long-term adjustment after prostate cancer.

Breast cancer affects not only the person diagnosed. Loved ones of people diagnosed with cancer are vulnerable to psychological distress. The spouse, family and relatives of the person diagnosed with cancer become secondary patients (Mullan, 1985). In the immediate outpouring of sympathy, empathy and support for the person undergoing treatment the needs of the family and significant others of the person identified as the 'cancer victim' can be easily overlooked or neglected (Mullan, 1985). Further research, for instance, into the usefulness of couples-focused self-compassion could provide guidance for developing resources to support improved communication and emotional health in couples. The same principle could be applied to counselling for family disharmony; psycho-education about self-compassion could be used to support balanced relating within a family system.

Applying an Attachment Theory (Bowlby, 1982) lens to the topic of self-compassion also holds relevance for research into the effects of childhood attachment style and adaptation to living as an adult survivor of cancer. Such an investigation may then provide direction for broader understanding of the relationship between a capacity for empathy and compassion in the professional counsellor and a client's emotional experience during the therapeutic process. Research into self-compassion, adult attachment and the demands of professional counselling - such as feeling the

emotions of others and responsivity to the needs of others – could shed valuable light on new ways to address professional functioning, self-care, and compassion fatigue.

Research into whether self-compassion has relevancy for BC survivors who identify as Aboriginal, as well as the relevancy of the concept of SC for subgroups of the Australian population that may have negative perceptions of dominant Western health discourse. This may be achieved through exploration of the implications of including narrative communication using, for example, storytelling or personal narratives, in preference to more informational forms of communication to develop awareness and understanding of SC. For example, group psycho-educative programs that highlight SC as part of post-treatment regimes for Aboriginal women with BC would advance insight into the relationship between self-compassion, cultural difference and the experience of BC. The potential influence of self-compassion on end-user's cultural perceptions of health care offers a research direction that could guide investigation of dilemmas in treatment adherence in a range of chronic illnesses, not just breast cancer or cancer.

Further articulation and interpretation of the importance of SC as a central tenet in counselling people with cancer of all types may help extend our understanding of how an individual's self-relationship may then influence their relationship to their health and overall wellbeing. The question of who cares for the carers of people with cancer and other forms of chronic illness highlights the need for further research into whether cultivation of self-compassion provides both direct and indirect benefits to both carer and the person cared for.

### **10.3 Chapter summary**

This chapter has reviewed limitations inherent in the study. Areas for future research have also been highlighted.

As a recently developed domain of research, the concept of self-compassion and self-compassion training has been identified as a valuable addition and adaptive approach to managing stress and coping with adverse life challenges. The practice of self-compassion appears to offer help to significant numbers of people with a range of issues including persistent negative self-beliefs, recovery from trauma, and coping

with chronic illness treatment adherence and chronic pain. Further research is needed to evaluate the usefulness of SC as a support for people with forms of cancer other than BC, for example, men with prostate cancer. SC and its application in the training of health care workers, therapists and frontline mental health carers has been identified as an area for further research. Continued research and evaluation of self-compassion, self-compassion training and self-compassion practice as both an individual and group intervention offers a clear for ward direction to extend the range of effective, emotionally beneficial interventions.

## **Chapter Eleven**

### **Conclusion**

In the 21<sup>st</sup> century the power of biomedicine has made serious illness may seem something of an aberration. Humans, today, generally expect they will live a long and healthy life. A paradox is that at the same time, there exists hopeful anticipation that medical research will continue to present findings that offer higher rates of survival from illnesses and medical conditions once considered certain death sentences.

#### **11.1 The current situation**

With one in eight Australian women likely to experience BC in her lifetime the statistics on the impact of BC on the Australian population are well known. Steady advances in medical science and early detection have transformed the landscape of diagnosis and treatment for BC. Early detection of BC, an expansive body of medical research, and ongoing development in medical technology and medical procedures, now combine to offer women diagnosed improved optimism about longer-term survival rates (Doyle, 2008; Miller et al., 2016), with critical five-year survival rates increased to confidently optimistic levels (Seok et al., 2010). Those advances in treatment have led to unignorable positive survival rates. The result is that women with BC currently comprise the largest group of cancer survivors in the United States of America (Ellsworth, Valente, Shriver, Bittman, & Ellsworth, 2012; Mallinckrodt, Armer, & Heppner, 2012). The statistical data for BC survival in Australia is consistent with that of other Western countries with BC also comprising the largest group of cancer survivors (Australian Institute of Health and Welfare, 2017). Hopeful as the current statistics on physical survival of BC appear,

existential concerns are an ever-present companion for survivors of a disease where risk of recurrence can forecast a poor prognosis (Koch et al., 2014; Lichtenthal et al., 2017; Worden, 1989). This means that the result of unaddressed fear of recurrence indicates the fearful state is likely to remain stable over time (Lebel et al., 2014). A biomedical response has, traditionally, not catered for emotional and existential needs in the long-term BC survivor. The biomedical response can offer a standardised patient-centred care package that would include monitoring for cancer recurrence and overall wellbeing. Ideally improved understanding and ability to meet existential needs of BC survivors means considering a woman's personal BC diagnosis, her stage of survivorship, and her reaction to diagnosis and treatment. It therefore becomes increasingly important to include a focus on self-compassion as a means of attending to potentially unhelpful notions of service to others, fear of selfishness, and lack of self-kindness.

## **11.2 The future: Emotional wellbeing and the aging survivor**

Public health policy is not traditionally a domain that can ensure attention is devoted to the emotional wellbeing of long-term BCS. However, as governments and societies in general orient themselves to the increasing prevalence and financial, emotional and social cost of a chronic health condition such as BCS, increasing awareness of the fit between BC, mental health, aging, and quality of life is likely to continually highlight a need to review how best to care for survivors' emotional needs. Psychosocial interventions tailored to enhance the internal process of self-compassion can assist a 'moving on' in a 'hasten steadily' way that fosters greater emotional wellbeing and life satisfaction (Seligowski, Miron, & Orcutt, 2015). Interventions that contribute effectively to psychological health and wellbeing could be expected to result in reduction of the overall cost of health care for communities. Ideally those interventions would provide optimal, or improved, quality of life and satisfaction with care outcomes for BC survivors (Butow et al., 2015).

Transition to long-term BC survivorship heralds in a new range of psychosocial challenges as a survivor resumes their social and employment roles and activities, encounters less contact with breast care professionals, or as will be the case for some BCS, continues to rely on treatment such as hormonal therapy to reduce the risk of recurrence (Koch et al., 2014). Emotional distress can be activated

by the experience of late after-effects of BC, such as vulnerability to impaired health and functioning (de Moor et al., 2013). Attempts to ‘tame’ negative emotional reaction to the disease by countering BC with externally-imposed positive attitudes may have limited effect. Emotional sustenance for survivorship over the long term requires significant re-consideration. The appeal of putting a cosmetic face of optimistic cheer on the challenges of BC survivorship avoids the reality of an agonising encounter with existential concerns. Similarly, reliance on socially accepted, or dictionary-type explanations, of psychological processes, or rationally-focused solutions to BC-related emotional challenges may not guide creation of interventions helpful for positively responding to the needs of BC survivors. And yet, whatever has been found to be effective and efficient methods of easing emotional distress has been regarded, in the literature, as a positive process of extending understanding and development of greater knowledge about improvement in long-term health outcomes for survivors. Gathering the perspectives of women who have survived BC beyond the five-year survival mark provides information that can confidently support the design and implementation of psychosocial interventions.

### **11.3 The women in this study**

BC offers survivors a unique opportunity to become emotionally intimate with themselves as well as the chance to locate meaning and purpose in that experience. Despite having to wrestle with the personal calamity that is BC, the women who participated in this study spoke of their life as being infinitely changed through their experience of the disease. For many, the change brought a re-alignment with their values and strengths, as well as awareness and re-evaluation of what now mattered most for them; for example, time to be in relationships that made life worth living, as well as the ability to unquestioningly accept their emotions - both positive and negative. Yet for others, at the time of participation, the future still contained the dark spectre of depression, with no sense of their being able to locate a safe psychological place inside themselves, or in the outside world.

All participants spoke of the harrowing journey they had made a) through treatment, b) through accompanying a partner through BC, or c) through the process of offering counselling support. They spoke of the constant effort required to ensure continuation of the ‘healing’ process – a process concerned not just with

physiological recovery, but one that included existential and emotional need such as a desire to seek spiritual healing (Schreiber & Edward, 2015). Despite the rigours of the treatment process, some women survivors talked about BC being “*the wake up call I needed*”, pointing out that the disease had given “*permission to do what I need to do to get myself into a better place*”. Although none of the survivors who participated would have welcomed a recurrence of breast cancer as a way to gain personal insights, self-connectedness, new friendships, or a feeling of life being “*blessed*”, the return to a previous way of life that was not personally coherent, kind, or respectful to them was non-negotiable. And yet, in spite of the stories shared, and with new-found respect and validation for themselves (Schreiber & Edward, 2015), old habits of not thinking well of themselves quietly persisted, albeit in an unclear, shadowy form. This quiet, but pernicious, dynamic continued to place at risk of erosion, gains made through an heroic struggle to be among the growing numbers of those who had survived.

To ‘be’ self-compassionate was something new, uncertain, and ‘untested’ in the lived experience of the BC survivors in this study. Interpretations of the term were relative but incomplete. Many participants regarded self-compassion as a skill to learn and to be ‘done’, rather than attitudinal and behavioural development and integration of a way of being. Self-kindness and a more accepting and less judgmental relationship with themselves remained dependent on reducing feelings of shame, guilt and blame related to fear of being judged as selfish or self-centred. However, what was clear was their passion for being alive had helped shift these women’s emotional proximity closer to being able to acknowledge and prioritise their self-worth.

#### **11.4 Survival and self-compassion**

Long-term BC survivorship, a survivor’s psychosocial needs, and maintenance of emotional wellbeing as a BC survivor ages is a research frontier that offers a significant amount of territory to be explored, or revisited. Not more than half a century ago BC was a disease that could result in surgical disfigurement, and a less than positive outlook for women diagnosed (Chang et al., 2016; Olson, 2002). Issues of adaptation to survivorship and living with the after-effects of BC have long been the concern of researchers in the fields of psychology and the social sciences

(Clark, 2017). In the search to better understand the transition from BC patient to living with the after effects of BC as a chronic illness, research has looked extensively at what it is that determines quality of life, and positive or poor adaptation. The intention in this study was to explore the experience of self-compassion in women survivors of BC. The construct of self-compassion was considered in this project as a potential contributor for assisting psychological repair after emotional disruption from BC.

SC can function as a powerful and effective accessory to the scope of relief provided by conventional psychosocial interventions that have already been tested and recognised as useful for BCS. As women, and their significant others, age the survivor will encounter specific age-related psychosocial needs. Health care needs of survivors may be compromised or compounded by psychosocial concerns such as loss and bereavement, the effect of shrinking financial resources, as well as reduced physical energy levels. Physiological issues such as second cancers or recurrence of BC will also precipitate significant additional emotional distress. Therapeutic support through counselling is most effective when offered from an understanding of a client's own personal values and beliefs (Cooper & McLeod, 2011; McLeod, 2013). The findings in this study indicate that fundamental to harmonious wellbeing for survivors in older age will be self-compassionate self-recognition, and a capacity for self-assurance that who they are has not been replaced by identification only as a person who has survived breast cancer. Directing warmth and self-understanding inwards to oneself appears to offer an important and efficacious change mechanism that can reduce psychological distress, integrate an orientation to care for themselves, and foster greater harmonious emotional balance for survivors of BC (Shahar et al., 2015).

Integration into the structure of the personality of the key ingredients of SC brings the capacity to self-soothe and reassure oneself (Falconer, King, & Brewin, 2015). SC and giving warmth to oneself in difficult times can engender hope and optimism for new attitudes, behaviours and meanings to emerge in the integration of the BC experience. To be self-compassionate is not about adding another task to a list of what needs to be attended to each day. Self-compassionate communication is not about pushing on so as to maintain an upbeat demeanour, or overlay difficult



feelings with positive thinking. What the construct of self-compassionate relating presents is a way for survivors of life-threatening and chronic illness to move hopefully towards a new, personally acceptable future in which the person experiences release from 'life' denying negative self-criticism. The new horizon they move toward offers a refreshed personal future.

Extension of life, or cure of cancer, is not the dominant relevancy of SC for counselling for BCS. Nor is SC a panacea for all psychosocial 'ills' connected with BC. However, the construct of SC can support a shift in paradigms of care for BCS. SC requires looking deeper and learning more about oneself, not as a form of self-castigation for mistakes made, or to find a reason from external environments to explain what may have gone wrong in life. SC is a way to cherish and nurture the self.

### **11.5 Conclusion: Revisiting the aims of this study**

The intention of this study was to illuminate the idiosyncratic as well as the common factors in the experience of SC in women who live with the legacy of BC. Primarily, the aim was to contribute to the body of existing research data that seeks to understand what women most need from health care systems, in addition to what personally enriching process might enhance their long journey through cancer survival.

One aim of the study was that the findings might serve as a basis for exploring, creating, and testing SC-focused interventions that 'resource' emotional and spiritual wellbeing. To do so could serve as a means of increasing the depth of understanding of how a woman who lives long term with the after-effects of BC experiences emotional support from providers of post-treatment care.

This study also sought to extend available knowledge about the emotional and existential aspects of living, long-term with BC. Part of the consideration was whether engagement in arts-based mindful activities to generate self-compassionate relating could be a useful and constructive way to open the for BC survivors. Powerful though they may be in the hands of a skilled technician, neither the

microscope, nor the surgeon's scalpel can heal emotional suffering, restore lost hopes and dreams, or remove fears of a BC survivor who faces an uncertain future.

Findings in this study could potentially assist helping professionals extend the basis on which they understand the ways women BC survivors relate, post-treatment, with their body and with significant others. Another useful outcome would be to discover whether a brief intervention for training survivors in self-compassion could enrich the range of intra- and inter-personal responses to self-identity post-cancer treatment.

Women diagnosed with BC have had no pre-diagnosis preparation for having a life-threatening illness or for processing the rapid changes that take place once a diagnosis is made. They may not, at the time of diagnosis feel ill, or have experienced being ill in the time prior to diagnosis. Systems that become firmly fixed in a woman's existence once diagnosis is made impose treatment realities and protocols, labels, expectations, assumptions, and socially constructed meanings to having cancer and what it means to become part of those who survive – or who do not. Neither may a woman, at time of diagnosis, necessarily have encountered the concept of self-compassion or have developed comfort with a self-relationship characterised by kindness to self and a capacity to 'sit with' uncomfortable feelings.

Optimism surrounding BC survivorship could conceal the possibility that while a woman may more than likely be saved physically, she nevertheless will remain something of a 'mistress' in another unintended relationship. That relationship becomes 'another lover', one that requires vigilance, or that is not always kind and compassionate to her emotions, needs and desires. That 'other lover' exists in an inalienable connection to medications that prevent or minimise opportunity of recurrence, life-preserving medical tests, a relationship with her body that demands vigilance and attention, and paradoxically, for those who are willing, a relationship with a deep and personal source of life. For survivors of BC self-compassion presents a resource to be able to truthfully maintain "the delicate balance between being too kind and too harsh with oneself, between being too easy in welcoming imperfections and too merciless in resisting them (Bransen, 2015, p. 317).

This study explored and reviewed SC as an integral part of an ontological process for women in which they simultaneously encounter a journey of physical and emotional hardship, and healing, that activates a process of self-transformation. The findings have important implications for the training of counsellors within an Australian context. In addition the findings hold significance for counsellors in practice. The indications from this study suggest the practice of self-compassion would be a beneficial self-development skill for the wellbeing of an individual and ultimately for the wellbeing of communities.

## **Appendices**

### **List of Appendices**

- Appendix 1 - Interview Schedule – Women survivors of breast cancer
- Appendix 2 - Interview Schedule: Significant others
- Appendix 3 - Interview Schedule: Counsellors who have worked with women who have had BC
- Appendix 4 - Information letter for participants
- Appendix 5 - Informed consent form
- Appendix 6 - Observations from Session 1 - Personal Reflection Program
- Appendix 7 - Images of women survivors responses to creative arts-based activities in the Personal Reflection Program
- Appendix 8 - Researcher's personal reflection journal summary

# APPENDIX 1

## Information Letter for Participants



### INFORMATION LETTER

Dear potential participant

My name is Helen Wilson. I am a student at The University of Notre Dame Australia and am enrolled in a Doctor of Philosophy degree, researching in the discipline of counselling. As part of my course I need to complete a research project.

The title of the project is *Beyond the Ribbon: An exploration of the experience of self-compassion in self and other relating in women survivors of breast cancer*

My research concerns how women living with breast cancer re-establish and maintain constructive, self-compassionate relating with their body, their sense of self and with significant others post-diagnosis and treatment.

The purpose of the study is to investigate three areas: 1) the extent to which women's experience of living with breast cancer affects their feelings and attitudes about themselves and their body; 2) what women feel they need to confidently maintain a balanced and attentive self-relationship; and, 3) whether an early post-treatment program, focused on enhancing a self-compassionate attitude to self could be a useful support for positive adaptation to living with cancer.

I am inviting three groups of participants to join this study:

- 1) Women survivors of breast cancer
- 2) Persons who are significant others in the lives of women with breast cancer
- 3) Counsellors who are working therapeutically with women with breast cancer.

Participants in each group will take part in one (1) tape-recorded interview. For participants in Group 1 it is anticipated the interview process will be between 1 and 2 hours.

Participants in Group 1 will also be asked to take part in three (3) 1-hour Opening to Self-Compassion (OtSC) group sessions and to attend 3 x 4 hour sessions (12 hours in total) of a personal reflection program involving creative-arts-based activities. It is anticipated the three 1-hour OtSC sessions will be either audio-taped and/or video-taped. None of the sessions in the 3-session Personal Reflection Program will be recorded using either audio or video-tape.

For participants in Group 2 it is anticipated the interview will take approximately 1 hour. For participants in Group 3 it is anticipated the interview will take 45 minutes.

Information collected during the interviews, Opening to Self-Compassion group sessions, as well as any discussion had or artefacts, drawings or writings produced during the 6-session personal reflection program will be strictly confidential. This confidence will only be broken in the instance of legal requirements such as court subpoenas, freedom of information

requests or mandated reporting by some professionals. To protect the anonymity of participants in a project with a small sample size, a code will be ascribed to each of the participants to minimise the risk of identification.

The protocol adopted by the University of Notre Dame Australia Human Research Ethics Committee for the protection of privacy will be adhered to and relevant sections of the *Privacy Act* are available at <http://www.nhmrc.gov.au/>

You will be offered a transcript of the interview, and I would be grateful if you would comment on whether you believe we have captured your experience.

Before the interview I will ask you to sign a consent form. You may withdraw from the project at any time.

Data collected will be stored securely in the University's School of Arts and Sciences for five years. No identifying information will be used and the results from the study will be made freely available to all participants.

Due to the sensitive nature of this issue, the interview may raise some difficult feelings for you. If this happens I will make sure that support is available for you if you desire it. You will be provided with relevant counselling information at the interview and contacted by the researcher one week afterward the individual interview.

The Human Research Ethics Committee of the University of Notre Dame Australia has approved the study.

Prof. Martin Philpott of the School of Arts and Sciences is supervising the project. If you have any queries regarding the research, please contact me directly or Prof. Philpott by phone (08) 9433 0218 or by email at [Martin.Philpott@nd.edu.au](mailto:Martin.Philpott@nd.edu.au)

I thank you for your consideration and hope you will agree to participate in this research project.

Yours sincerely,

Helen Wilson

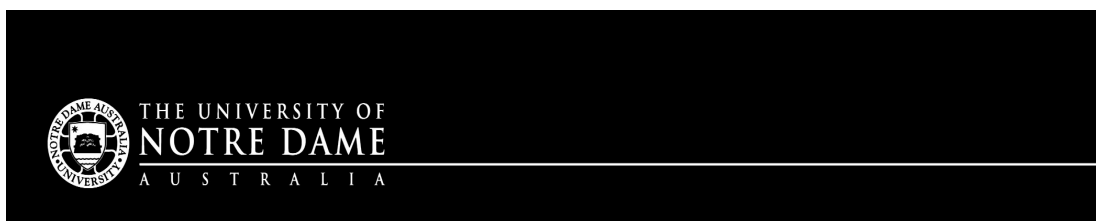
Tel: (08) 9433 0221

Email: [helenmargaret.wilson@nd.edu.au](mailto:helenmargaret.wilson@nd.edu.au)

*If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943.*

## APPENDIX 2

### Informed Consent Form



#### CONSENT FORM

*Beyond the Ribbon: An exploration of the experience of self-compassion in self and other relating in women survivors of breast cancer*

I, *(participant's name)* \_\_\_\_\_ hereby agree to being a participant in the above research project.

- I have read and understood the Information Sheet about this project and any questions have been answered to my satisfaction.
- I understand that I may withdraw from participating in the project at any time without prejudice.
- I understand that all information gathered by the researcher will be treated as strictly confidential, except in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals.
- Whilst the research involves small sample sizes I understand that a code will be ascribed to all participants to ensure that the risk of identification is minimised.
- I understand that the protocol adopted by the University Of Notre Dame Australia Human Research Ethics Committee for the protection of privacy will be adhered to and relevant sections of the *Privacy Act* are available at <http://www.nhmrc.gov.au/>
- I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed.

<b>PARTICIPANT'S SIGNATURE:</b>		<b>DATE:</b>	
<b>RESEARCHER'S FULL NAME:</b>	HELEN MARGARET WILSON		
<b>RESEARCHER'S SIGNATURE:</b>		<b>DATE:</b>	

*If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943.*

## APPENDIX 3

### Interview Schedule: Women survivors of breast cancer

	Question	Rationale
	<p>Introduction and greeting.                      Reiterate the time allowed for the interview.                      Review the outline for the proposed research as per the information statement emailed.                      If not already done so, discuss the Informed Consent form and have this document signed by the participant.                      Ask participant if they feel ready to begin the interview.</p>	<p>Build rapport with participant through conversation about their participation – what it requires of them, the time the interview will take.                      Orients the participant with the rationale behind the research project and the anticipated aims and outcomes.</p>
<b>Q1</b>	<p>Can you tell me something of how it has been for you since diagnosis and treatment?</p>	<p>Builds connection with participants to develop rapport. Participants can disclose how they have experienced this recent time. Can also set a context for consideration of their self-relationship.</p>
<b>Q2</b>	<p>Self image                      What can you tell me about the impact of treatment in terms of your image of yourself?                      a) physically                      b) psychologically/emotionally</p>	<p>Beginning to focus on a key theme of the study. Opening the potential for comment about disparate aspects of ‘self’.</p>
<b>Q3</b>	<p>Relationship with body                      How would you describe your relationship with your body –                      a) prior to diagnosis                      b) since completing treatment</p>	<p>Focus becomes centred on more sensitive issues. May reveal participants actions, intents, and perceptions of their relationship with their body.</p>
<b>Q4</b>	<p>Self compassion                      Could you tell me something about what the term self-compassion might mean                      a) for you                      b) for women with breast cancer</p>	<p>Opens topic of participant’s reflection or thoughts about the concept of kindness and non-judgmental approach to Self. Introduction of question about a ‘bigger picture’ perspective.</p> <p>Q2, Q3 and Q4, provide feedback to researcher</p>



		about participant views and allows comparison to be made with relevant literature.
<b>Q5</b>	Thinking about the recent past, would you be able to tell me of a time when you, or a friend, were able to be self-compassionate?	
<b>Q6</b>	What do you think women with breast cancer might need in order to nurture themselves and care for their bodies?	Open question with specific focus on participants thoughts and feelings about recovery (as opposed to more negatively-geared emotional experiences).
<b>Q7</b>	Is there anything you would say you have discovered about yourself from the experience of breast cancer?	
<b>Q8</b>	Is there anything more you would like to say, or think might be useful for me to know about the experience of breast cancer?	

## APPENDIX 4

### Interview Schedule: Significant others

	Proposed question	Rationale
	<p>Introduction and greeting.            Reiterate the time allowed for the interview.            Review the outline for the proposed research as per the information statement emailed.            If not already done so, discuss the Informed Consent form and have this document signed by the participant.            Ask participant if they feel ready to begin the interview.</p>	<p>Build rapport with participant through conversation about their participation – what it requires of them, the time the interview will take.            Orients the participant with the rationale behind the research project and the anticipated aims and outcomes.</p>
<b>Q1</b>	<p>How would you describe the way in which you perceived your (<i>wife, parent, partner, sibling</i>) related with herself prior to diagnosis?</p> <p>Could you describe the quality of life you perceived she had prior to diagnosis?</p>	<p>Linking with participants, developing rapport.            Participants can disclose their perception of relating with self and others pre-diagnosis and treatment.</p>
<b>Q2</b>	<p>What can you tell me about your perception of the impact of treatment in terms of her image of herself?</p> <p style="padding-left: 40px;">a) physically            b) psychologically/emotionally</p>	<p>Beginning to focus on a key theme of the study.</p>
<b>Q3</b>	<p>Have there been any significant and not-so-significant changes in attitudes to life and beliefs about life since being diagnosed and treated? If so, can you tell me something about those changes?</p>	
<b>Q4</b>	<p>Could you tell me something about your perception of the term self-compassion?</p> <p>What does the term mean to you?</p>	<p>Opens topic of reflection or thoughts about the concept of a kind and non-judgmental approach to self.</p>
<b>Q5</b>	<p>From your experience, is there anything more that could be done to promote and encourage a healthy self-relationship with body, mind and feelings for women living with breast cancer?</p>	

## APPENDIX 5

### Interview Schedule: Counsellors who have worked with survivors of BC

	Proposed question	Rationale
	<p>Introduction and greeting.            Reiterate the time allowed for the interview.            Check on their understanding of the timeframe to ensure there is sufficient time for the interview.            Review the outline for the proposed research as per the plain language statement emailed.            If not already done so, discuss the Informed Consent form and have this document signed by the participant.            Ask participant if they now feel ready to begin the interview.</p>	<p>Build rapport with participant through conversation about their participation – what it requires of them, the time the interview will take.            Re-orient the participant with the rationale behind the research project and the anticipated aims and outcomes.</p>
<b>Q1</b>	<p>Can you tell me how long you have been working in the field of counselling, and how long and in what context you have been working with women with breast cancer.</p>	<p>Opens the conversation            Participants can disclose how they have experienced this recent time. Can also set a context for consideration of their self-relationship.</p> <p>Provides an insight into the professional exposure to women diagnosed with BC who seek emotional support from counsellors in either breast cancer care organisations or other services.</p>
<b>Q2</b>	<p>What can you tell me about your perception of the impact of treatment in terms of a woman's image of herself            a) physically            b) psychologically/emotionally</p>	<p>Beginning to focus on a key theme of the study.</p>
<b>Q3</b>	<p>What have been your observations about changes in the way a woman relates with herself and others after being diagnosed and treated for breast cancer?</p>	
<b>Q4</b>	<p>Have you observed significant and not-so-significant changes in women's attitudes to life and beliefs about life since their diagnosis and treatment? If so, can you tell me something about those changes?</p>	

<b>Q5</b>	To what extent and in what ways has <b><u>your</u></b> experience of journeying through cancer with this person affected <b><u>your</u></b> attitudes and beliefs about life?	This question provides valuable information about
<b>Q6</b>	Could you tell me something about your perception of the term self-compassion?	Opens topic of reflection or thoughts about the concept of a kind and non-judgmental approach to self.
<b>Q7</b>	What about the idea of self-kindness? From your work with women would you say there is a general understanding of being kind to self? Would you say self-kindness is something women allow to nurture themselves?	
<b>Q8</b>	From your professional experience is there anything more that could be done to promote and encourage a healthy self-relationship with body, mind and feelings for women living with breast cancer?	

## APPENDIX 6

### Observations from Session 1 of the Breast Cancer Participants' Personal Reflection Program

#### SESSION 1

Friday, October 5, 2012

Facilitator: HW (researcher)

Co-facilitator – 'Leisbeth' (not her real name)

**STEP 1:** Each person gave a brief introduction of themselves to Leisbeth

**STEP 2:** HW (already known to participants) and Leisbeth introduce themselves to group members. Discussion about the plan for the four-hour session and the aims of the session. Outline given of the types of activities to be offered and the process of sharing at the end of each activity. The women were invited to share only what they felt comfortable with. It was made clear that there was no expectation of how they would or should 'do' the activities or the extent of personal disclosure within the group. Space and time was allowed for any questions about arts-based activities. Participants were informed they could choose to not participate in any or all activities.

**STEP 3:** After allowing some time to address the practical aspects of the session and settle in we began the expressive therapies program with a 'warm up activity' - *Drawing on My Thoughts and Emotions*. This activity involved using crayons, and other art materials supplied by the researcher/facilitator. Participants were invited to 'warm up' with three drawings; the instructions given were not about 'doing' a drawing, but to engage in slow gentle breathing, to soften the gaze, and see what came to mind in response to several guiding words about different feelings.

***First drawing:*** participants were invited to use colours lines and shapes to represent something that goes with how they were feeling in the present moment.

**Second drawing:** participants invited to use colours, lines, shapes to represent thoughts that emerge as I think about the things I like most about myself.

**Third drawing:** participants then invited to be ‘open’ to whatever thoughts come into their mind and to choose colours, lines, shapes that might reflect those thoughts.

The format of this activity was to make ‘contact’ with feelings being experienced in the present, then to turn thoughts to positive things about the self, and then to open the process to something that might emerge from the process of doing the first and second images.

**Outcome:** All participants engaged eagerly - to my surprise. After completion of the third drawing, the ‘space’ was opened for a group sharing. Again, there was little hesitation in participation in this group discussion.

Shirley began the sharing. She said she had drawn balloons, because releasing balloons is, for her, a happy thing to do. Shirley had just suffered a recent bereavement of a young grandson killed in an active war zone. Shirley repeated many times during the four-hour session that “I can’t draw”. Despite making these statements Shirley engaged well with the activities and the tentativeness when using crayons to express herself seemed to ease by the time we reached the final art-based activity for the day.

Lara had also engaged in the art activity, and when sharing, commented: “when the word cancer comes to you, you discard anything that is not precious in your life. You quickly decide what you want to keep and what you want to throw out”. Lara went on to refer to this as not only an outer process, but primarily an inner one.

Geneva commented that counselling should be integrated into the care ‘package’ for cancer patients, saying, “they don’t even know they need it, and while you’re told about it, I doubt very many people would take up the suggestion”. After the group sharing, we moved on to an activity using miniature objects as a means of finding different language to express.

***Here and Now:*** This activity used miniature objects and words for thoughts, for mood/feelings and what I would like to have for myself for today. The aim of this activity was to guide participants to find a focal point or intention for something they would like to gain from taking part in the PRP. Participants were thoughtful and reflective in the choosing of the miniature objects (see images at pp. 418-424). Again, I was pleasantly surprised at the level of engagement with the process of experiential activities that would stimulate deeper thinking. The women were each able to enter the sharing phase with relative ease. Their sharings had a poignancy as they reflected on what they would like to have for themselves. Comments included having the feeling of freedom and peace, as well as a return to some fun moments in life indicated both the strain of the journey they were on in combination with what could be interpreted as a vision for their own future.

***Body outline drawing:*** This activity devised in 1988 by Mark Pearson, invited the women to draw a body outline ('gingerbread person' shape). The rationale and steps of the activity as outlined in Pearson and Wilson (2009) were explained. Participants were then given time to scan through the body and to map on the outline anything they found. As a final part of the activity, participants were invited to sit back, take some deep breaths and see if they could imagine a place inside where a flower or flowering plant was growing. They were then asked to imagine what the flower would be, and what it might mean, or what is happening to the flower/plant. They then drew the flower somewhere on the page, either in the body outline shape or out to the side. Flowers 'found/imagined' by participants included – boronia "growing right under my nose" (this was connected to memories of childhood and pleasant remembrances brought forward by the fragrance of brown boronia), lotus flower (two participants imagined a lotus flower), another imagined Singapore orchids, and for another participant a red rose was the flower 'found' (she shared with the group that this was because she loved red roses).

Each group member was invited to engage in a homework activity for personal reflection before we meet in one week's time: The homework was a journal writing activity and to take time to do another Body Map. They were asked to write a brief question and answer dialogue with their body (based on Progoff's dialogue with the body). The suggestion was for each person to do the 'homework' activities once

over the coming seven days. All agreed they would take time for reflection, however, the suggestion to the group was to take a mindful approach to the homework. This meant to undertake the activities as a time for self-reflection, an opportunity to discover more about themselves rather than as a process to be completed for someone else and the results returned to an authority figure or 'teacher'. The invitation was to do the activity only if they wanted to and felt it would be useful for giving time to their own wellbeing.

**Researcher's observations:** We're off to a good start! Everyone seems open to connecting with each other. They seem very happy to include Leisbeth in their discussions. I was concerned the expressive therapies activities could cause some of the women to feel ill at ease. In particular I was concerned about the emergence of negative comparisons and evaluation of their creative 'products' in the session. This was not the case. There was a lot of laughter even in spite of a background of deep sadness for Shirley whose grandson had been recently died.

I noticed that the women commented many times during the day that they felt having this small group was a great benefit for them. Two of the group were not feeling calm and relaxed in themselves (one was recently bereaved, and one did not specify exactly why her mood was unsettled). Validation and acceptance given in verbal statements by the remaining group members meant that both women felt nurtured and cared for by the group.

Comments from each woman were deeply personal although not related to cancer or their illness experience. Discussions were about the details of their lives in the moment, what they were struggling with personally and emotionally, what they were enjoying, and what they hoped to do in the future. An indication of their moving into a new life was in the example of one woman who brought her camera and took close-up photos of flowers in the garden where we met. She commented that she had realised how much she loved taking photographs. One person commented that the best thing about the group was that none of the women belonged to her past, so they had no link to, or investment in, the previous 'life' she had lived.



Another surprising aspect of this first meeting was that the women talked openly about their relationships with significant others in their lives. Most of the dialogue centred around what sounded like quiet resignation about feeling a lack of the support they felt they needed. Their perception was that support had not been forthcoming from partner or family. Lara commented that “others just don’t understand [about BC], that’s why this small group is so important [to me]”.

Prior to ending the group the women realised they all enjoyed going to see a movie. A decision was then made to meet each month for a movie and lunch date so as to keep contact. This seemed a very positive step forward. The women had decided to meet simply because they enjoyed each other’s company and wanted to extend the social contact.

Part of my debrief after the first session was to prepare a list of possible activities for the next session in three week’s time. It seemed helpful to take time this afternoon to reflect on what happened in the group and then think about the direction that could be taken in the next session.

Each of the subsequent sessions had a prepared format that could be followed. My observation was that with each session more time was needed for the women to discuss with each other the changes they had been making in their lives since the previous session. Changes included taking a holiday, not worrying so much about having things done around the house, taking time to indulge in creative pursuits, and, importantly, making time to meet with each other on a regular basis to share lunch and talk.

## **APPENDIX 7**

### **Images of art responses by women survivors to creative arts activities in the Personal Reflection Program**

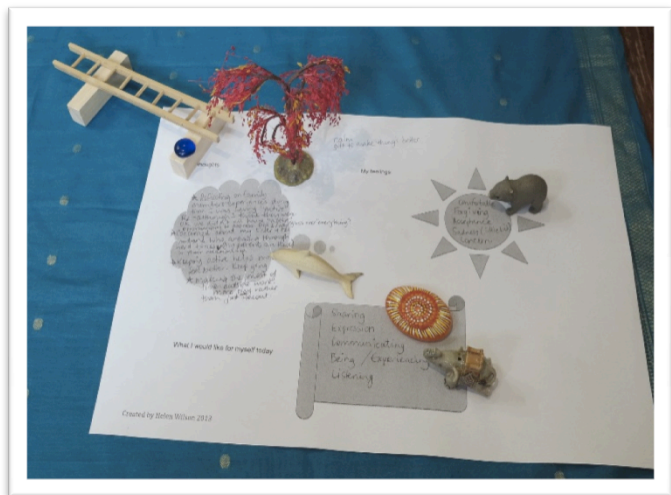
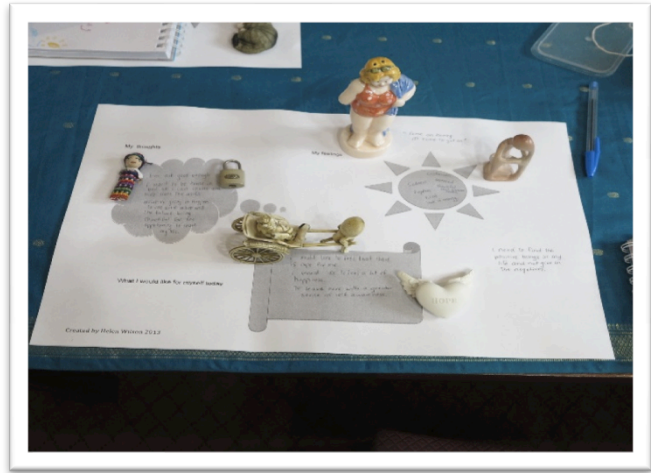
#### **Personal Reflection Program (PRP) sessions**

As a result of requests from participants, they were re-assured any artefacts created during these experiential sessions would not be analysed as a means of extracting significant data. They were asked if they would, however, be willing to allow photographs of their work to be included in the final thesis. Assurance was given those images would be accompanied by minimal comment and would be used only as a way to highlight an overall theme or therapeutic experience. The process of the group interactions and participant involvement in those sessions was monitored and observed by the researcher using the concepts of participant observation research. Notes made immediately on completion of sessions served to emphasise or highlight themes that had emerged from both individual interviews, and the OtSC sessions.

No images have been included of the body outline drawing activity. While participants engaged well with this activity the images created were not offered for inclusion in this thesis. The body outline drawing was created by each participant and this was then followed by an invitation to ‘search’ for a range of feelings (nominated by the facilitator) in the body and to record what was ‘found’ using colours, lines and shapes on the body outline. Some of the images had scant details recorded in response to prompts such as “where in your body do you feel a sense of happiness?” or “where in your body do you feel a sense of sadness?”. Other body outline drawings were complex and detailed with brightly coloured markings.

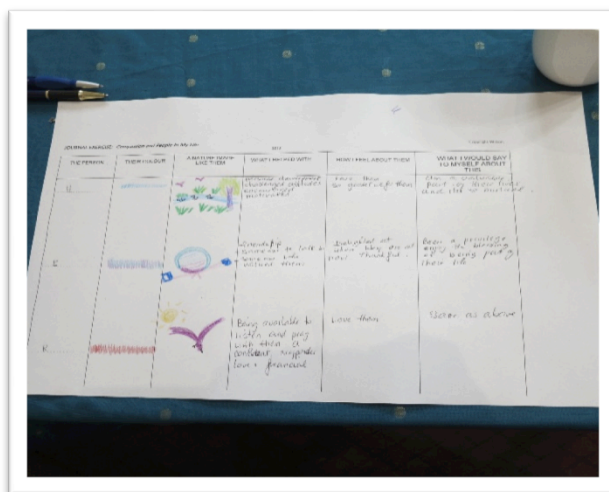
1 Warm-up activities using writing and selecting miniature objects to record thoughts, feelings and hoped for outcome for themselves from the sessions. Words such as “life sparkles”, “peace”, and “freedom” were used. The women enjoyed this

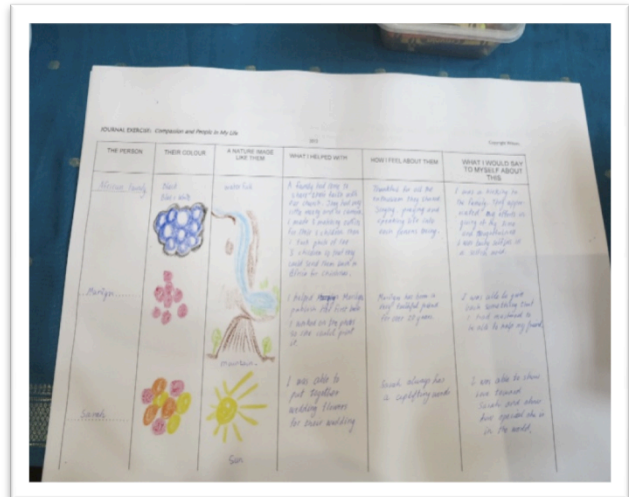
activity and shared openly. Two different representations of the worksheet were presented: The first two images are one format, the second three images show the worksheet formatted slightly differently but with the same themes.



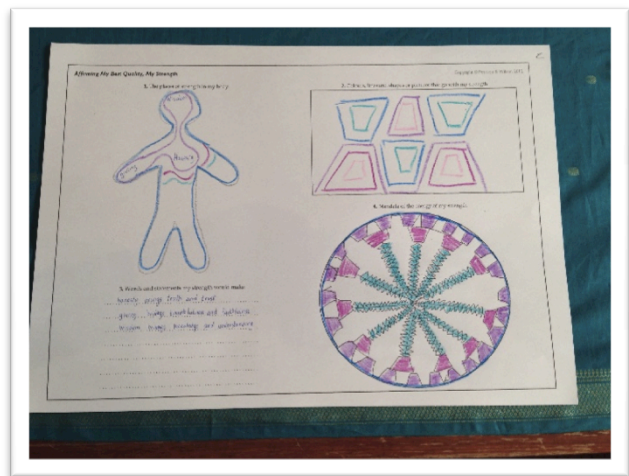


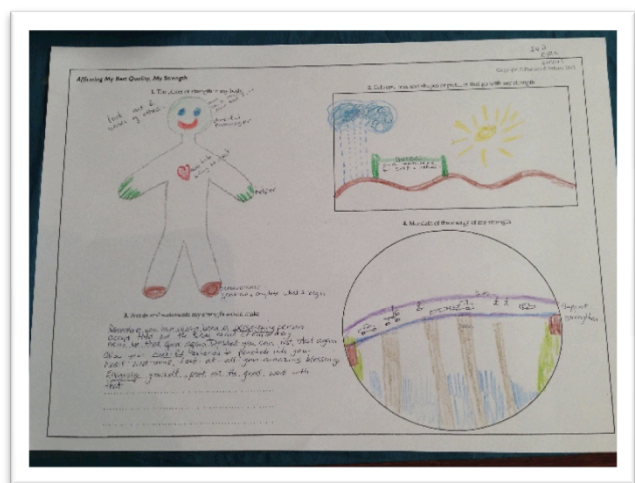
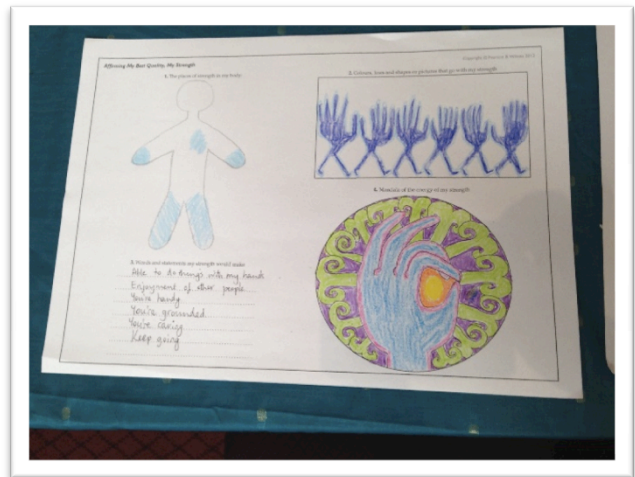
2 Drawing/writing activity as a catalyst for self-recollection of times when compassion was offered to others and what that has meant for my sense of self. The last section of the worksheet asked participants to record what they would say to themselves about the compassion they offered others.



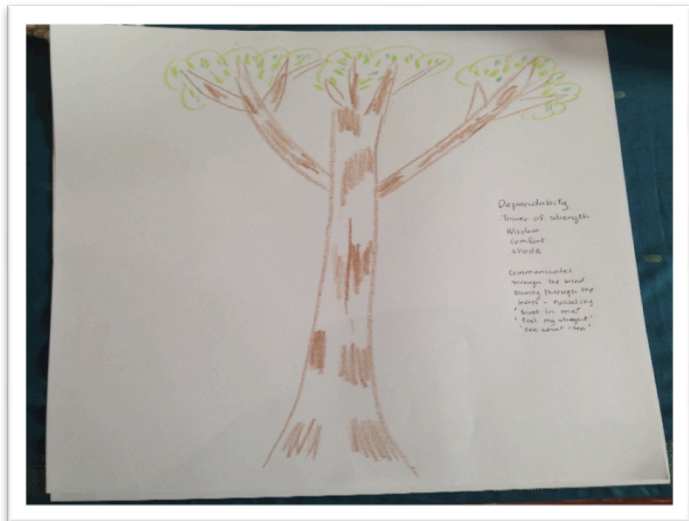
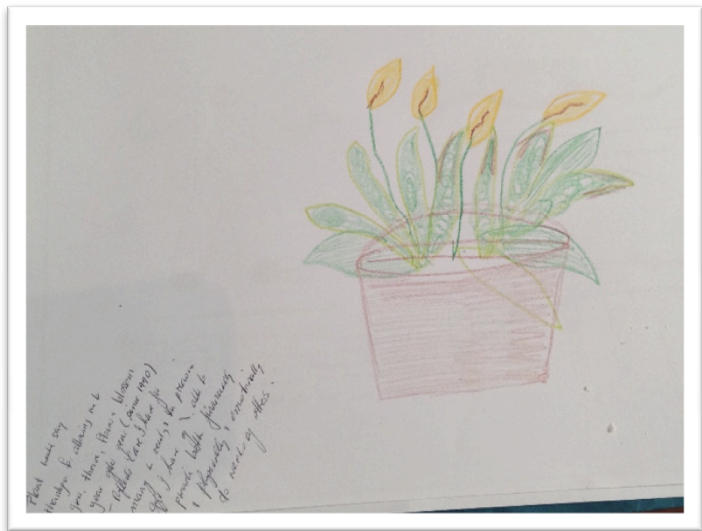
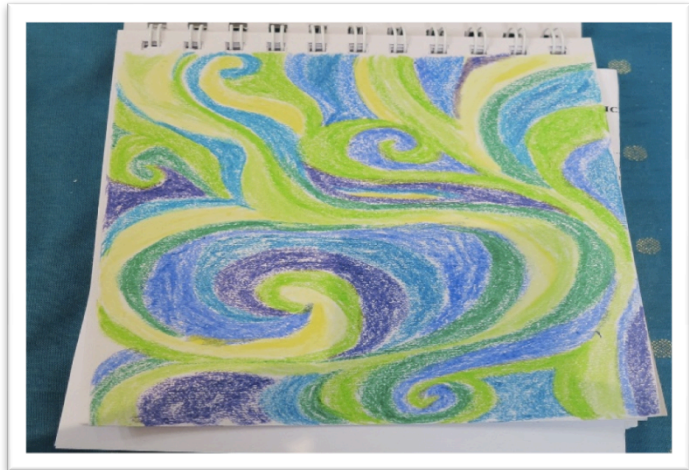


3 A self-discovery worksheet afforded opportunity for a participant to consider a personal characteristic that she regarded as a ‘strength’ (perhaps previously unrecognised or undervalued) and that could support a positive sense of self during survivorship.





4 An activity about affirming self, finding the meaning in their strength and to depict this using colours, lines, shapes or images. After the art process participants had time then to reflect and record their thoughts in words using the image as a reflection point. Participants enjoyed finding and depicting a personal strength and the meaning of that strength for their life.



5 'Free' painting with watercolours was a time at the end of each session when the women explored using colours, lines and shapes as a completion, integration,

activity for ending each PRP session. There was no instruction given other than to experiment, 'play' and allow an image to emerge on the page. This was a particularly pleasurable time for each of the women. After completion of the research project one participant chose to have one of her paintings framed to hang on her living room wall.







#### AND ...THE FINAL WORD

In the final personal reflection session one participant said she enjoyed “just having fun with colours”. Another participant commented about using watercolours and wet paper to explore the ‘unknown’ as a self-expressive activity, saying “*We should’ve done this [expressive therapies] sooner... we’d have told you a lot more...*”

## **APPENDIX 8**

### **Summary of Researcher's Personal Reflection Journal**

Over the course of this PhD I encountered a range of questions, feelings, and ponderings about what it means to be kind to oneself and to develop an abiding self-love despite life circumstances. Preconceived notions I had about self-compassion were tested. Assumptions I had made about women and their self-relationship were constantly reviewed. I felt in awe of the capacity of women to soothe and nurture others who experience physical or emotional pain while at the same time feeling isolated or struggling to make sense of things in their own lives.

The interview process with 17 women brought me sharply face to face with breast cancer. The discussions with these women forced me to reflect on the aim of my research. The focus group sessions offered me an opportunity to discover more about how life post-BC was influenced and shaped by what had happened prior to diagnosis and what had happened for the women during treatment for the disease. The personal reflection program brought me into a much deeper understanding of the uniqueness of each woman.

My thought processes began to wrestle with a psychodynamic query. This query was that while breast cancer had brought each of the women into the research project, and while some of the life changes they made after treatment ended sounded very familiar, each woman's intimate relationship with themselves before BC continued to 'colour' the lens through which they 'saw' life as a survivor.

As each phase of the project unfolded I found it more possible to separate from the 'therapist self' and take on the occasional role of the naive observer. This shift was made more possible through a constant reminder to myself that the role of researcher working with a potentially vulnerable population involved acute awareness of the fact that the women had not requested any therapeutic intervention.

The women were interested, primarily, in sharing the narrative of their experience, most probably for the benefit of women who may be diagnosed in the future. The key focus was to gain participants' perceptions of their illness; in essence, was that perception negative or positive. I saw my role as simply a conduit for open discussion about living post-BC. This became more pertinent as I worked through the verbatim transcripts. I regarded my role was also to report the findings in a way that could both advantage future users of breast cancer care services, and bring to attention the potential for BC survivors to build capacity for self-kindness.

My intention to complete this PhD in as short a time as possible meant I thought I could listen to the interviews, transcribe them and discover themes quite quickly. Brief notes I made at the time recorded my sense of “deep sadness – even sorrow - at what I am now hearing as if for the first time. And, not my grief but an existential sadness.”. The interviews with the three significant others left me with a profound sense of the challenges inherent in the journey partners, husbands and loved ones make as they move through BC as if “looking at the event through a veil, not fully in the experience, and yet unable, for the most part, to extricate themselves from the experience (almost) of voyeur and captive”. One of the husbands interviewed gave me a wake-up call to the intense need for others to feel heard about their experience. His words when I first greeted him at the appointed time and place for our interview indicated the distress he had been feeling when he announced that he was pleased to finally get the “chance to tell my story”.

One of the most immediate challenges for me involved the need, and desire, to manage a dynamic tension between my training as a counsellor and my role as a researcher. With each response to questions in the interviews I found myself tempted to ask a question that would take the participant into some self-exploration. To resist that internal urge to ‘cure’ a participant’s emotional disorientation and discomfort through ‘caring’ meant holding a focus on an awareness that being ‘cured’ of that discomfort may be the very thing that could inhibit acceptance - or provision - of compassionate ‘care’ from self or others. This challenge involved being able to bear silent witness to narratives of physical suffering, emotional and social dislocation, as well as to stories that reverberated with subtle and not-so-subtle reminders of a general and lifelong lack of self-worth, and frequent negative self-evaluation. Yet,

participants seemed to have accepted an unspoken ‘rule’ that they were the ones who had to make family relationships work. I wondered how these women went about proving their worth and wondered also whether they had relied on their willingness to accept the socialised messages about what they had to do to be regarded as a ‘good’ woman.

My way of maintaining separation between the role of researcher and the professional of counsellor was to reflect on the interaction with each woman and to create brief notes about my thoughts. Some extracts from those notes reveal thoughts about women’s ways of coping, of managing, and of experiencing their external world. For example, one of my notes commented that “Carole became a completely different person when she laughed. Who might she be? I wonder what brings light and joy to life for her?”. This note was in response to an observation that one participant in the personal reflection sessions carried a demeanour that could be interpreted as a person who was very unhappy with life. The ‘face’ shown to the world was very different to the vibrant, capable, jazz-music loving person the group met as we worked through the PRS. Another note I had made held the comment “each of the women seems engaged in consolidating a new narrative about who they are or who they now want to be”. Another reflective note highlighted my impression of the “defining experience” that BC was for each of the women. That same note went on to question whether these women had ever had time and space in which to recognise and acknowledge personally defining moments. My note states “they may not have been aware of defining moments before their BC. Apart from childbirth it sounds as though they have carried on through life without too much fuss made of their defining moments”. A further note reflected my wondering whether their BC experience would eventually be placed in that same ‘treasure chest’ of internalised experiences that they relegate to the ‘background of life’, and from which they will move on back into a way of life with much about it that is reminiscent of how they related with themselves and others in the past. “BC has brought them to this moment of re-arranging their life in a way that brings an opportunity to make the shift from survival, to what a client many years ago called ‘thrival’? Before exit comes existence ... a question to ponder about illness”.

Another strategy to maintain a deeply reflective stance on the participants' data was to engage in creating my own sandplay on a regular basis. This step was taken to make sure I could continue to step aside from a mindset influenced by my own perceptions of what kindness and warmth to oneself meant. Taking time to use the reflective space that creation of a sandplay image can offer assisted the process of 'holding' the moment of difficult feelings rather than using that moment as a springboard to the next action step. Each sandplay image was kept intact for several days to allow further contemplation. Time to reflect on the image and allow deeper knowing of self to grow was a reminder of the how a person could benefit from self-compassion. Creation of a sandplay helped me externalise, symbolically, the questions I had and the tension I experienced. The images created in the Sandtray were reviewed with a qualified Sandplay Therapist whose support helped me to not, unwittingly, obscure clarity. Persistent themes in the images created at the time of reviewing all data collected for this project were "facing options", "alone with the struggle", "fear of the unknown", "hidden gifts" in addition to themes that reflected concerns about honouring the stories of participants. Four images taken from the series of process Sandplays are included here (pp.430-432).

### **Looking through different eyes**

For the first personal reflection session a co-facilitator joined the group. This step had received ethical clearance prior to commencement of the project. After that group session, 'Leisbeth' the co-facilitator and I met to debrief about what had happened. This helped me maintain objectivity. Leisbeth commented that "this group is very important to these women ... it doesn't have the shroud of breast cancer." During the four hours of the group Leisbeth observed the women as "recognising profound moments of experiencing themselves.". One particular comment about a participant was that "she presents as a tough little thing, but she's a lot softer than she presents. She's very loving but doesn't know any other way to be except tough on the outside.". Another observation Leisbeth commented on related to her experience of Shirley. What Leisbeth felt she experienced with Shirley was that "the death of her grandson has helped her open up and acknowledge the depth of her feeling-self".

In the debrief with Leisbeth we also discussed breast cancer through a metaphor of “the other lover”. Our discussions led us to ponder whether BC in the ‘form’ of that other lover could be seen as demanding of their attention, their physical being, their emotional life, intimacy, and their body. The conversation went on to wonder whether the encounter with this unanticipated ‘lover’ had brought to light old ways of being that no longer served them well. ‘Kissed by breast cancer’ was a metaphor we discussed. In following the creative thoughts of that metaphor we explored between ourselves the idea of BC as a type of ‘kiss of life’ that awakened each participant from a sleep about who they were, their self-worth, and the value of their life. Part of my thinking looped around whether this particular group of women had led a life in which service for others meant life had become over-domesticated and had therefore ‘lost’ contact with essential aspects of themselves. BC may have brought release from constriction, which activated the potential for freedom from previously unquestioned constraints. Leisbeth and I agreed that our ponderings could definitely not be indicative of or relevant to the experience of the larger proportion of women survivors of BC. The ideas had connection only with our experience of this particular Western Australian group of women.

When it came to discussion of self-compassion during the interviews, focus group sessions, or the personal reflection sessions, I found I was constantly drawn to looking at the whole person and their life story and particularly how it related to the central tenets of self-compassion, not just the story relevant to their illness and subsequent survival experience. An alertness to there being a sense of a ‘wounded self’ in each of the women began to grow. Interest in a link between childhood attachment experiences and self-compassion in women’s adult life generated a deeper interest in the residual power of negative familial injunctions. I wondered if these injunctions may have accidentally (or, sadly on purpose) eroded a capacity for women to value their feminine nature and to without question turn inward the care, love and support they learned to give others.

In the OtSC group sessions what stood out was that the topic of intimacy, sensuality and sexuality was ‘skirted’ around. This was not a comfortable topic for the women. There was a definite sense of disenfranchisement from their essential feminine nature, gauged through the non-specific responses given during the OtSC

group sessions. The original question asked sought to gain information about possible detrimental effects of BC on women's sense of themselves as a sensual and sexual being. Typically, responses given were practical examples of ways of relating with self through increased personal care. Some examples were buying pretty underwear, wearing different colour wigs, attending make-up classes, and socialising more when possible.

What seemed puzzling was the remnants of concern in women participants about bringing shame on themselves if they were to respond to the needs of others from a purely self-focussed way. In other words, the concern they had was related to shame they would feel if they were 'judged' by self or others as being selfish. It seemed that being of service to others meant to place self-need at the end of the list of things needing attention.

These notes from my recorded observations of the first PRP session have been included to provide context and a sense of the group format and processes involved in participation.



Sandplay 1 – July, 2014 - *A new land with light and dark. The analysis of the data reveals commonalities and contradictions. BC seems a world of paradox, growth*

*and an unfamiliar land (building on top of the mound). Wisdom and trust are needed to guide the 'visitor' to new and unfamiliar surroundings.*



*Sandplay 2 – September, 2014 - Thinking and organising – feeling as though I need to be highly organised so there is a structure to hold the 'whole' of the body of work. My brain hurts – it is working overtime on a labour of love.*



*Sandplay 3 – May 2015 - Voyaging to an uncertain destination – at this stage it seems as if analysis of the findings is luring me into a more and more indistinct world of words while at the same time I have a sense of being guided to go through a*



*more narrow aperture than I had seen before or, upon glimpsing the path forward, do not think it possible to confidently move forward.*



*Sandplay 4 – November, 2016 - Still some hurdles. This sandplay represented the process of bringing together all elements of the thesis. There were the gleaming jewels (findings), the portal (discussion), and the corralled section where emergence from mystery into light would hopefully happen (implications of SC for counselling and relevance of SC for counselling). To the upper left of the sandtray was the goal – peaceful and reflecting the colour blue: a colour of harmony.*

*The Sandplay process was continued until August, 2017. In 2017 weekly sandtrays were completed and discussed with a qualified Sandplay Therapist as a means of keeping the vision and passion alive and to move forward to the point of completion.*

## References

- Acitelli, L. K., & Badr, H. J. (2005). My illness or our illness? Attending to the relationship when one partner is ill. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples coping with stress: Emerging perspectives on dyadic coping* (pp. 121-136). Washington, D.C.: American Psychological Association.
- Aguirre-Camacho, A., Pelletier, G., Gonzalez-Marquez, A., Blanco-Donoso, L. M., Garcia-Borreguero, P., & Moreno-Jimenez, B. (2017). The relevance of experiential avoidance in breast cancer distress: Insights from a psychological group intervention. *Psycho-Oncology*, 26(4), 469-475. doi:10.1002/pon.4162
- Ahmed, K., Marchand, E., Williams, V., Coscarelli, A., & Ganz, P.A. (2016). Development and pilot testing of a psychosocial intervention program for young breast cancer survivors. *Patient Education and Counseling*, 99, 414-420. doi:10.1016/j.pec.2015.09.014
- Aisbett, D. L. (2006). Interpretive phenomenological approaches to rural mental health research. *Rural Social Work & Community Practice*, 11, 52-58.
- Akin, A. (2010). Self-compassion and interpersonal cognitive distortions. *Hacettepe Universitesi Journal of Education*, 31, 01-09.
- Akin, U. (2014). Self-compassion as a predictor of proactivity. *International Online Journal of Educational Sciences*, 6(1), 103-111. Retrieved from <http://dx.doi.org/10.15345/ijoes.2014.01.011>
- Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education & Literacy Studies*, 5(2), 9-19. Doi:10.7575/ajac.ijels.v.5n.2p.9
- Alfano, C. M., & Rowland, J. H. (2006). Recovery issues in cancer survivorship: A new challenge for supportive care. *Cancer Journal*, 12(5), 432-443. doi:10.1097/00130404-200609000-00012
- Alma, H. A. (2008). Self-development as a spiritual process: The role of empathy and imagination in finding spiritual orientation. *Pastoral Psychology*, 57(1/2), 59-63. doi:10.1007/s11089-008-0168-4
- Alma, H. A., & Smaling, A. (2006). The meaning of empathy and imagination in health care and health studies. *International Journal of Qualitative Studies on Health and Well-Being*, 1(4), 195-211. doi:10.1080/17482620600789438
- Anderson, B. O. (2014). Breast cancer: Thinking globally. *Science*, 343(6178), 1403. doi:10.1126/science.1253344
- Ando, N., Iwamitsu, Y., Kuranami, M., Okazaki, S., Nakatani, Y., Yamamoto, K., . . . Miyaoka, H. (2011). Predictors of psychological distress after diagnosis in breast cancer patients and patients with benign breast problems. *Psychosomatics*, 52(1), 56-64. doi:<http://dx.doi.org/10.1016/j.psych.2010.11.012>
- Andreu, Y., Galdón, M. J., Durá, E., Martínez, P., Pérez, S., & Murgui, S. (2012). A longitudinal study of psychosocial distress in breast cancer: Prevalence and

- risk factors. *Psychology & Health*, 27(1), 72-87.  
<http://dx.doi.org/10.1080/08870446.2010.542814>
- Arch, J. J., Brown, K. W., Dean, D. J., Landy, L. N., Brown, K. D., Laudenslager, L. N. (2014). Self-compassion training modulates alpha-amylase, heart rate variability, and subjective responses to social evaluative threat in women. *Psychoneuroendocrinology*, 42, 49-58. doi:10.1016/j.psyneuen.2013.12.018
- Arman, M., & Rehnsfeldt, A. (2003). The hidden suffering among breast cancer patients: A qualitative metasynthesis. *Qualitative Health Research*, 13, 510-527. doi:10.1177/1049732302250721
- Arraras, J. I., Wright, S. J., Jusue, G., Tejedor, M., & Calvo, J. I. (2002). Coping style, locus of control, psychological distress and pain-related behaviours in cancer and other diseases. *Psychology, Health & Medicine*, 7(2), 181-187. Retrieved from  
<http://search.ebscohost.com.ipacez.nd.edu.au/login.aspx?direct=true&db=s3h&AN=6428837&site=ehost-live&scope=site>
- Ashing-Giwa, K. T., Oadilla, G. V., Tejero, J. S., & Kim, J. (2004). Breast cancer survivorship in a multiethnic sample: Challenges in recruitment and measurement. *Cancer*, 101(3), 450-465. doi:10.1002/cncr.20370
- Ashworth, P. (1999). "Bracketing" in phenomenology: Renouncing assumptions in hearing about student cheating. *Qualitative Studies in Education*, 12(6), 707-721. doi:10.1080/095183999235845
- Augustin, L. S. A., Libra, M., Crispo, A., Grimaldi, M., De Laurentiis, M., Rinaldo, M., . . . Montella, M. (2017). Low glycemic index diet, exercise and vitamin D to reduce breast cancer recurrence (DEDiCa): Design of a clinical trial. *BMC Cancer*, 17(1), 69. doi:10.1186/s12885-017-3064-4
- Australian Government, Department of Jobs and Small Business (n.d.). Job Outlook: Counsellors. Located at:  
<https://joboutlook.gov.au/occupation.aspx?code=2721>
- Australian Institute of Health and Welfare. (2017). Cancer in Australia: In brief 2017. *Cancer series no. 102. Cat. no. CAN101*. Retrieved from  
<http://www.aihw.gov.au/publication-detail/?id=60129558546>
- Averill, J. R. (2012). The Future of social constructionism: Introduction to a special section of Emotion Review. *Emotion Review*, 4(3), 215-220. Retrieved from doi:10.1177/1754073912439811
- Avila, M., Coimbra, J. L., Park, C. L., & Matos, P. M. (2017). Attachment and posttraumatic growth after breast cancer: A dyadic approach. *Psycho-Oncology*, 26, 1929-1935. doi:10.1002/pon.4409.
- Baker, L. R., & McNulty, J. K. (2011). Self-compassion and relationship maintenance: The moderating roles of conscientiousness and gender. *Journal of Personality and Social Psychology*, 100(5), 853-873. doi:10.1037/a0021884
- Baník, G., & Gajdošová, B. (2014). Positive changes following cancer: Posttraumatic growth in the context of other factors in patients with cancer. *Supportive Care in Cancer*, 22(8), 2023-2029. doi:10.1007/s00520-014-2217-0
- Banks, T., Pearce, S., French, H., Lloyd, A.-M., & Lewis, I. (2017). Counselling for people affected by cancer: The impact outside a healthcare setting. *Counselling and Psychotherapy Research*, 17(3), 227-233. Retrieved from  
<http://dx.doi.org/10.1002/capr.12131>
- Barlow, M. R., Goldsmith Turow, R. E., Gerhart, J. (2017). Trauma appraisals, emotion regulation difficulties and self-compassion predict posttraumatic

- stress symptoms following childhood abuse. *Child Abuse and Neglect*, 65, 37-47. doi:10.1016/j.chiabu.2017.01.006
- Bateman, A., & Fonagy, P. (2013). Mentalization-based treatment. *Psychoanalytic Inquiry*, 33(6), 595-613. Retrieved from doi:10.1080/07351690.2013.835170
- Baucom, D. H., Kirby, J. S., Pukay-Martin, N. D., Porter, L. S., Fredman, S. J., Gremore, T. M., . . . Atkins, D. (2012). Men's psychological functioning in the context of women's breast cancer. *Journal of Marital and Family Therapy*, 38(2), 317-329. doi:10.1111/j.1752-0606.2009.00133.x
- Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., Wiesenthal, N., Aldridge, W., . . . Keefe, F. J. (2009). A couple-based intervention for female breast cancer. *Psycho-Oncology*, 18(3), 276-283. doi:10.1002/pon.1395
- Beasley, J., Newcomb, P., Trentham-Dietz, A., Hampton, J., Bersch, A., Passarelli, M., . . . Willett, W. (2011). Post-diagnosis dietary factors and survival after invasive breast cancer. *Breast Cancer Research and Treatment*, 128(1), 229-236. doi:10.1007/s10549-010-1323-z
- Beatty, L., & Kissane, D. (2017). Anxiety and depression in women with breast cancer. *Cancer Forum*, 41(1), 55-61. doi:10.15345/iojes.2014.01.011
- Becker, H., Henneghan, A., & Mikan, S. (2015). When do I get my brain back? Breast cancer survivors' experiences of cognitive problems. *Clinical Journal of Oncology Nursing*, 19(2), 180-184. doi:10.1188/15.CJON.180-184
- Bell, K. (2014). The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease. *Social Science & Medicine*, 110, 56-63. doi:org/10.1016/j.socscimed.2014.03.031
- Ben-Arye, E., & Visser, A. (2012). The role of health care communication in the development of complementary and integrative medicine. *Patient Education and Counseling*, 89(3), 363-367. doi:10.1016/j.pec.2012.10.003
- Bennett, J. A., Winters-Stone, K. M., Dobek, J., & Nail, L. M. (2013). Frailty in older breast cancer survivors: Age, prevalence, and associated factors. *Oncology Nursing Forum*, 40(3), E126-E134. doi:10.1188/13.ONF.
- Bennett, K. K., Compas, B. E., Beckjord, E., & Glinder, J. G. (2005). Self-blame and distress among women with newly diagnosed breast cancer. *Journal of Behavioral Medicine*, 28(4), 313-323. doi:10.1007/s10865-005-9000-0
- Benoit, L., Veach, P., & LeRoy, B. (2007). When you care enough to do your very best: Genetic counselor experiences of compassion fatigue. *Journal of Genetic Counseling*, 16(3), 299-312. doi:10.1007/s10897-006-9072-1
- Berry, K. A., Kowalski, K. C., & Ferguson, L. J., McHugh, T. -L. F. (2007). An empirical phenomenology of young adult women exercisers' body self-compassion. *Qualitative Research in Sport and Exercise*, 2(3), 293-312. doi:10.1080/19398441.2010.517035
- Bessen, T., Chen, G., Street, J., Elliott, J., Karnon, J., Keefe, D., & J Ratcliffe, J. (2014). What sort of follow-up services would Australian breast cancer survivors prefer if we could no longer offer long-term specialist-based care? A discrete choice experiment. *British Journal of Cancer*, 110, 859-867. doi:10.1038/bjc.2013.800
- Bettencourt, B. A., Talley, A. E., Molix, L., Schlegel, R., & Westgate, S. J. (2008). Rural and urban breast cancer patients: Health locus of control and psychological adjustment. *Psycho-Oncology*, 17(9), 932-939. doi:10.1002/pon.1315
- Birnie, K., Speca, M., & Carlson, L. E. (2010). Exploring self-compassion and empathy in the context of Mindfulness-Based Stress Reduction (MBSR).

- Stress & Health: Journal of the International Society for the Investigation of Stress*, 26(5), 359-371. doi:10.1002/smi.1305
- Bitsika, V., Sharpley, C. F., & Christie, D. R. H. (2010). 'What made me unhappy'. Experiences of, and responses to, lifestyle changes in breast cancer patients. *British Journal of Guidance & Counselling*, 2, 179-189. doi:10.1080/03069881003601015
- Björneklett, H. G., Lindemalm, C., Ojutkangas, M. L., Berglund, A., Letocha, H., Strang, P., & Bergkvist, L. (2012). A randomized controlled trial of a support group intervention on the quality of life and fatigue in women after primary treatment for early breast cancer. *Supportive Care in Cancer*, 20(12), 3325-3334. doi:10.1007/s00520-012-1480-1
- Bleiker, E. M., Hendriks, J. H., Otten, J. D., Verbeek, A. L., & van der Ploeg, H. M. (2008). Personality factors and breast cancer risk: A 13-year follow-up. *Journal of the National Cancer Institute*, 100(3), 213-218. doi:10.1093/jnci/djm280
- Block, K. I., Dafter, R., & Greenwald, H. P. (2006). Cancer, the mind, and the problem of self-blame. *Integrative Cancer Therapies*, 5(2), 123-130. doi:10.1177/1534735406289106
- Boehm, K., Cramer, H., Staroszynski, T., & Ostermann, T. (2014). Arts therapies for anxiety, depression, and quality of life in breast cancer patients: A systematic review and meta-analysis. *Evidence-Based Complementary and Alternative Medicine*, 103297. doi:10.1155/2014/103297
- Bohart, A. C., & Tallman, K. (1999). *How clients make therapy work: The process of active self-healing*. Washington, DC: American Psychological Association.
- Boinon, D., Sultan, S., Charles, C., Stulz, A., Guillemeau, C., Delalogue, S., & Dauchy, S. (2013). Changes in psychological adjustment over the course of treatment for breast cancer: the predictive role of social sharing and social support. *Psycho-Oncology*, 23(3), 291-298. doi:10.1002/pon.3420
- Bolger, N., Foster, M., Vinokur, A. D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology*, 70(2), 283-294. doi:10.1037/0022-3514.70.2.283
- Boutin, D. L. (2007). Effectiveness of Cognitive Behavioral and Supportive-Expressive Group Therapy for women diagnosed with breast cancer: A review of the literature. *The Journal for Specialists in Group Work*, 32(3), 267-284. doi:10.1080/01933920701431594
- Bower, J., Ganz, B., & Aziz, N. (2005). Altered cortisol response to psychological stress in breast cancer survivors with persistent fatigue. *Psychosomatic medicine*, 67(2), 277-280. doi:10.1097/01.psy.0000155666.55034.c6
- Bowlby, J. (1982). Attachment and loss: Retrospect and prospect. *The American Journal of Orthopsychiatry*, 52(4), 664-678. doi:10.1111/j.1939-0025.1982.tb01456.x
- Boyd, C. (2001). Breast cancer: The value and meaning of breasts. *Cancer Forum*, 25(3), 160-161. Retrieved from <https://cancerforum.org.au/article/2001/november/breast-cancer-the-value-and-meaning-of-breasts/>
- Boykin, D. M., Himmerich S. J., Pinciotti, C. M., Miller, L. M., Miron, L. R., & Orcutt, H. K. (2018). Barriers to self-compassion for female survivors of childhood maltreatment: The roles of fear of self-compassion and psychological inflexibility. *Child Abuse & Neglect*, 76, 216-224. doi:10.1016/j.chiabu.2017.11.003

- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research, 4*, 1-8. doi:10.1177/2333393617742282
- Bransen, J. (2015). Self-knowledge and self-love. *Ethical Theory and Moral Practice, 18*(2), 309-321. Retrieved from <https://doi.org/10.1007/s10677-015-9578-4>
- Breines, J. G., & Chen, S. (2012). Self-compassion increases self-improvement motivation. *Personality and Social Psychology Bulletin, 38*(9), 1133-1143. doi:10.1177/0146167212445599
- Breines, J. G., Thoma, M. V., Gianferante, D., Hanlin, L., Chen, X., & Rohleder, N. (2014). Self-compassion as a predictor of interleukin-6 response to acute psychosocial stress. *Brain, Behavior, and Immunity, 37*, 109. doi:10.1016/j.bbi.2013.11.006
- Brennan, M. E., & Houssami, N. (2011). Overview of long term care of breast cancer survivors. *Maturitas, 69*(2), 106-112. Retrieved from <http://dx.doi.org/10.1016/j.maturitas.2011.03.010>
- Brenner, R. E., & Vogel, D. L. (2018). Do self-compassion and self-coldness distinctly relate to distress and well-being? A theoretical model of self-relating. *Journal of Counseling Psychology, 65*(3), 346-357. doi:10.1037/cou0000257
- Brien, M., Stricker, C., Foster, J., Ness, K., Arlen, A., & Schwartz, R. (2014). Navigating the Seasons of Survivorship in community oncology. *Clinical Journal of Oncology Nursing, 18*(1), 9-14. doi:10.1188/14.CJON.S1.9-14
- Brion, J. M., Leary, M. R., & Drabkin, A. S. (2014). Self-compassion and reactions to serious illness: The case of HIV. *Journal of Health Psychology, 19*(2), 218-229. doi:10.1177/1359105312467391
- Broom, B. (1997). *Somatic illness and the patient's other story*. New York, NY: Free Association Books Ltd.
- Broom, B. C., Booth, R. J., & Schubert, C. (2012). Symbolic diseases and “mindbody” co-emergence: A challenge for psychoneuroimmunology. *EXPLORE: The Journal of Science and Healing, 8*(1), 16-25. doi:<http://dx.doi.org/10.1016/j.explore.2011.10.005>
- Brown, R. F., Butow, P. N., Henman, M. J., Dunn, S. M., Boyle, F., & Tattersall, M. H. N. (2002). Responding to the active and passive patient: Flexibility is the key. *Health Expectations, 5*(3), 236-245. doi:10.1046/j.1369-6513.2002.00183.x
- Brunault, P., Champagne, A. L., Huguet, G., Suzanne, I., Senon, J. L., Body, G., . . . Camus, V. (2016). Major depressive disorder, personality disorders, and coping strategies are independent risk factors for lower quality of life in non-metastatic breast cancer patients. *Psycho-Oncology, 25*(5), 513-520. doi:10.1002/pon.3947
- Brüne, M., & Schaub, D. (2012). Mental state attribution in schizophrenia: What distinguishes patients with “poor” from patients with “fair” mentalising skills? *European Psychiatry, 27*(5), 358-364. doi:<https://doi.org/10.1016/j.eurpsy.2010.10.002>
- Bulsara, C., Styles, I., Ward, A. & Bulsara, M. (2006). The psychometrics of developing a Patient Empowerment Scale. *Journal of Psychosocial Oncology, 24*(2), 1-16. 10.1300/J077v24n02\_01
- Bulsara, C., Ward, A., & Joske, D. (2004). Haematological cancer patients: achieving a sense of empowerment by use of strategies to control illness.

- Journal of Clinical Nursing*, 13(2), 251-258. doi:10.1046/j.1365-2702.2003.00886.x
- Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M., & Ramirez, A. (2005). Depression and anxiety in women with early breast cancer: Five year observational cohort study. *British Medical Journal*, 330(7493),702. doi:10.1136/bmj.38343.670868.D3
- Burke, S. M., Sabiston, C. M., & Vallerand, R. J. (2012). Passion in breast cancer survivors: Examining links to emotional well-being. *Journal of Health Psychology*, 17(8), 1161-1175. doi:10.1177/1359105311429202
- Bussell, V. A., & Naus, M. J. (2010). A longitudinal investigation of coping and posttraumatic growth in breast cancer survivors. *Journal of Psychosocial Oncology*, 28(1), 61-78. doi:10.1080/07347330903438958
- Butler, J. (2016). Rediscovering Husserl: Perspectives on the Epoché and the Reductions. *The Qualitative Report*, 21(11), 2033-2043. Retrieved from <http://nsuworks.nova.edu/tqr/vol21/iss11/8>
- Butler, L. D., Koopman, C., Neri, E., Giese-Davis, J., Palesh, O., Thorne-Yocam, K. A., . . . Spiegel, D. (2009). Effects of Supportive- Expressive Group Therapy on pain in women With metastatic breast cancer. *Health Psychology*, 28(5), 579-587. doi:10.1037/a0016124
- Butow, P. N., Fardell, J. E., & Smith, A. (2015). Fear of cancer recurrence: An overview and Australian perspective. *Cancer Forum*, 39(2), 95-100. Retrieved from <http://search.informit.com.au/ipacez.nd.edu.au/documentSummary;dn=289262376228028;res=IELHEA>
- Büyükaşık-Çolak, C., Gündoğdu-Aktürk, E., & Bozo, Ö. (2012). Mediating role of coping in the dispositional optimism–posttraumatic growth relation in breast cancer patients. *The Journal of Psychology*, 146(5), 471-483. doi:10.1080/00223980.2012.654520
- Caelli, K., Ray, L., & Mill, J. (2003). ‘Clear as mud’: Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), 1-13. doi:10.1177/160940690300200201
- Calhoun, L. G., & Tedeschi, R. G. (2014). *Handbook of posttraumatic growth: Research and practice*. East Sussex: Psychology Press.
- Callebaut, L., Molyneux, P., & Alexander, T. (2017). The relationship between self-blame for the onset of a chronic physical health condition and emotional distress: A systematic literature review. *Clinical Psychology & Psychotherapy*, 24(4), 965-986. Retrieved from <http://dx.doi.org/10.1002/cpp.2061>
- Campbell-Enns, H., & Woodgate, R. (2015). The psychosocial experiences of women with breast cancer across the lifespan: A systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, 13(1), 112-121. doi:10.11124/jbisrir-2015-1795
- Campos, R. C., Besser, A., Ferreira, R., Blatt, S. J., & Glazer, S. (2012). Self-criticism, neediness, and distress among women undergoing treatment for breast cancer: A preliminary test of the moderating role of adjustment to illness. *International Journal of Stress Management*, 19(2), 151-174. doi:10.1037/a0027996
- Cancer Australia. (2011). Breast cancer statistics. Retrieved from <http://canceraustralia.nbooc.org.au/breast-cancer/about-breast-cancer/breast-cancer-statistics>

- Cancer Council (2014). Breast cancer in men. Retrieved from <https://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer/breast-cancer-in-men.html>
- Candea, D.-M., & Sventagotai-Tatar, A. (2014). Shame, body image and eating disorders: A conceptual and empirical map. In K. G. Lockhart (Ed.), *Psychology of shame: New research*. Hauppauge, NY: Nova Science Publishers, Inc.
- Cann, A., Calhoun, L. G., Tedeschi, R. G., & Solomon, D. T. (2010). Posttraumatic growth and depreciation as independent experiences and predictors of well-being. *Journal of Loss and Trauma, 15*, 151-166. doi:10.1080/15325020903375826
- Canzona, M. R., Garcia, D., Fisher, C. L., Raleigh, M., Kalish, V., & Ledford, C. J. W. (2016). Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. *Patient Education and Counseling, 99*(11), 1814-1820. doi:10.1016/j.pec.2016.06.019
- Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast cancer survivors: Information and support after treatment. *Clinical Nursing Research, 16*(4), 278-293. doi:10.1177/1054773807306553
- Carlson, L. E., Speca, M., Patel, K. D., & Goodey, E. (2004). Mindfulness-based stress reduction in relation to quality of life, mood, symptoms of stress and levels of cortisol, dehydroepiandrosterone sulfate (DHEAS) and melatonin in breast and prostate cancer outpatients. *Psychoneuroendocrinology, 29*(4), 448-474. Retrieved from [http://dx.doi.org/10.1016/S0306-4530\(03\)00054-4](http://dx.doi.org/10.1016/S0306-4530(03)00054-4)
- Carlson, L. E., Tamagawa, R., Stephen, J. Drysdale, E., Zhong, L., & Speca, M. (2016). Randomised-controlled trial of mindfulness-based cancer recovery versus supportive expressive group therapy among distressed breast cancer survivors (MINDSET): Long-term follow-up results. *Psycho-Oncology, 25*(7), 750-759. doi:[10.1002/pon.4150](https://doi.org/10.1002/pon.4150)
- Carvalho, A. F., Hyphantis, T., Sales, P. M. G., Soeiro-de-Souza, M. G., Macedo, D. S., Cha, D. S., . . . Pavlidis, N. (2014). Major depressive disorder in breast cancer: A critical systematic review of pharmacological and psychotherapeutic clinical trials. *Cancer Treatment Reviews, 40*(3), 349-355. doi:10.1016/j.ctrv.2013.09.009
- Carver, C.S., Smith, R.G., Petronis, V.M., & Antoni, M.H. (2006). Quality of life among long-term survivors of breast cancer: Different types of antecedents predict different outcomes. *Psycho-Oncology, 15*(9), 749-758. doi:10.1002/pon.1006
- Casellas-Grau, A., Vives, J., Font, A., & Ochoa, C. (2016). Positive psychological functioning in breast cancer: An integrative review. *Breast, 27*, 136-138. doi:10.1016/j.breast.2016.04.001
- Casey, D., & Murphy, K. (2009). Issues in using methodological triangulation in research. *Nurse Researcher, 16*(4), 40-55. doi:10.7748/nr2009.07.16.4.40.c7160
- Champion, V.L., Wagner, L. I., Monahan, P. O., Daggy, J., Smith, L., Cohee, A., . . . Sledge, G. W. Jr. (2014). Comparison of younger and older breast cancer survivors and age-matched controls on specific and overall quality of life domains. *Cancer, 120*(15), 2237-2246. doi:10.1002/cncr.28737
- Chang, J. M., Kosiorek, H. E., Dueck, A. C., Casey, W. J., Rebecca, A. M., Mahabir, R., . . . Pockaj, B. A. (2016). Trends in mastectomy and reconstruction for



- breast cancer: A twelve year experience from a tertiary care center. *The American Journal of Surgery*, 212(6), 1201-1210. Retrieved from doi:<http://dx.doi.org/10.1016/j.amjsurg.2016.08.020>
- Chapman, E., & Smith, J. A. (2002). Interpretive Phenomenological Analysis and the new genetics. *Journal of Health Psychology*, 7(2), 125-130. doi:10.1177/1359105302007002397
- Charney, D. S. (2004). Psychobiological mechanisms of resilience and vulnerability: Implications for successful adaptation to extreme stress. *American Journal of Psychiatry*, 161(2), 21. doi:10.1176/appi.ajp.161.2.195
- Cheung, S. Y., & Delfabbro, P. (2016). Are you a cancer survivor? A review on cancer identity. *Journal of Cancer Survivorship*, 10(4), 759-771. doi:10.1007/s11764-016-0521-z
- Chida, Y., Hamer, M., Wardle, J., & Steptoe, A. (2008). Do stress-related psychosocial factors contribute to cancer incidence and survival? *Nature Clinical Practice Oncology*. 5(8), 466-475. doi:10.1038/ncponc1134
- Chiu, L. (2000). Transcending breast cancer, transcending death: A Taiwanese population. *Nursing Science Quarterly*, 13(1), 64-72. doi:10.1177/08943180022107302
- Christopher, J. C., & Maris, J. A. (2010). Integrating mindfulness as self-care into counselling and psychotherapy training. *Counselling and Psychotherapy Research*, 10(2), 114-125. doi:10.1080/14733141003750285
- Chronopoulou, K., Sakkas, D., & Damigos, D. (2016). Caregiving burden and psychological distress of breast cancer patients' husbands after mastectomy. *International Journal of Caring Sciences*, 9(3), 909-913.
- Clark, J. (2017). Covering up disfigurement and laughing it off: Reinforcing inequality in breast cancer support groups. *Sociological Inquiry*, 87(1), 27-48. Retrieved from <http://dx.doi.org/10.1111/soin.12137>
- Classen, C., Butler, L. D., Koopman, C., et al. (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer. A randomized clinical intervention trial. *Archives of General Psychiatry*, 58(5), 494-501. doi:10.1001/archpsyc.58.5.494
- Clough-Gorr, K. M., Ganz, P. A., & Silliman, R. A. (2010). Older breast cancer survivors: Factors associated with self-reported symptoms of persistent lymphedema over 7 year s of follow-up. *Breast Journal*, 16(2), 147-155. doi:10.1111/j.1524-4741.2009.00878.x
- Cochran, J. L., & Cochran, N. H. (2015). *The heart of counseling: Counseling skills through therapeutic relationships*. New York, NY: Routledge.
- Cohen, S. L. (2011). Coming to our senses: The application of somatic psychology to group psychotherapy. *International Journal of Group Psychotherapy*, 61(3), 396-413. Retrieved from <http://dx.doi.org/10.1521/ijgp.2011.61.3.396>
- Colby, D.A., & Shifren, K. (2013). Optimism, mental health, and quality of life: A study among breast cancer patients. *Psychology, Health & Medicine*, 18(1), 10-20. doi:10.1080/13548506.2012.686619
- Collins, K., Liu, Y., Schootman, M., Aft, R., Yan, Y., Dean, G., Eilers, M. & Jeffe, D. (2011). Effects of breast cancer surgery and surgical side effects on body image over time. *Breast Cancer Research and Treatment*, 126(1), 167-176. doi:10.1007/s10549-010-1077-7
- Combs, D. J. Y., Campbell, G., Jackson, M., & Smith, R. H. (2010). Exploring the consequences of humiliating a moral transgressor. *Basic and Applied Social*

- Psychology*, 32(2), 128-143. Retrieved from doi:10.1080/01973531003738379
- Condon, P., & Feldman Barrett, L. (2013). Conceptualizing and experiencing compassion. *Emotion*, 13(5), 817-821. doi:10.1037/a0033747
- Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, 51, S67-S79. Retrieved from doi:10.1177/0022146510383495
- Cooper, M., & McLeod, J. (2011). *Pluralistic counselling and psychotherapy*. London, UK: Sage Publications Ltd.
- Coote, A. (2015). Returning home: One woman's journey from depression to joyous living. In S. L. Brooke and C. E. Myers (Eds). *The Use of the Creative Therapies in Treating Depression*, (pp. 177 – 198). Springfield, Ill: Charles C. Thomas Publisher.
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer; A controlled comparison study. *Health Psychology*, 20(3), 176-185. doi:10.1037//0278-6133.20.3.176
- Corey, G. (2015). *Issues and ethics in the helping professions* (9th ed.): Stamford, CT: Brooks/Cole/Cengage Learning.
- Corey, G., & Corey, M. S. (2014). *I never knew I had a choice: Explorations in personal growth* (10th ed.). Belmont, CA: Brooks/Cole.
- Corney, R., Puthussery, S., & Swinglehurst, J. (2016). Couple relationship in families with dependent children after a diagnosis of maternal breast cancer in the United Kingdom: Perspectives from mothers and fathers. *Journal of Psychosocial Oncology*, 413-431. doi:10.1080/07347332.2016.1199080
- Coyne, E. (2013). The strengths and resources used by families of young women with breast cancer. *The Australian Journal of Cancer Nursing*, 14(2), 10-16.
- Cozaru, G. C., Papari, A. C., & Sandu, M. L. (2014). The effects of psycho-education and counselling for women suffering from breast cancer in support groups. *Procedia - Social and Behavioral Sciences*, 128, 10-15. doi:10.1016/j.sbspro.2014.03.110
- Cozolino, L. J. (2010). *The neuroscience of psychotherapy: Healing the social brain: Building and rebuilding the human brain* (2nd ed.). New York, NY: W.W. Norton & Company.
- Crago, H. (2012). A curriculum for counselling. *Psychotherapy in Australia*, 18(3), 72-74. Retrieved from: <[https://search-informit-com-au.ezproxy.usc.edu.au/documentSummary;dn=316806019536926;res=IELHEA](https://search.informit-com-au.ezproxy.usc.edu.au/documentSummary;dn=316806019536926;res=IELHEA)>
- Cresswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA.: Sage Publications Inc.
- Cresswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage Publications Inc.
- Cromptvoets, S. (2003). Reconstructing the self: Breast cancer and the post-surgical body. *Health Sociology Review*, 12(2), 137-145. doi:10.5172/hesr.12.2.137
- Cronin-Davis, J., Butler, A., Mayers, C. A. (2009). Occupational therapy and interpretative phenomenological analysis: Comparable research companions? *British Journal of Occupational Therapy*, 72(8), 332-338. doi: 10.1177/030802260907200802
- Cunningham, L. (2005). *Relational sandplay*. Desoto, TX: Mustard Seed Press.

- Curbow, B., Somerfield, R., Baker, F., Wingard, J. R., & Legro, M. W. (1993). Personal changes, dispositional optimism, and psychological adjustment to bone marrow transplantation. *Journal of Behavioral Medicine, 16*, 423-443.
- Curl, K. (2011). Assessing stress reduction as a function of artistic creation and cognitive focus. *Art Therapy: Journal of the American Art Therapy Association, 25*(4), 164-169. doi:10.1080/07421656.2008.10129550
- Curran, M. S. (2011). Helping your patients cope with a cancer diagnosis. *Nursing Made Incredibly Easy, 9*(4), 55-56. doi:10.1097/01.NME.0000398462.81200.41
- Custers, J. A. E., Becker, E. S., Gielissen, M. F. M., Van Laarhoven, H. W. M., Rinck, M., & Prins, J. B. (2015). Selective attention and fear of cancer recurrence in breast cancer survivors. *Annals of Behavioral Medicine, 49*(1), 66-73. Retrieved from <http://dx.doi.org/10.1007/s12160-014-9632-9>
- Cvetković, J., & Nenadović, M. (2016). Depression in breast cancer patients. *Psychiatry Research, 240*, 343-347. doi:10.1016/j.psychres.2016.04.048
- Dafter, R., Greenwald, H. P., & Block, K. I. (2006). Cancer, the mind, and the problem of self-blame. *Integrative Cancer Therapies, 5*(2), 123-130. doi:10.1177/1534735406289106
- Dahm, K. A., Meyer, E. C., Neff, K. D., Kimbrel, N. A., Gulliver, S. B., & Morissette, S. B. (2015). Mindfulness, self-compassion, Posttraumatic Stress Disorder symptoms, and functional disability in U.S. Iraq and Afghanistan war veterans. *Journal of Traumatic Stress, 28*(5), 460-464. Retrieved from doi:10.1002/jts.22045
- Dal Maso, L., Zucchetto, A., Talamini, R., Serraino, D., Stocco, C. F., Vercelli, M., . . . health study, g. (2008). Effect of obesity and other lifestyle factors on mortality in women with breast cancer. *International Journal of Cancer, 123*(9), 2188-2194. doi:10.1002/ijc.23747
- Dallos, R., & Vetere, A. (2005). *Researching psychotherapy and counseling*. Berkshire, UK: Open University Press.
- Danhauer, S. C., Case, L. D., Tedeschi, R., Russell, G., Vishnevsky, T., Triplett, K., Ip, E.H., & Avis, N. E. (2013). Predictors of posttraumatic growth in women with breast cancer. *Psycho-Oncology, 22*, 2676-2683. doi:10.1002/pon.3298
- Danhauer, S. C., Russell, G., Case, L. D., Sohl, S. J., Tedeschi, R., . . . Avis, N. E. (2015). Trajectories of posttraumatic growth and associated characteristics in women with breast cancer. *Annals of Behavioral Medicine, 49*, 650-659. doi:10.1007/s12160-014-9696-1
- de Moor, J. S., Mariotto, A. B., Parry, C., Alfano, C. M., Padgett, L., Kent, E. E., . . . Rowland, J. H. (2013). Cancer survivors in the United States: Prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiology Biomarkers, 22*(4), 561-570. doi:10.1158/1055-9965.EPI-12-1356
- Den Oudsten, B. L., Van Heck, G. L., Van der Steeg, A. F. W., Roukema, J. A., & De Vries, J. (2010). Clinical factors are not the best predictors of quality of sexual life and sexual functioning in women with early stage breast cancer. *Psycho-Oncology, 19*(6), 646-656. doi:10.1002/pon.1610
- Dennett, T. (2009). Jo Spence's camera therapy: Personal therapeutic photography as a response to adversity. *European Journal of Psychotherapy & Counselling, 11*(1), 7-19. doi:10.1080/13642530902723041

- Deshields, T., Tibbs, T., Fan, M. Y., & Taylor, M. (2006). Differences in patterns of depression after treatment for breast cancer. *Psycho-Oncology*, *15*(5), 398-406. doi:10.1002/pon.962
- Desmond, T. (2016). *Self-compassion in psychotherapy: Mindfulness-based practices for healing and transformation*. New York, NY: W.W. Norton & Company.
- Diamond, W. J. (2010). Allostatic medicine: Bringing stress, coping and chronic disease into focus. Part 1. *Integrative Medicine: A Clinician's Journal*, *8*(6), 40-44.
- Dibbel-Hope, S. (2000). The use of dance/movement therapy in psychological adaptation to breast cancer. *Arts Psychotherapy*, *27*, 51-68. doi:10.1016/S0197-4556(99)00032-5
- Diener, E., & Chan, M. Y. (2011). Happy people live longer: Subjective well-being contributes to health and longevity. *Applied Psychology: Health and Well-Being*, *3*(1), 1-43. doi:10.1111/j.1758-0854.2010.01045.x
- Dizon, D. S. (2009). Quality of life after breast cancer: Survivorship and sexuality. *The Breast Journal*, *15*(5), 500-504. doi:10.1111/j.1524-4741.2009.00766.x
- Documet, P. I., Trauth, J. M., Key, M., Flatt, J., & Jernigan, J. (2012). Breast cancer survivors' perception of survivorship. *Oncology Nursing Forum*, *39*(3), 309-315. doi:10.1188/12.ONF.309-315
- Dodds, J. (1999). *Cancer as bad luck or warning symbol? Constructed meanings of illness and healing*. Torbay, WA: Creative Interactions.
- Dolbeault, S., Cayrou, S., Brédart, A., Viala, A. L., Desclaux, B., Saltel, P., . . . Dickes, P. (2009). The effectiveness of a psycho-educational group after early-stage breast cancer treatment: results of a randomized French study. *Psycho-Oncology*, *18*(6), 647-656. doi:10.1002/pon.1440
- Donovan-Kicken, E., & Caughlin, J. P. (2010). A multiple goals perspective on topic avoidance and relationship satisfaction in the context of breast cancer. *Communication Monographs*, *77*(2), 231-256. doi:10.1080/03637751003758219
- Dossey, L. (2007). Compassion. *Explore: The Journal of Science and Healing*, *3*(1), 1-5. doi:10.1016/j.explore.2006.08.004
- Downs-Holmes, C., & Silverman, P. (2011). Breast cancer: Overview and updates. *The Nurse Practitioner*, *36*(12), 20-26. doi:10.1097/01.NPR.0000407602.29522.d7
- Doyle, N. (2008). Cancer survivorship: evolutionary concept analysis. *Journal of Advanced Nursing*, *62*(4), 499-509. doi:10.1111/j.1365-2648.2008.04617.x
- Drageset, S., Lindstrøm, T. C., Giske, T., & Underlid, K. (2011). Being in suspense: Women's experiences awaiting breast cancer surgery. *Journal of Advanced Nursing*, *67*(9), 1941-1951. doi:10.1111/j.1365-2648.2011.05638.x
- Drageset, S., Lindstrøm, T. C., & Underlid, K. (2010). Coping with breast cancer: Between diagnosis and surgery. *Journal of Advanced Nursing*, *66*(1), 149-158. doi:10.1111/j.1365-2648.2009.05210.x
- Duggleby, W., Wendy, D., Heather, D., Dan, C., & Roanne, T. (2014). The quality of life of male spouses of women with breast cancer: Hope, self-efficacy, and perceptions of guilt. *Cancer Nursing*, *37*(1), E28-E35. doi:10.1097/NCC.0b013e31827ca807
- Dumalaon-Canaria, J. A., Hutchinson, A. D., Prichard, I., & Wilson, C. (2014). What causes breast cancer? A systematic review of causal attributions among breast cancer survivors and how these compare to expert-endorsed risk

- factors. *Cancer Causes & Control*, 25(7), 771-785. doi:10.1007/s10552-014-0377-3
- Duncan, B. L., Miller, S. D., Wampold, B. E., & Hubble, M. A. (2010). *The heart and soul of change: Delivering what works in therapy* (2nd ed.). Washington, DC: American Psychological Association.
- Dunne, S., Sheffield, D., & Chilcot, J. (2016). Brief report: Self-compassion, physical health and the mediating role of health-promoting behaviours. *Journal of Health Psychology*, 23(7), 993-999. doi:10.1177/1359105316643377
- Dupasquier, J., Kelly, A., Moscovitch, D., & Vidovic, V. (2018). Practicing self-compassion weakens the relationship between fear of receiving compassion and the desire to conceal negative experiences from others. *Mindfulness*, 9(2), 500-511. doi:10.1007/s12671-017-0792-0
- Duric, V. M., Butow, P. N., Sharpe, L., Boyle, F., Beith, J., Wilcken, N. R. C., . . . Stockler, M. R. (2007). Psychosocial factors and patients' preferences for adjuvant chemotherapy in early breast cancer. *Psycho-Oncology*, 16, 48-59. doi:10.1002/pon.1045
- Durkin, J., & Joseph, S. (2009). Growth following adversity and its relation with subjective well-being and psychological well-being. *Journal of Loss & Trauma*, 14(3), 228-234. doi:10.1080/15325020802540561
- Duvall, S.-S. (2014). Not "Simply the Breast": Media discourses of celebrity, breastfeeding, and normalcy. *Feminist Media Studies*, 15(2), 1-17. doi:10.1080/14680777.2014.919334
- Ehrenreich, B. (2009). *Bright-sided: How the relentless promotion of positive thinking has undermined America*. New York, N.Y.: Metropolitan Books, Henry Holt & Co..
- Eliason, G. T., Samide, J. L., Williams, G., & Lepore, M. F. (2010). Existential theory and our search for spirituality. *Journal of Spirituality in Mental Health*, 12(2), 86-111. doi:10.1080/19349631003730068
- Ellsworth, R., Valente, A., Shriver, C., Bittman, B., & Ellsworth, D. (2012). Impact of lifestyle factors on prognosis among breast cancer survivors in the USA. *Expert review of Pharmacoeconomics & Outcomes Research*, 12(4), 451-464. doi:10.1586/erp.12.37
- Elmir, R., Jackson, D., Beale, B., & Schmied, V. (2010). Against all odds: Australian women's experiences of recovery from breast cancer. *Journal of Clinical Nursing*, 19(17/18), 2531-2538. doi:10.1111/j.1365-2702.2010.03196.x
- Else-Quest, N. M., LoConte, N. K., Schiller, J. H., & Hyde, J. S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology and Health*, 24(8), 949-964. doi:10.1080/08870440802074664
- Elsheshtawy, E. A., Abo-Elez, W. F., Ashour, H. S., Farouk, O., & El Zaafarany, M. I. E. (2014). Coping strategies in Egyptian ladies with breast cancer. *Breast Cancer: Basic and Clinical Research*, 8, 97-102. doi:10.4137/BCBCR.S14755
- Embree, L. (2009). Phenomenology and social constructionism: Constructs for political identity. *Journal of Phenomenological Psychology*, 40(2), 127-139. doi:10.1163/004726609X12482630041807
- Enache, R. G. (2012). The relationship between anxiety, depression and self-esteem in women with breast cancer after surgery. *Procedia - Social and Behavioral Sciences*, 33, 124-127. doi:<http://dx.doi.org/10.1016/j.sbspro.2012.01.096>

- Englander, M. (2016). The phenomenological method in qualitative psychology and psychiatry. *International Journal of Qualitative Studies on Health and Well-being*, 11(1), 30682. doi:<http://dx.doi.org/10.3402/qhw.v11.30682>
- Enns, C. Z. (2003). Contemporary adaptations of traditional approaches to the counseling of women. In M. Kopala & M. A. Keitel (Eds.), *Handbook of counseling women* (pp. 3-21). Thousand Oaks, CA: Sage Publications Ltd.
- Eskelinen, M., & Ollonen, P. (2011). Assessment of 'cancer-prone personality' characteristics in healthy study subjects and in patients with breast disease and breast cancer using the commitment questionnaire: A prospective case-control study in Finland. *Anticancer Research*, 31(11), 4013-4017.
- Esteva, F. J., & Hortobagyi, G. N. (2008). Gaining ground on breast cancer. *Scientific American*, 18(3), 88. doi:10.1038/scientificamerican0708-88sp.
- Eun-Ok., I. (2013). Practical guidelines for feminist research in nursing. *Advances in Nursing Science*, 36(2), 133-145. doi:10.1097/ANS.0b013e318290204e
- Ezzy, D. (2002). *Qualitative analysis: Practice and innovation*. London, UK: Routledge.
- Falconer, C. J., King, J. A., & Brewin, C. R. (2015). Demonstrating mood repair with a situation-based measure of self-compassion and self-criticism. *Psychology and Psychotherapy: Theory, Research and Practice*, 88(4), 351-365. doi:10.1111/papt.12056
- Falconier, M., Nussbeck, F., Bodenmann, G., Schneider, H., & Bradbury, T. (2015). Stress from daily hassles in couples: Its effects on intradyadic stress, relationship satisfaction, and physical and psychological well-being. *Journal of Marital and Family Therapy*, 41(2), 221-235. doi:10.1111/jmft.12073
- Falk Dahl, C. A., Reinertsen, K. V., Nesvold, I. L., Fosså, S. D., & Dahl, A. A. (2010). A study of body image in long-term breast cancer survivors. *Cancer*, 116(15), 3549-3557. doi:10.1002/cncr.25251
- Fallowfield, L., & Jenkins, V. (2015). Psychosocial/ survivorship issues in breast cancer: Are we doing better? *Journal of the National Cancer Institute*, 107(1), 1. doi:10.1093/jnci/dju335
- Fann, J. R., Thomas-Rich, A. M., Katon, W. J., Cowley, D., Pepping, M., McGregor, B. A., & Gralow, J. (2008). Major depression after breast cancer: A review of epidemiology and treatment. *General Hospital Psychiatry*, 30(2), 112-126. <http://dx.doi.org/10.1016/j.genhosppsych.2007.10.008>
- Fatiregun, O. A., Olagunju, A. T., Erinfolami, A. R., Fatiregun, O. A., Arogunmati, O. A., & Adeyemi, J. D. (2016). Anxiety disorders in breast cancer: Prevalence, types, and determinants. *Journal of Psychosocial Oncology*, 34(5), 432-447. doi:10.1080/07347332.2016.1196805
- Favez, N., Notari, S. C., Charvoz, L., Notari, L., Ghisletta, P., Ruedin, B. P., & Delaloye, J.-F. (2016). Distress and body image disturbances in women with breast cancer in the immediate postsurgical period: The influence of attachment insecurity. *Journal of Health Psychology*, 21(12), 2994-3003. doi:10.1177/1359105315589802
- Fingeret, M. C., Teo, I., & Epner, D. E. (2014). Managing body image difficulties of adult cancer patients: Lessons from available research. *Cancer*, 120(5), 633-641. Retrieved from <http://dx.doi.org/10.1002/cncr.28469>
- Finlay, L. (2009). Exploring lived experience: Principles and practice of phenomenological research. *International Journal of Therapy & Rehabilitation*, 16(9), 474-481. doi:10.12968/ijtr.2009.16.9.43765

- Fischbeck, S., Maier, B. O., Nehring, C., Beutel, M. E., & Weber, M. (2012). Assessing somatic, psychosocial, and spiritual distress of patients with advanced cancer: Development of the Advanced Cancer Patients' Distress Scale. *American Journal of Hospice & Palliative Medicine*, 30(4), 339-346. doi:10.1177/1049909112453640
- Fisher, M. L., & Exline, J. J. (2010). Moving toward self-forgiveness: Removing barriers related to shame, guilt, and regret. *Social and Personality Psychology Compass*, 4(8), 548-558. doi:10.1111/j.1751-9004.2010.00276.x
- Fledderus, M., Bohlmeijer, E. T., Pieterse, M. E., & Schreurs, K. M. G. (2012). Acceptance and Commitment Therapy as guided self-help for psychological distress and positive mental health: A randomized controlled trial. *Psychological Medicine*, 42(3), 485. doi:10.1017/S0033291711001206
- Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: Developing a Gadamerian-based research method. *Nursing Inquiry*, 10(2), 113-120.
- Flood, A. (2010). Understanding phenomenology. *Nurse Researcher*, 17(2), 7-15. doi: org/10.7748/nr2010.01.17.2.7.c7457
- Fobair, P., Koopman, C., DiMiceli, S., O'Hanlan, K., Butler, L. D., Classen, C., . . . Spiegel, D. (2002). Psychosocial intervention for lesbians with primary breast cancer. *Psycho-Oncology*, 11(5), 427-438. doi:10.1002/pon.624
- Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology*, 15(7), 579-594. doi:10.1002/pon.991
- Forti, A. (2011). *Mindfulness and quality of life among breast cancer survivors: The mediating role of self-kindness and alexithymia*. Carolina, USA: Harvard Health Publications.
- Forti, A., & Cashwell, C. (2012). Self-compassion, alexithymia and quality of life among breast cancer survivors. *Psycho-Oncology*, 21, 97. doi:10.1111/j.1099-1611.2011.03029.x
- Forzoni, S., Perez, M., Martignetti, A., & Crispino, S., Art therapy with cancer patients during chemotherapy sessions: An analysis of the patients' perception of helpfulness. *Palliative and Supportive Care*, 8(1), 41-48. Retrieved from <https://doi.org/10.1017/S1478951509990691>
- Fosha, D. (2009). Emotion and recognition at work: Energy, vitality, pleasure, truth, desire, and the emergent phenomenology of transformational experience. In D. Fosha, D. J. Siegel, & M. F. Solomon (Eds.), *The healing power of emotion: Affective neuroscience, development & clinical practice* (pp. 172-203). New York, NY: W.W. Norton & Company.
- Fosha, D., Siegel, D. J., & Solomon, M. F. (Eds.). (2009). *The healing power of emotion: Affective neuroscience, development & clinical practice*. New York, NY: W.W. Norton & Company.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36(6), 16. 717-732. doi:10.1046/j.1440-1614.2002.01100.x
- Franks, M., & Whitaker, R. (2007). The image, mentalisation and group art psychotherapy. *International Journal of Art Therapy*, 12(1), 3-16. Retrieved from <http://dx.doi.org/10.1080/17454830701265188>
- Frazzetto, P., Vacante, M., Malaguarnera, M., Vinci, E., Catalano, F., Cataudella, E., . . . Biondi, A. (2012). Depression in older breast cancer survivors. *BMC Surgery*, 12(Suppl 1), S14. doi:10.1186/1471-2482-12-S1-S14

- Friedman, L. C., Romero, C., Elledge, R. . . . Osborne, C. (2007) Attribution of blame, self-forgiving attitude and psychological adjustment in women with breast cancer. *Journal of Behavioral Medicine*, 30 (4), 351–357. doi:10.1007/s10865-007-9108-5
- Friedman, L. C., Barber, C. R., Chang, J., Tham, Y. L., Kalidas, M., Rimawi, M. F., . . . Elledge, R. (2010). Self-blame, self-forgiveness, and spirituality in breast cancer survivors in a public sector setting. *Journal of Cancer Education*, 25(3), 343-348. doi:10.1007/s13187-010-0048-3
- Frierson, G., Thiel, D., & Andersen, B. (2006). Body change stress for women with breast cancer: The breast-impact of treatment scale. *Annals of Behavioral Medicine*, 32(1), 77-91. doi:10.1207/s15324796abm3201\_9
- Fullagar, S., & O'Brien, W. (2014). Social recovery and the move beyond deficit models of depression: A feminist analysis of mid-life women's self-care practices. *Social Science & Medicine*, 117, 116-124. doi:<http://dx.doi.org/10.1016/j.socscimed.2014.07.041>
- Furzer, B., Petterson, A., Wright, K., Wallman, K., Ackland, T., & Joske, D. (2014). Positive patient experiences in an Australian integrative oncology centre. *BMC Complementary and Alternative Medicine*, 14(1), 158. doi:10.1186/1472-6882-14-158
- Galgut, C. (2007). The psychological impact of breast cancer assessed: The testimony of a psychotherapist and breast cancer sufferer. *Self & Society*, 35(1), 5-19. doi:10.1080/03060497.2007.11083962
- Galletta, A. (2013). Mastering the semi-structured interview and beyond: From research design to analysis and publication. *Qualitative Studies in Psychology*. New York, NY: New York University Press.
- Gambling, T., & Long, A. F. (2010). The realisation of patient- centred care during a 3- year proactive telephone counselling self-care intervention for diabetes. *Patient Education and Counseling*, 80(2), 219-226. doi:10.1016/j.pec.2009.11.007
- Ganz, P. A., & Hahn, E. E. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, 26(5), 759-767. di:10.1200/jco.2007.14.2851
- Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of the National Cancer Institute*, 94(1), 39-49. doi:10.1093/jnci/94.1.39
- Gatrell, C. (2009). Safeguarding subjects? A reflexive appraisal of researcher accountability in qualitative interviews. *Qualitative Research in Organizations and Management: An International Journal*, 4(2), 110-122. Doi: 10.1108/17465640910978382
- Geffen, J. R. (2010). Integrative oncology for the whole person: A multidimensional approach to cancer care. *Integrative Cancer Therapies*, 9(1), 105-121. Retrieved from <http://dx.doi.org/10.1177/1534735409355172>
- George, A. & Pedersen, I. N. (2017). Analyzing pictorial artifacts from psychotherapy and art therapy whe overcoming stress and trauma. *The Arts in Psychotherapy*, 54, 56-68. doi:10.1016/j.aip.2017.02.001
- Gerber, Z., Tolmacz, R., & Doron, Y. (2015). Self-compassion and forms of concern for others. *Personality and Individual Differences*, 86, 394-400. Retrieved from doi:<http://dx.doi.org/10.1016/j.paid.2015.06.052>



- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266-275. doi:10.1037/0003-066X.40.3.266
- Germer, C. K. (2009). *The mindful path to self-compassion: Freeing yourself from destructive thoughts and emotions*. New York, NY: Guilford Press.
- Germer, C. K., & Neff, K. D. (2013). Self-compassion in clinical practice. *Journal of Clinical Psychology*, 69(8), 856-867. doi:10.1002/jclp.22021
- Gibbons, A., Groarke, A., Curtis, R., & Groarke, J. (2017). The effect of mode of detection of breast cancer on stress and distress. *Psycho-Oncology*, 26(6), 787-792. doi:10.1002/pon.4227
- Gibson, A. F., Lee, C., & Crabb, S. (2014). 'If you grow them, know them': Discursive constructions of the pink ribbon culture of breast cancer in the Australian context. *Feminism & Psychology*, 24(4), 521-541. doi:10.1177/0959353514548100
- Gilbert, E., Savard, J., Gagnon, P., Savard, M. H., Ivers, H., & Foldes-Busque, G. (2016). To be or not to be positive: Development of a tool to assess the relationship of negative, positive, and realistic thinking with psychological distress in breast cancer. *Journal of Health Psychology*, 23(5), 731-742. Retrieved from <http://journals.sagepub.com/doi/abs/10.1177/1359105316681062>
- Gilbert, E., Ussher, J. M., & Perz, J. (2010). Sexuality after breast cancer: A review. *Maturitas*, 66(4), 397-407. doi:10.1016/j.maturitas.2010.03.027
- Gilbert, P. (Ed.). (2007). *Psychotherapy and counselling for depression* (3rd ed.). Los Angeles: Sage Publications Inc.
- Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*, 15(3), 199-208. doi:10.1192/apt.bp.107.005264
- Gilbert, P., & Irons, C. (2005). Focused therapies and compassionate mind training for shame and self-attacking. In P. Gilbert (Ed.), *Compassion: Conceptualisations, research and use in psychotherapy* (pp.263-325). New York, N.Y.: Routledge.
- Gilbert, P., McEwan, K., Matos, M., & Rivis, A. (2011). Fears of compassion: Development of three self-report measures. *Psychology and Psychotherapy: Theory, Research and Practice*, 84, 239-255. doi:10.1348/147608310X526511
- Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, 13(6), 353-379. Retrieved from <http://dx.doi.org/10.1002/cpp.507>
- Gilligan, C. (2011). Looking back to look forward: Revisiting *In a different voice*. Retrieved from [http://nrs.harvard.edu/urn-3:hul.ebook:CHS\\_Classicsat](http://nrs.harvard.edu/urn-3:hul.ebook:CHS_Classicsat)
- Giorgi, A. (2010). Phenomenological Psychology: A brief history and its challenges. *Journal of Phenomenological Psychology*, 41(2), 145-179. doi:10.1163/156916210X532108
- Goetz, J. L., Keltner, D., & Simon-Thomas, E. (2010). Compassion: An evolutionary analysis and empirical review. *Psychological Bulletin*, 136(3), 351-374. doi:10.1037/a0018807
- Goldstein, J. (2003). *Insight meditation: A psychology of freedom*. Boston, MA: Shambhala Publications.
- Goss, K., & Allan, S. (2009). Shame, pride and eating disorders. *Clinical Psychology & Psychotherapy*, 16(4), 303-316. doi:10.1002/cpp.627

- Graham, J., Christian, L., & Kiecolt-Glaser, J. (2006). Stress, age, and immune function: Toward a lifespan approach. *Journal of Behavioral Medicine, 29*(4), 389-400. doi:10.1007/s10865-006-9057-4
- Graves, K. D., Schmidt, J. E., Bollmer, J., Fejfar, M., Langer, S., Blonder, L. X., & Andrykowski, M. A. (2005). Emotional expression and emotional recognition in breast cancer survivors: A controlled comparison. *Psychology and Health, 20*(5), 579-595. doi:10.1080/0887044042000334742
- Graziottin, A., & Rovei, V. (2007). Sexuality after breast cancer. *Sexologies, 16*(4), 292-298. doi:10.1016/j.sexol.2007.06.008
- Greenhalgh, T., & Taylor, R. (1997). How to read a paper: Papers that go beyond numbers (qualitative research). *British Medical Journal, 315*(7110), 740-743. Retrieved from <http://www.jstor.org.ezproxy.usc.edu.au:2048/stable/25175748>
- Greenberg, L. S. (2012). Emotions, the great captains of our lives: Their role in the process of change in psychotherapy. *American Psychologist, 67*(8), 697-707. doi:10.1037/a0029858
- Greenlee, H., Molmenti, C. L. S., Crew, K. D., Awad, D., Kalinsky, K., Brafman, L., . . . Hershman, D. L. (2016). Survivorship care plans and adherence to lifestyle recommendations among breast cancer survivors. *Journal of Cancer Survivorship, 10*(6), 956-963. Retrieved from <https://doi.org/10.1007/s11764-016-0541-8>
- Greer, S., & Morris, T. (1978). The study of psychological factors in breast cancer: Problems of method. *Social Science and Medicine, 12*, 129-134. doi:10.1016/0271-7123(78)90040-8
- Groarke, A., Curtis, R., Groarke, J. M., Hogan, M. J., Gibbons, A., & Kerin, M. (2017). Post-traumatic growth in breast cancer: How and when do distress and stress contribute? *Psycho-Oncology, 26*(7), 967-974. doi:10.1002/pon.4243
- Groër, M. (2010). Allostasis: A model for women's health. In K. Kendall-Tackett (Ed). *The psychoneuroimmunology of chronic disease: Exploring the links between inflammation, stress, and illness*, (pp. 183-218). Washington, DC: American Psychological Association. [doi.org/10.1037/12065-000](https://doi.org/10.1037/12065-000)
- Guterman, J., & Rudes, J. (2008). Social constructionism and ethics: Implications for counseling. *Counseling and Values, 52*(2), 136-144. doi:10.1002/j.2161-007X.2008.tb00097.x
- Hahn, R. C., & Petitti, D. B. (1988). Minnesota Multiphasic Personality Inventory-rated depression and the incidence of breast cancer. *Cancer, 61*(4), 845-848. Retrieved from [http://dx.doi.org/10.1002/1097-0142\(19880215\)61:4](http://dx.doi.org/10.1002/1097-0142(19880215)61:4)
- Halifax, J. (2011). The precious necessity of compassion. *Journal of Pain and Symptom Management, 41*(1), 146-153. doi:10.1016/j.jpainsymman.2010.08.010
- Hall, L. C. (2013). Pink ribbon blues: How breast cancer culture undermines women's health. *Contemporary Sociology, 42*(2), 279-280. doi:10.1177/0094306113477381rr
- Hall, C. W., Row, K. A., Wuensch, K. L., & Godley, K. R. (2013). The role of self-compassion in physical and psychological well-being. *Journal of Psychology, 147*(4), 311-323. doi:10.1080/00223980.2012.693138
- Halpern, M. T., Viswanathan, M., Evans, T. S., Birken, S. A., Basch, E., & Mayer, D. K. (2015). Models of cancer survivorship care: Overview and summary of

- current evidence. *Journal of Oncology Practice*, 11(1), e19-e27.  
doi:10.1200/jop.2014.001403
- Haltiwanger, E., Rojo, R., & Funk, K. (2011). Living with cancer: Impact of expressive arts. *Occupational Therapy in Mental Health*, 27(1), 65-86.  
doi:10.1080/0164212X.2011.543965
- Hamer, J., & Warner, E. (2017). Lifestyle modifications for patients with breast cancer to improve prognosis and optimize overall health. *Canadian Medical Association Journal*, 189(7), E268-E274. doi:10.1503/cmaj.160464
- Han, J., Grothuesmann, D., Neises, M., Hill, U., & Hillemanns, P. (2010). Quality of life and satisfaction after breast cancer operation. *Archives of Gynecology & Obstetrics*, 282(1), 75-82. doi:10.1007/s00404-009-1302-y
- Hanchate, A., Clough-Gorr, K., Ash, A., Thwin, S., & Silliman, R. (2010). Longitudinal patterns in survival, comorbidity, healthcare utilization and quality of care among older women following breast cancer diagnosis. *Journal of General Internal Medicine*, 25(10), 1045-1050.  
doi:10.1007/s11606-010-1407-9
- Harbeck, N., & Gnant, M. (2017). Breast cancer. *The Lancet*, 389(10074), 1134-1150. doi:10.1016/S0140-6736(16)31891-8
- Hareli, S., & Hess, U. (2012). The social signal value of emotions. *Cognition & Emotion*, 26(3), 385-389. doi:10.1080/02699931.2012.665029
- Harris, J., Bowen, D. J., Badr, H., Hannon, P., Hay, J., & Sterba, K. R. (2009). Family communication during the cancer experience. *Journal of Health Communication*, 14, 76-84. doi:10.1080/10810730902806844
- Hass-Cohen, N., Clyde Findlay, J., Carr, R., & Vanderlan, J. (2014). "Check, change what you need to change and/or keep what you want": An Art Therapy neurobiological-based trauma protocol. *Art Therapy*, 31(2), 69-78. Retrieved from <http://dx.doi.org/10.1080/07421656.2014.903825>
- Hegel, M. T., Moore, C. P., Collins, E. D., Kearing, S., Gillock, K. L., Riggs, R. L., . . . Ahles, T. A. (2006). Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer. *Cancer*, 107(12), 2924-2931. doi:10.1002/cncr.22335
- Helsel, P. B. (2015). Witnessing the body's response to trauma: Resistance, ritual, and nervous system activation. *Pastoral Psychology*, 64(5), 681-693. Retrieved from <http://dx.doi.org.ipacez.nd.edu.au/10.1007/s11089-014-0628-y>
- Henderson, C., Evans-Lacko, S., & Thornicroft, G. (2013). Mental illness stigma, help seeking, and public health programs. *American Journal of Public Health*, 103(5), 777. doi:10.2105/AJPH.2012.301056
- Henman, M. J., Butow, P. N., Brown, R. F., Boyle, F., & Tattersall, M. H. N. (2002). Lay constructions of decision-making in cancer. *Psycho-Oncology*, 11(4), 295-306. doi:10.1002/pon.566
- Heppner, P. P., Tierney, C. G., Wang, Y. W., Armer, J. M., Whitlow, N. M., & Reynolds, A. (2009). Breast cancer survivors coping with Lymphedema: What all Counselors need to know. *Journal of Counseling & Development*, 87(3), 327-338. doi:10.1002/j.1556-6678.2009.tb00114.x
- Hesse-Biber, S. N., & Leavy, P. (2013). *Feminist research practice: A primer* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Hewitt, M. E., & Holland, J. C. (2004). *Meeting psychosocial needs of women with breast cancer*. Washington, DC:National Academies Pres Retrieved from <http://ebookcentral.proquest.com/lib/unda/detail.action?docID=3376317>

- Hewitt, N., & Holland, J. (2006). Cancer survivors. In M. E. Hewitt, S. Greenfield, & E. Stovall (Eds.), *From cancer patient to cancer survivor: Lost in transition*. Washington, D.C.: National Academies Press. Retrieved from <http://ebookcentral.proquest.com/lib/unda/detail.action?docID=3378015>.
- Higginbottom, G. M. A. (2004). Sampling issues in qualitative research. *Nurse Researcher*, 12(1), 7-19. Retrieved from <http://web.a.ebscohost.com/ehost/detail/detail?vid=0&sid=b45cc0ea-72b7-414a-8b2e-0aba96e2a500%40sessionmgr4009&bdata=JnNpdGU9ZWwhvc3QtbGl2ZQ%3d%3d#AN=106676798&db=c8hh>
- Hill, J., Holcombe, C., Clark, L., Boothby, M. R. K., Hincks, A., Fisher, J., . . . Salmon, P. (2011). Predictors of onset of depression and anxiety in the year after diagnosis of breast cancer. *Psychological Medicine*, 41(7), 1429-1436. doi:10.1017/S0033291710001868
- Holland, J. C., & Lewis, S. (2000). *The human side of cancer: Living with hope, coping with uncertainty*. New York: Harper Collins.
- Ho, H. R. T., Lo, Y. P. H., & Luk, Y. M. (2016). A good time to dance? A mixed-methods approach of the effects of Dance Movement Therapy for breast cancer patients during and after radiotherapy. *Cancer nursing*, 39(1), 32-41. doi:10.1097/NCC.0000000000000237
- Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., Lo, S. K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*, 16(9), 9. doi:10.1002/pon.1137
- Hollis-Walker, L., & Colosimo, K. (2010). Mindfulness, self-compassion, and happiness in non-meditators: A theoretical and empirical examination. *Personality and Individual Differences*, 50(2), 222-227. doi:10.1016/j.paid.2010.09.033
- Holmes, M. D., Chen, W. Y., Feskanich, D., Kroenke, C. H., & Colditz, G. A. (2005). Physical activity and survival after breast cancer diagnosis. *Journal of the American Medical Association*, 293(20), 2479-2486. doi:10.1001/jama.293.20.2479
- Holmström, I. & Röing, M. (2010). Patient empowerment: The relation between patient-centeredness and patient empowerment. *Patient Education and Counseling*, 79(2), 167-172. doi:10.1016/j.pec.2009.08.008
- Homan, K. J., & Sirois, F. M. (2017). Self-compassion and physical health: Exploring the roles of perceived stress and health-promoting behaviors. *Health Psychology Open*, 4(2). doi:10.1177/2055102917729542
- Hopko, D. R., Armento, M. E. A., Robertson, S. M. C., Ryba, M. M., Carvalho, J. P., Colman, L. K., . . . Lejuez, C. W. (2011). Brief behavioral activation and problem-solving therapy for depressed breast cancer patients: Randomized trial. *Journal of Consulting and Clinical Psychology*, 79(6), 834-849. doi:10.1037/a0025450
- Hopko, D. R., Clark, C. G., Cannity, K., & Bell, J. L. (2015). Pretreatment depression severity in breast cancer patients and its relation to treatment response to Behavior Therapy. *Health Psychology*. doi:10.1037/hea0000252
- Howell, D., Mayo, S., Currie, S., Jones, G., Boyle, M., Hack, T., . . . Simpson, J. (2012). Psychosocial health care needs assessment of adult cancer patients: A

- consensus-based guideline. *Supportive Care in Cancer*, 20(12), 3343-3354. doi:10.1007/s00520-012-1468-x
- Huang, S., & Gan, Y. (2018). Memory as a cognitive representation of post-traumatic growth. *Anxiety, Stress, & Coping*, 31(1), 59-68. doi:10.1080/10615806.2017.1364730
- Hulbert-Williams, N., Neal, R., Morrison, V., Hood, K., & Wilkinson, C. (2012). Anxiety, depression and quality of life after cancer diagnosis: What psychosocial variables best predict how patients adjust? *Psycho-Oncology*, 21(8), 857-867. doi:10.1002/pon.1980
- Husebo, A. M. L., Karlsen, B., Allan, H. Soreide, J. A., Bru, E. (2015). Factors perceived to influence exercise adherence in women with breast cancer participating in an exercise programme during adjuvant chemotherapy: A focus group study. *Journal of Clinical Nursing*, 24(3-4), 500-510. doi/10.1111/jocn.12633
- Hvidt, E. A. (2017). The existential cancer journey: Travelling through the intersubjective structure of homeworld/alienworld. *Health*, 21(4), 375-391. doi:10.1177/1363459315617312
- Ivey, A. E., Ivey, M. B., & Zalaquett, C. P. (2016). *Essentials of intentional interviewing: Counseling in a multicultural world* (3rd ed.). Boston, MA: Cengage Learning.
- Jacobs, K., & Manzi, T. (2000). Evaluating the social constructionist paradigm in housing research. *Housing, Theory and Society*, 17(1), 35-42. doi:10.1080/140360900750044764
- Jacobs, L., & Finlayson, C. A. (Eds.). (2010). *Early diagnosis and treatment of cancer series: Breast cancer*. Philadelphia, PA.: Saunders Elsevier.
- James, J., Verplanken, B., & Rimes, K.A. (2015). Self-criticism as a mediator in the relationship between unhealthy perfectionism and distress. *Personality and Individual Differences*, 79, 123-128. doi:10.1016/j.paid.2015.01.030
- James, F. R., Wootton, S., Jackson, A., Wiseman, M., Copson, E. R., & Cutress, R. I. (2015). Obesity in breast cancer: What is the risk factor? *European Journal of Cancer*, 51(6), 705-720. doi:<http://dx.doi.org/10.1016/j.ejca.2015.01.057>
- James, K., Verplanken, B., & Rimes, K. A. (2015). Self-criticism as a mediator in the relationship between unhealthy perfectionism and distress. *Personality and Individual Differences*, 79, 123-128. doi:10.1016/j.paid.2015.01.030
- Jang, S.-H., Kang, S.-Y., Lee, H.-J., & Lee, S.-Y. (2016). Beneficial effect of Mindfulness-Based Art Therapy in patients with breast cancer: A randomized controlled trial. *EXPLORE: The Journal of Science and Healing*, 12(5), 333-340. Retrieved from <http://www.sciencedirect.com/science/article/pii/S1550830716300659> doi:<http://dx.doi.org/10.1016/j.explore.2016.06.003>
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York, NY: The Free Press.
- Janz, N. K., Friese, C. R., Li, Y., Graff, J. J., Hamilton, A. S., & Hawley, S. T. (2014). Emotional well-being years post-treatment for breast cancer: prospective, multi-ethnic, and population-based analysis. *Journal of Cancer Survivorship*, 8(1), 131-142. doi:10.1007/s11764-013-0309-3
- Järvinen, M., & Miller, G. (2015). Social constructionism turned into human service work. *Qualitative Sociology Review*, 11(2), 198-214.
- Jatoi, I., Bandos, H., Jeong, J. H., Anderson, W. F., Romond, E. H., Mamounas, E. P., & Wolmark, N. (2015). Time-varying effects of breast cancer adjuvant

- systemic therapy. *Journal of the National Cancer Institute*, 108(1).  
doi:10.1093/jnci/djv304
- Jensen-Johansen, M. B., Christensen, S., Valdimarsdottir, H., Zakowski, S., Jensen, A. B., Bovbjerg, D. H., & Zachariae, R. (2013). Effects of an expressive writing intervention on cancer-related distress in Danish breast cancer survivors: Results from a nationwide randomized clinical trial. *Psycho-Oncology*, 22(7), 1492-1500. Retrieved from <http://dx.doi.org/10.1002/pon.3193>
- Joeng, J. R., & Turner, S. L. (2015). Mediators between self-criticism and depression: Fear of compassion, self-compassion, and importance to others. *Journal of Counseling Psychology*, 62(3), 453-463. doi:10.1037/cou0000071
- Joeng, J. R., Turner, S. L., Kim, E. Y., Choi, S. A., Kim, J. K. & Lee, Y. J. (2017). Data for Korean college students' anxious and avoidant attachment, self-compassion, anxiety and depression. *DOAJ: Data in Brief*, 13, 316-319. doi:10.1016/j.dib.2017.06.006
- John-Steiner, V., & Mahn, H. (1996). Sociocultural approaches to learning and development: A Vygotskian framework. *Educational Psychologist*, 31(3/4), 191-206. doi:10.1080/00461520.1996.9653266
- Johnston, L. B. (2014). Surviving critical illness: New insights from mixed-methods research. *Smith College Studies in Social Work*, 84(1), 76-106. doi:10.1080/00377317.2014.860834
- Kaakinen, P., Kyngäs, H., & Kääriäinen, M. (2013). Predictors of good-quality counselling from the perspective of hospitalised chronically ill adults. *Journal of Clinical Nursing*, 22(19-20), 2704-2713. doi:10.1111/jocn.12144
- Kagan, S. H. (2014). Ageism and compassion for our future selves. *Journal of Older People Nursing*, 10(1), 1-2. doi:10.1111/opn.12081
- Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science & Medicine*, 67(1), 79-87. doi:<http://dx.doi.org/10.1016/j.socscimed.2008.03.036>
- Kaptein, A. A., Schoones, J. W., Fischer, J. J., Thong, M. S. Y., Kroep, J. R., & Koos, J. M. v.d.H. (2015). Illness perceptions in women with breast cancer: A systematic literature review. *Current Breast Cancer Reports*, 7(3), 117-126. doi:10.1007/s12609-015-0187-y
- Karnilowicz, W., Ali, L., & Phillimore, J. (2014). Community research within a social constructionist epistemology: Implications for “Scientific Rigor”. *Community Development*, 45(4)1-15. doi:10.1080/15575330.2014.936479
- Karris, M., & Caldwell, B. E. (2015). Integrating Emotionally Focused Therapy, self-compassion, and Compassion-Focused Therapy to assist shame-prone couples who have experienced trauma. *The Family Journal: Counseling and Therapy for Couples and Families*, 23(4), 346-357. doi:10.1177/1066480715601676
- Katz, A. (2011). Sexually speaking. Breast cancer and women's sexuality: Acknowledging and discussing the consequences of treatment. *American Journal of Nursing*, 111(4), 63-67.
- Kayser, K. (2005). Enhancing dyadic coping during a time of crisis: A theory-based intervention with breast cancer patients and their partners. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.). *Couples coping with stress: Emerging perspectives on dyadic coping* (pp. 175-194). Washington, DC.: American Psychological Association.

- Kayser, K., Feldman, B. N., Borstelmann, N. A., & Daniels, A. A. (2010). Effects of a randomized couple-based intervention on quality of life of breast cancer patients and their partners. *Social Work Research, 34*(1), 20-32. Retrieved from <http://www.jstor.org.ezproxy.usc.edu.au:2048/stable/42659741>
- Kearney, D. J., Mcdermott, K., Malte, C.A., Martinez, M. E., Simpson, T. L. (2013). Effects of participation in a mindfulness program for veterans with posttraumatic stress disorder: A randomized controlled pilot study. *Journal of Clinical Psychology, 69*(1), 14-27. doi:10.1002/jclp.21911
- Kees, N. L., Carlson, L. A., Parmley, R., Dahlen, P., Evans, K., Marbley, A. F., . . . Snyder, B. (2005). Women and counseling: A vision for the future. *Journal of Counseling & Development, 83*(3), 381-383. doi:10.1002/j.1556-6678.2005.tb00359.x
- Keitel, M. A., & Kopala, M. (2000). *Counseling women with breast cancer : A guide for professionals*. Thousand Oaks, CA: Sage Publications Inc.
- Keitel, M. A., & Kopala, M. (2003). *Counseling women with breast cancer : A guide for professionals*. Thousand Oaks, CA: Sage Publications Inc.
- Kelly, A. C., & Dupasquier, J. (2015). Social safeness mediates the relationship between recalled parental warmth and the capacity for self-compassion and receiving compassion. *Personality and Individual Differences, 89*, 157-161. doi:10.1016/j.paid.2015.10.017
- Kelly, A. C., Vimalakanthan, K., & Miller, K. E. (2014). Self-compassion moderates the relationship between body mass index and both eating disorder pathology and body image flexibility. *Body Image, 11*(4), 446-453. Retrieved from <http://www.sciencedirect.com/science/article/pii/S1740144514000813> doi:<http://dx.doi.org/10.1016/j.bodyim.2014.07.005>
- Kelly, A. C., Zuroff, D. C., Foa, C. L., & Gilbert, P. (2010). Who benefits from training in self-compassionate self-regulation? A study of smoking reduction. *Journal of Social and Clinical Psychology, 29*(7), 727-755. Retrieved from doi:10.1521/jscp.2010.29.7.727
- Kelly, A. C., Zuroff, D. C., & Shapira, L. B. (2009). Soothing oneself and resisting self-attacks: The treatment of two intrapersonal deficits in depression vulnerability. *Cognitive Therapy & Research, 33*(3), 301-313. doi:10.1007/s10608-008-9202-1
- Keltner, D., & Haidt, J. (2001). Social functions of emotions. In T. J. Mayne & G. A. Bonanno (Eds.), *Emotions: Current issues and future directions* (pp. 192-213). New York, NY: Guilford Press.
- Kempke, S., Van Houdenhove, B., Luyten, P., Goossens, L., Bekaert, P., & Van Wambeke, P. (2011). Unraveling the role of perfectionism in chronic fatigue syndrome: Is there a distinction between adaptive and maladaptive perfectionism? *Psychiatry Research, 186*(2-3), 373-377. doi:10.1016/j.psychres.2010.09.016
- Kendall-Tackett, K. (2009). Psychological trauma and physical health: A psychoneuroimmunology approach to etiology of negative health effects and possible interventions. *Psychological Trauma: Theory, Research, Practice, and Policy, 1*(1), 35-48. Retrieved from <http://dx.doi.org/10.1037/a0015128>
- Kenen, R., Ardern-Jones, A., & Eeles, R. (2003). Living with chronic risk: Healthy women with a family history of breast/ovarian cancer. *Health, Risk & Society, 5*(3), 315-331. doi:10.1080/13698570310001607003
- Keyes, K. M., McLaughlin, K. A., Demmer, R. T., Cerdá, M., Koenen, K. C., Uddin, M., & Galea, S. (2013). Potentially traumatic events and the risk of six

- physical health conditions in a population-based sample. *Depression and Anxiety*, 30(5), 451-460. Retrieved from <http://dx.doi.org/10.1002/da.22090>
- Kiecolt-Glaser, J. K., McGuire, L., Robles, T. F., & Glaser, R. (2002). Psychoneuroimmunology: Psychological influences on immune function and health. *Journal of Consulting & Clinical Psychology*, 70(3), 537-547. doi:10.1037//0022-006X.70.3.537
- Kim, J., Han, J. Y., Shaw, B., McTavish, F., & Gustafson, D. (2010). The roles of social support and coping strategies in predicting breast cancer patients' emotional well-being: Testing mediation and moderation models. *Journal of Health Psychology*, 15(4), 543-552. doi:10.1177/1359105309355338
- Kirchberg, T. M., Neimayer, R. A., & James, R. K. (1998). Beginning counselors' death concerns and empathic responses to client situations involving death and grief. *Death Studies*, 22(2), 99-120. doi:10.1080/074811898201623
- Kissane, D. (2014). Demoralization: A life-preserving diagnosis to make for the severely medically ill. *Journal of Palliative Care*, 30(4), 255-258. Retrieved from <https://search-proquest-com.ezproxy.usc.edu.au/docview/1640765604?accountid=28745>
- Kissane, D. W., Bloch, S., Miach, P., Smith, G. C., Seddon, A., Keks, N. (1997). Cognitive-existential group therapy for patients with primary breast cancer: Techniques and themes. *Psycho-Oncology*, 6(1), 25-33. doi: 10.1002/(SICI)1099-1611(199703)6:1<25::AID-PON240>3.0.CO;2-N
- Kissane, D. W., Bloch, S., Smith, G. C., Miach, P., Clarke, D. M., Ikin, J., . . . McKenzie, D. (2003). Cognitive-Existential Group Psychotherapy for women with primary breast cancer: A randomised controlled trial *Psycho-Oncology*, 12(6), 523-546. doi:10.1002/pon.683
- Kissane, D. W., Grabsch, B., Clarke, D. M., Christie, G., Clifton, D., Gold, S., . . . Smith, G. C. (2004). Supportive-Expressive Group Therapy: The transformation of existential ambivalence into creative living while enhancing adherence to anti-cancer therapies. *Psycho-Oncology*, 13(11), 755-768. doi:10.1002/pon.798
- Klawiter, M. (2004). Breast cancer in two regimes: The impact of social movements on illness experience. *Sociology of Health & Illness*, 26(6), 845-874. doi:[10.1111/j.1467-9566.2004.421\\_1.x](https://doi.org/10.1111/j.1467-9566.2004.421_1.x)
- Klein, J. (2008). Differences in male breast cancer stage, tumor size at diagnosis, and survival rate between metropolitan and nonmetropolitan regions. (Unpublished Doctoral dissertation). Walden University, College of Health Sciences, Minneapolis, Minnesota.
- Klimecki, O. M., Leiberg, S., Ricard, M., & Singer, T. (2014). Differential pattern of functional brain plasticity after compassion and empathy training. *Social Cognitive and Affective Neuroscience*, 9(6), 873-879. doi:10.1093/scan/nst060
- Knight, Z. (2002). Heal my heart: Stories of hurt and healing from group therapy. *Indo-Pacific Journal of Phenomenology*, 2(2), 1-15. Retrieved from <http://dx.doi.org/10.1080/20797222.2002.11433875>
- Knobf, M. T. (2007). Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing*, 23(1), 71-83. Retrieved from doi:<https://doi.org/10.1016/j.soncn.2006.11.009>
- Knox, R., & Cooper, M. (2010). Relationship qualities that are associated with moments of relational depth: The client's perspective. *Person-Centered &*



- Experiential Psychotherapies*, 9(3), 236-256.  
doi:10.1080/14779757.2010.9689069
- Koch, L., Bertram, H., Eberle, A., Holleczeck, B., Schmid-Höpfner, S., Waldmann, A., . . . Arndt, V. (2014). Fear of recurrence in long-term breast cancer survivors—still an issue. Results on prevalence, determinants, and the association with quality of life and depression from the Cancer Survivorship: A multi-regional population-based study. *Psycho-Oncology*, 23(5), 547-554. doi:10.1002/pon.3452
- Koczwara, B., & Ward, P. (2015). Response to Bell, K., The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease, *Social Science & Medicine*, 128, 342-343.  
doi:<http://dx.doi.org/10.1016/j.socscimed.2014.10.017>
- Köhle, N., Drossaert, C. H. C., Jaran, J., Schreurs, K. M. G., Leeuw, I. M. V.-d., & Bohlmeijer, E. T. (2017). User-experiences with a web-based self-help intervention for partners of cancer patients based on acceptance and commitment therapy and self-compassion: A qualitative study. *BMC Public Health*, 17(1), 225. doi:10.1186/s12889-017-4121-2
- Koithan, M. (2009). Let's talk about complementary and alternative therapies. *The Journal for Nurse Practitioners*, 5(3), 214-215.  
doi:<http://dx.doi.org/10.1016/j.nurpra.2008.12.011>
- Kokavec, A. (2016). Community based psychosocial education can improve mood disturbance in breast cancer survivors at various stages of their recovery. *Behavioural and Cognitive Psychotherapy*, 44(6), 730-736.  
doi:10.1017/S1352465816000187
- Koo, H.-Y., Seo, Y.-G., Cho, M.-H., Kim, M.-J., & Choi, H.-C. (2016). Weight change and associated factors in long-term breast cancer survivors. *PLoS One*, 11(7), e0159098. doi:10.1371/journal.pone.0159098
- Koraleski, S., Ryan, K., & Carlson, D. (2014). Spiritual effects of a community-based meaning-focused breast cancer survivorship group. *Psycho-Oncology*, 23, 10.
- Kornblith, A. B., Powell, M., Regan, M. M., Bennett, S., Krasner, C., Moy, B., . . . Winer, E. (2007). Long-term psychosocial adjustment of older vs younger survivors of breast and endometrial cancer. *Psycho-Oncology*, 16(10), 895-903. doi:10.1002/pon.1146
- Kreiger, T., Altenstein, D., Baettig, I., Doerig, N., & Holtforth, M.G. (2013). Self-compassion in depression: Associations with depressive symptoms, rumination, and avoidance in depressed outpatients. *Behaviour Therapy*, 44(3), 501-513. doi:[10.1016/j.beth.2013.04.004](http://dx.doi.org/10.1016/j.beth.2013.04.004)
- Krishnamoorthy, S., & Honn, K. V. (2006). Inflammation and disease progression. *Cancer and Metastasis Reviews*, 25(3), 481-491. doi:10.1007/s10555-006-9016-0
- Kristeller, J. L., & Johnson, T. (2005). Cultivating loving kindness: A two-stage model of the effects of meditation on empathy, compassion, and altruism. *Zygon® Journal of Religion & Science*, 40(2), 391-408. doi:10.1111/j.1467-9744.2005.00671.x
- Kruk, J. (2012). Self-reported psychological stress and the risk of breast cancer: A case-control study. *Stress*, 15(2), 162-171.  
doi:10.3109/10253890.2011.606340

- Kruk, J., & Aboul-Enein, H. Y. (2004). Psychological stress and the risk of breast cancer: a case-control study. *Cancer detection and prevention*, 28(6), 399-408. doi:10.1016/j.cdp.2004.07.009
- Krychman, M. L., & Katz, A. (2012). Breast cancer and sexuality: Multi-modal treatment options. *The Journal of Sexual Medicine*, 9(1), 5-13. doi:10.1111/j.1743-6109.2011.02566.x
- Kukar, M., Watroba, N., Miller, A., Kumar, S., & Edge, S. (2014). Fostering coordinated survivorship care in breast cancer: Who is lost to follow-up? *Research and Practice*, 8(2), 199-204. doi:10.1007/s11764-013-0323-5
- Kurman, J. (2003). The role of perceived specificity level of failure events in self-enhancement and in constructive self-criticism. *Personality and Social Psychology Bulletin*, 29(2), 285-294. doi:10.1177/0146167202239053
- Kushi, L. H., Kwan, M. L., Lee, M. M., & Ambrosone, C. B. (2007). Lifestyle factors and survival in women with breast cancer. *The Journal of Nutrition*, 137(1), 236S-242S. Retrieved from <http://jn.nutrition.org/content/137/1/236S.short>
- Kvillemo, P., & Bränström, R. (2014). Coping with breast cancer: A meta-analysis. *PLoS ONE*, 9(11), e112733. doi:10.1371/journal.pone.0112733
- Kyranou, M., Paul, S. M., Dunn, L. B., Puntillo, K., Aouizerat, B. E., Abrams, G., . . . Miaskowski, C. (2013). Differences in depression, anxiety, and quality of life between women with and without breast pain prior to breast cancer surgery. *European Journal of Oncology Nursing*, 17(2), 190-195. doi:10.1016/j.ejon.2012.06.001
- Kyranou, M., Puntillo, K., Dunn, L. B., Aouizerat, B. E., Paul, S. M., Cooper, B. A., . . . Miaskowski, C. (2014). Predictors of initial levels and trajectories of anxiety in women before and for 6 months after breast cancer surgery. *Cancer Nursing*, 37(6), 406-417. doi:10.1097/NCC.0000000000000131
- Lam, W. W. T., Shing, Y. T., Bonanno, G. A., Mancini, A. D., & Fielding, R. (2012). Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. *Psycho-Oncology*, 21(1), 90-99. doi:10.1002/pon.1876
- Landridge, D., & Hagger-Johnson, G. (2009). *Introduction to research methods and data analysis in psychology* (2nd ed.). London, UK: Pearson Education.
- Larkin, M., Eatough, V., & Osborn, M. (2011). Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory & Psychology*, 21(3), 318-337. doi:10.1177/0959354310377544
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. doi:10.1191/1478088706qp062oa
- Launay, J., Pearce, E., Wlodarski, R., van Duijn, M., Carney, J., & Dunbar, R. I. M. (2015). Higher-order mentalising and executive functioning. *Personality and Individual Differences*, 86, 6-14. doi:<https://doi.org/10.1016/j.paid.2015.05.021>
- Lawn, S., Delany, T., Sweet, L., Battersby, M., & Skinner, T. (2015). Barriers and enablers to good communication and information-sharing practices in care planning for chronic condition management. *Australian Journal of Primary Health*, 21(1), 84-89. doi:10.1071/PY13087
- Leary, M. R., Tate, E. B., Adams, C. E., Allen, A. B., & Hancock, J. (2007). Self-compassion and reactions to unpleasant self-relevant events: The implications

- of treating oneself kindly. *Journal of Personality and Social Psychology*, 92(5), 887-904. doi:10.1037/0022-3514.92.5.887
- Lebel, S., Maheu, C., Lefebvre, M., Secord, S., Courbasson, C., Singh, M., . . . Catton, P. (2014). Addressing fear of cancer recurrence among women with cancer: A feasibility and preliminary outcome study. *Journal of Cancer Survivorship*, 8(3), 485-496. Retrieved from <https://doi.org/10.1007/s11764-014-0357-3>
- Lebel, S., Rosberger, Z., Edgar, L., & Devins, G. M. (2008). Predicting stress-related problems in long-term breast cancer survivors. *Journal of Psychosomatic Research*, 65(6), 513-523. doi:10.1016/j.jpsychores.2008.07.018
- Lechner, S. C., Zakowski, S. G., Antoni, M. H., Greenhawt, M., Block, K., & Block, P. (2003). Do sociodemographic and disease-related variables influence benefit-finding in cancer patients? *Psycho-Oncology*, 12(5), 491-499. doi:10.1002/pon.671
- Lee, V., Cohen, S. R., Edgar, L., Laizner, A. M., & Gagnon, A. J. (2006). Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social Science & Medicine*, 62(12), 3133-3145. doi:10.1016/j.socscimed.2005.11.041
- Lee, V., & Loiselle, C. (2012). The salience of existential concerns across the Cancer Control Continuum. *Palliative & Supportive Care*, 10(2), 123-133. doi:10.1017/S1478951511000745
- Leird, J. M. (2010). Libraries and seasons of cancer survivorship. *Journal of Hospital Librarianship*, 10(3), 279-288. doi:10.1080/15323269.2010.491693
- Leitner, L. M., & Faidley, A. J. (1999). Creativity in experiential personal construct psychotherapy. *Journal of Constructivist Psychology*, 12(4), 273-286. doi:10.1080/107205399266019
- LeRoy, A. S., Shields, A., Chen, M. A., Brown, R. L., & Fagundes, C. P. (2018). Improving breast cancer survivors' psychological outcomes and quality of life: Alternatives to traditional psychotherapy. *Current Breast Cancer Reports*, 10, 28-34. doi:10.1007/s12609-018-0266-y
- Lesiuk, T. (2015). The effect of mindfulness-based music therapy on attention and mood in women receiving adjuvant chemotherapy for breast cancer: A pilot study. *Oncology Nursing Forum*, 42(3), 276-282. doi:10.1188/15.ONF.276-282
- Leung, A. K. Y., Liou, S., Qiu, L., Kwan, L. Y. Y., Chiu, C.-Y., & Yong, J. C. (2014). The role of instrumental emotion regulation in the emotions-creativity link: How worries render individuals with high neuroticism more creative. *Emotion*, 14(5), 846-856. doi:10.1037/a0036965
- Levin, R. (2006). The breast/nipple/areola complex and human sexuality. *Sexual and Relationship Therapy*, 21(2), 237-249. doi:10.1080/14681990600674674
- Levine, E. G., & Levine, S. K. (2011). *Art in action : Expressive Arts Therapy and social change*. London: Jessica Kingsley Publishers.
- Levy, N. (2012). Towards a new environmental ethic in contemporary feminist theory. *Hecate*, 38(1 2), 9-23. Retrieved from [http://www.emsah.uq.edu.au.ezproxy.usc.edu.au:2048/awsr/new\\_site/hecate\\_archive/hecate.html](http://www.emsah.uq.edu.au.ezproxy.usc.edu.au:2048/awsr/new_site/hecate_archive/hecate.html)
- Li, J., Gao, W., Yu, L.-X., Zhu, S.-Y., & Cao, F.-L. (2017). Breast-related stereotype threat contributes to a symptom cluster in women with breast cancer. *Journal of Clinical Nursing*, 26(9-10), 1395-1404. doi:10.1111/jocn.13698

- Lichtenthal, W. G., Corner, G. W., Slivjak, E. T., Roberts, K. E., Li, Y., Breitbart, W., . . . Beard, C. (2017). A pilot randomized controlled trial of cognitive bias modification to reduce fear of breast cancer recurrence. *Cancer, 123*(8), 1424-1433. Retrieved from <http://dx.doi.org/10.1002/cncr.30478>
- Lieberman, M. A., & Goldstein, B. A. (2006). Not all negative emotions are equal: The role of emotional expression in online support groups for women with breast cancer. *Psycho-Oncology, 15*(2), 160-168. doi:10.1002/pon.932
- Lijovic, M., Davis, S. R., Fradkin, P., La China, M., Farrugia, H., Wolfe, R., & Bell, R. J. (2008). Use of a cancer registry is preferable to a direct-to-community approach for recruitment to a cohort study of wellbeing in women newly diagnosed with invasive breast cancer. *BMC Cancer, 8*, 1-8. doi:10.1186/1471-2407-8-126
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Lindsay, S. (2009). Prioritizing illness: Lessons in self-managing multiple chronic diseases. *Canadian Journal of Sociology, 34*(4), 983-1002.
- Lippman, M. E. (2016). Depression, inflammation and progression of human breast cancer. *Psychoneuroendocrinology, 71*, 2. doi:<http://dx.doi.org/10.1016/j.psyneuen.2016.07.014>
- Liss, M., & Erchull, M. J. (2015). Not hating what you see: Self-compassion may protect against negative mental health variables connected to self-objectification in college women. *Body Image, 14*, 5-12. doi:<http://dx.doi.org/10.1016/j.bodyim.2015.02.006>
- Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine, 47*(10), 1485-1494. Retrieved from doi:[http://dx.doi.org/10.1016/S0277-9536\(98\)00248-2](http://dx.doi.org/10.1016/S0277-9536(98)00248-2)
- Livneh, H., & Antonak, R. F. (2005). Psychosocial adaptation to chronic illness and disability: A primer for counselors. *Journal of Counseling & Development, 83*(1), 12-20. doi:10.1002/j.1556-6678.2005.tb00575.x
- Lo, C., Lin, J., Gagliese, L., Zimmermann, C., Mikulincer, M., & Rodin, G. (2010). Age and depression in patients with metastatic cancer: The protective effects of attachment security and spiritual wellbeing. *Ageing and Society, 30*(2), 325-336. doi:10.1017/S0144686X09990201
- Loh, S., Packer, T., Chinna, K., & Quek, K. (2013). Effectiveness of a patient self-management programme for breast cancer as a chronic illness: A non-randomised controlled clinical trial. *Research and Practice, 7*(3), 331-342. doi:10.1007/s11764-013-0274-x
- Long, O., Maratos, F. A., Gilbert, P., Evans, G., Volker, F., Rockliff, H., & Rippon, G. (2009). Having a word with yourself: Neural correlates of self-criticism and self-reassurance. *NeuroImage, 49*, 1849-1856. doi:10.1016/j.neuroimage.2009.09.019
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726-735. doi:10.1177/1049732304263638
- Love, B., Thompson, C. M., & Knapp, J. (2014). The need to be Superman: The psychosocial support challenges of young men affected by cancer. *Oncology Nursing Forum, 41*(1), E21. doi:10.1188/14.ONF.E21-E27
- Low, C. A., Stanton, A. L., Thompson, N., Kwan, L., & Ganz, P. A. (2006). Contextual life stress and coping strategies as predictors of adjustment to

- breast cancer survivorship. *Annals of Behavioral Medicine*, 32(3), 235-244.  
doi:10.1207/s15324796abm3203\_10
- Lu, Q., Man, J., You, J., & Leroy, A. S. (2015). The link between ambivalence over emotional expression and depressive symptoms among Chinese breast cancer survivors. *Journal of Psychosomatic Research*, 79(2), 153-158.  
doi:10.1016/j.jpsychores.2015.01.007
- Lutz, A., Brefczynski-Lewis, J., Johnstone, T., & Davidson, R. J. (2008). Regulation of the neural circuitry of emotion by compassion meditation: Effects of meditative expertise. *PLoS ONE*, 3(3), 1-10.  
doi:10.1371/journal.pone.0001897
- Mackenzie, C. R. (2014). 'It is hard for mums to put themselves first': How mothers diagnosed with breast cancer manage the sociological boundaries between paid work, family and caring for the self. *Social Science & Medicine*, 117, 96-106. doi:<http://dx.doi.org/10.1016/j.socscimed.2014.07.043>
- Madison, G. (2014). Palpable existentialism: A focusing-oriented therapy. *Psychotherapy in Australia*, 20(2), 36-42.
- Maes, M., & Smith, R. S. (1998). Fatty acids, cytokines, and major depression. *Biological Psychiatry*, 43(5), 313-314. doi:org/10.1016/S0006-3223(97)00401-0
- Magai, C., Consedine, N., Neugut, A. I., & Hershman, D. L. (2007). Common psychosocial factors underlying breast cancer screening and breast cancer treatment adherence: A conceptual review and synthesis. *Journal of Womens Health*, 16(1), 11-23. doi:10.1089/jwh.2006.0024
- Malchiodi, C. A. (1999). *Medical Art Therapy with adults*. London, UK: Jessica Kingsley Publishers.
- Malchiodi, C. A. (2005). *Expressive therapies*. New York, NY: Guilford Press.
- Malek, K. S., & Silliman, R. A. (2007). Cancer survivorship issues in older adults. In P. A. Ganz (Ed.), *Cancer survivorship: Today and tomorrow* (pp. 215-224). New York, NY: Springer.
- Mallinckrodt, B., Armer, J. M., & Heppner, P. P. (2012). A threshold model of social support, adjustment, and distress after breast cancer treatment. *Journal of Counseling Psychology*, 59(1), 150-160. doi:10.1037/a0026549
- Mancini, A. D., & Bonanno, G. (2009). Predictors and parameters of resilience to loss: Toward an individual differences model. *Personality*, 77(6), 1805-1832. doi:10.1111/j.1467-6494.2009.00601.x
- Mandelblatt, J. S., Clapp, J. D., Luta, G., Faul, L. A., Tallarico, M. D., McClendon, T. D., . . . Isaacs, C. (2016). Long-term trajectories of self-reported cognitive function in a cohort of older survivors of breast cancer: CALGB 369901 (Alliance). *Cancer*, 122(22), 3555-3563. Retrieved from <http://dx.doi.org/10.1002/cncr.30208>
- Manne, S., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., & Grana, G. (2004). Posttraumatic growth after breast cancer: Patient, partner, and couple perspectives. *Psychosomatic Medicine*, 66(3), 442-454.  
doi:10.1097/01.psy.0000127689.38525.7d
- Manning, M., & Bettencourt, B. A. (2011). Depression and medication adherence among breast cancer survivors: Bridging the gap with the theory of planned behaviour. *Psychology & Health*, 26(9), 1173-1187.  
doi:10.1080/08870446.2010.542815
- Markell, M. J. (2002). *Sand, water, silence: The embodiment of spirit explorations in matter and psyche*. London, UK. Jessica Kingsley Publishers

- Marroquín, B., Czamanski-Cohen, J., Weihs, K. L., & Stanton, A. L. (2016). Implicit loneliness, emotion regulation, and depressive symptoms in breast cancer survivors. *Journal of Behavioral Medicine, 39*(5), 832-844. doi:10.1007/s10865-016-9751-9
- Martin, E., Bulsara, C., Battaglini, C., Hands, B., & Naumann, F. L. (2015). Breast and prostate cancer survivor responses to group exercise and supportive group psychotherapy. *Journal of Psychosocial Oncology, 33*(6), 620-634. Retrieved from <http://dx.doi.org/10.1080/07347332.2015.1082166>
- Matua, G. A., & Van Der Wal, D. M. (2015). Differentiating between descriptive and interpretive phenomenological research approaches. *Nurse Researcher, 22*(6), 22. doi:10.7748/nr.22.6.22.e1344
- McCann, L., Illingworth, N., Wengström, Y., Hubbard, G., & Kearney, N. (2009). Transitional experiences of women with breast cancer within the first year following diagnosis. *Journal of Clinical Nursing, 19*, 1969-1976. doi:10.1111/j.1365-2702.2009.03134.x.
- McCaskill-Stevens, W., & Abrams, J. S. (2011). Comorbidities in the aging breast cancer population: Are current assessments leading to improved outcomes? *Journal of the National Cancer Institute, 103*(14), 1072-1073. doi:10.1093/jnci/djr239
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice, 15*(1), 7-15. doi:10.1111/j.1440-172X.2008.01724.x
- McGregor, B. A., Bowen, D. J., Ankerst, D. P., Andersen, M. R., Yasui, Y., McTiernan, A. (2004). *Health Psychology, 23*(4), 339-344. doi:10.1037/0278-6133.23.4.339
- McLeod, J. (2011). The relevance and contribution of hermeneutics. In J. McLeod (Ed.), *Qualitative research in counselling and psychotherapy* (pp. 22-34): Sage Publications Inc. doi:<http://dx.doi.org/10.4135/9781849209663>
- McLeod, J. (2013). *An introduction to counselling* (5th ed.). New York, NY: McGraw-Hill Education.
- McNiff, S. (2004). *Art heals: How creativity cures the soul*. Boston: Shambala.
- McNiff, S. (2009). *Integrating the arts in therapy: History, theory and practice*. Springfield, Ill.: Charles C. Thomas.
- Mearns, D., & Thorne, B. (2013). *Person-centred counselling in action* (4th ed.). London, UK: Sage Publications Inc.
- Mehnert, A., & Koch, U. (2008). Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research, 64*(4), 383-391. doi:10.1016/j.jpsychores.2007.12.005
- Meneses, K., & Benz, R. (2010). Quality of life in cancer survivorship: 20 years later. *Seminars in Oncology Nursing, 26*(1), 36-46. doi:10.1016/j.soncn.2009.11.006
- Mens, M. G., Helgeson, V. S., Lembersky, B. C., Baum, A., & Scheier, M. F. (2016). Randomized psychosocial interventions for breast cancer: Impact on life purpose. *Psycho-Oncology, 25*(6), 618-625. doi:10.1002/pon.3891
- Merkes, M. (2010). Mindfulness-Based Stress Reduction for people with chronic diseases. *Australian Journal of Primary Health, 16*(3), 200-210.
- Mesquita, B., & Frijda, N. H. (2011). An emotion perspective on emotion regulation. *Cognition and Emotion, 25*(5), 782-784. doi:10.1080/02699931.2011.586824

- Metcalf, C., Smith, G. D., Macleod, J., & Hart, C. (2007). The role of self-reported stress in the development of breast cancer and prostate cancer: A prospective cohort study of employed males and females with 30 years of follow-up. *European Journal of Cancer*, 43(6), 1060-1065. doi:<http://dx.doi.org/10.1016/j.ejca.2007.01.027>
- Midtgaard, J., Stelter, R., RØRth, M., & Adamsen, L. I. S. (2007). Regaining a sense of agency and shared self-reliance: The experience of advanced disease cancer patients participating in a multidimensional exercise intervention while undergoing chemotherapy: Analysis of patient diaries. *Scandinavian Journal of Psychology*, 48(2), 181-190. doi:10.1111/j.1467-9450.2007.00562.x
- Miller, K., & Massie, M. J. (2006). Depression and anxiety. *The Cancer Journal*, 12(5), 388-397. Retrieved from
- Miller, K. D. (2009). Revisiting the seasons of survival. *Cure*. Retrieved from <http://www.curetoday.com/publications/cure/2009/summer2009/Revisiting-the-Seasons-of-Survival>
- Miller, K. D., Merry, B., & Miller, J. (2008). Seasons of survivorship revisited. *Cancer Journal*, 14(6), 369-374. doi:10.1097/PPO.0b013e31818edf60
- Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., . . . Jemal, A. (2016). Cancer treatment and survivorship statistics, *CA: A Cancer Journal for Clinicians*, 66(4), 271-289. doi:10.3322/caac.21349
- Miron, L. R., Sherrill, A. M., & Orcutt, H. K. (2015). Fear of self-compassion and psychological inflexibility interact to predict PTSD symptom severity. *Journal of Contextual Behavioral Science*, 4(1), 37-41. doi:10.1016/j.jcbs.2014.10.003
- Mitchell, G., Murray, J., & Hynson, J. (2008). Understanding the whole person: Life-limiting illness across the life cycle. In G. Mitchell (Ed.), *Palliative care: A patient-centred approach* (pp. 79-107). Oxfordshire, UK: Radcliffe Publishing.
- Moerer-Urdahl, T., & Cresswell, J. W. (2004). Using Transcendental Phenomenology to explore the "ripple effect" in a leadership mentoring program. *International Journal of Qualitative Methods*, 3(2), 19-35.
- Moestrup, L., & Hansen, H. P. (2015). Existential Concerns About Death. *American Journal of Hospice and Palliative Medicine®*, 32(4), 427-436. doi:10.1177/1049909114523828
- Mols, F., Vingerhoets, A. J. J. M., Coebergh, J. W. W., & van de Poll-Franse, L. V. (2009). Well-being, posttraumatic growth and benefit finding in long-term breast cancer survivors. *Psychology & Health*, 24(5), 583-595. doi:10.1080/08870440701671362
- Montazeri, A., Jarvandi, S., Haghighat, S., Vahdani, M., Sajadian, A., Ebrahimi, M., & Haji-Mahmoodi, M. (2001). Anxiety and depression in breast cancer patients before and after participation in a cancer support group. *Patient Education and Counseling*, 45(3), 195-198. doi:10.1016/S0738-3991(01)00121-5
- Montgomery, M., & McCrone, S. H. (2010). Psychological distress associated with the diagnostic phase for suspected breast cancer: Systematic review. *Journal of Advanced Nursing*, 66(11), 2372-2390. Retrieved from <http://dx.doi.org/10.1111/j.1365-2648.2010.05439.x>
- Monti, D. A., Kash, K. M., Kunkel, E. J., Moss, A., Mathews, M., Brainard, G., . . . Newberg, A. B. (2013). Psychosocial benefits of a novel mindfulness

- intervention versus standard support in distressed women with breast cancer. *Psycho-Oncology*, 22(11), 2565-2575. doi:10.1002/pon.3320
- Moore, S. E. H. (2010). *Ribbon culture: Charity, compassion, and public awareness*. London, UK: Palgrave Macmillan.
- Moreno, J. (2005). The magical music shop. *Journal of Group Psychodrama and Sociometry*, 58(1), 35-43.
- Morrill, E. F., Brewer, N. T., O'Neill, S. C., Lillie, S. E., Dees, E. C., Carey, L. A., & Rimer, B. K. (2008). The interaction of post-traumatic growth and post-traumatic stress symptoms in predicting depressive symptoms and quality of life. *Psycho-Oncology*, 17, 948-953. doi:10.1002/pon.1313
- Morrissey, P. J. (2013). Trauma finds expression through art therapy. *Health Progress*, 94(3), 44.
- Morrow, S. L. (2007). Qualitative research in counseling psychology: Conceptual foundations. *Counseling Psychologist*, 35(2), 209-235. doi:10.1177/0011000006286990
- Morse, J. M. (2012). *Qualitative health research: Creating a new discipline*. Retrieved from <https://ebookcentral.proquest.com/lib/unda/reader.action?docID=1017563&pg=96>
- Morse, J. M., Bottorff, J. L., Neander, W. & Solberg, S. (1991). Comparative analysis of conceptualizations and theories of caring. *Image: Journal of Nursing Scholarship*, 23(2), 119-126. doi:10.1111/j.1547-5069.1991.tb00655.x
- Morse, J. M., Bottorf, J., Anderson, G., O'Brien, B., & Solberg, S. (2006). Beyond empathy: Expanding expressions of caring. *Journal of Advanced Nursing*, 53(1), 75-87. doi:10.1111/j.1365-2648.2006.03677.x
- Morse, W. C., Lowery, D. R., & Steury, T. (2014). Exploring saturation of themes and spatial locations in qualitative public participation geographic information systems research. *Society & Natural Resources*, 27(5), 557-571. Retrieved from <http://dx.doi.org/10.1080/08941920.2014.888791>
- Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications Inc.
- Mudaly, N., & Goddard, C. (2006). *The truth is longer than a lie: Children's experiences of abuse and professional interventions*. London, UK: Jessica Kingsley Publishers.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *The New England Journal of Medicine*, 313(4), 270-273. doi:10.1056/NEJM198507253130421
- Munoz-Plaza, C. E. (2016). Integrating qualitative research methods into care improvement efforts within a learning health system: Addressing antibiotic overuse. *Health Research Policy and Systems*, 14(1), 63. doi:10.1186/s12961-016-0122-3
- Muris, P., & Petrocchi, N. (2017). Protection or vulnerability? A meta-analysis of the relations between the positive and negative components of self-compassion and psychopathology. *Clinical Psychology & Psychotherapy*, 24(2), 373-383. Retrieved from <http://dx.doi.org/10.1002/cpp.2005>
- Myss, C. (1997). *Why people don't heal and how they can*. New York, N.Y.: Three Rivers Press.
- Mystakidou, K., Tsilika, E., Parpa, E., Kyriakopoulos, D., Malamos, N., & Damigos, D. (2008). Personal growth and psychological distress in advanced breast



- cancer. *The Breast*, 17(4), 382-386.  
doi:<http://dx.doi.org/10.1016/j.breast.2008.01.006>
- Naaman, S., Radwan, K., & Johnson, S. (2009). Coping with early breast cancer: Couple adjustment processes and couple-based intervention. *Psychiatry: Interpersonal & Biological Processes*, 72(4), 321-345.  
doi:10.1521/psyc.2009.72.4.321
- Naff, K. (2014). A framework for treating cumulative trauma with Art Therapy. *Journal of the American Art Therapy Association*, 31(2).  
doi:10.1080/07421656.2014.903824
- Nasiri, A., Taleghani, F., & Irajpour, A. (2012). Men's sexual issues after breast cancer in their wives: A qualitative study. *Cancer Nursing*, 35(3), 236-244.  
doi:10.1097/NCC.0b013e31822d48e5
- Naumann, F., Martin, E., Philpott, M., Smith, C., Groff, D., & Battaglini, C. (2012). Can counseling add value to an exercise intervention for improving quality of life in breast cancer survivors? A feasibility study. *The Journal of Supportive Oncology*, 10(5), 188. doi:10.1016/j.suponc.2011.09.004
- Navon, L., & Morag, A. (2004). Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science & Medicine*, 58(11), 2337-2347.  
doi:10.1016/j.socsimed.2003.08.029
- Neal, J. (2000). Work as service to the divine: Giving our gifts selflessly and with joy. *American Behavioral Scientist*, 43(8), 1316-1333.  
doi:10.1177/00027640021955883
- Neborsky, R. J. (2003). A clinical model for the comprehensive treatment of trauma using an affect experiencing-attachment theory approach. In M. F. Solomon & D. J. Siegel (Eds.), *Healing trauma: Attachment, mind, body, and brain* (pp. 282-321). New York, NY: W.W. Norton & Company.
- Neely, M., Schallert, D., Mohammed, S., Roberts, R., & Chen, Y.-J. (2009). Self-kindness when facing stress: The role of self-compassion, goal regulation, and support in college students' well-being. *Motivation and Emotion*, 33(1), 88-97. doi:10.1007/s11031-008-9119-8
- Neff, K. D. (2003). Self-compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and Identity*, 2(2), 85-101.  
doi:10.1080/15298860309032
- Neff, K. D. (2009). The role of self-compassion in development: A healthier way to relate to oneself. *Human Development*, 52(4), 211-214.  
doi:10.1159/000215071
- Neff, K. D. (2011). Self-compassion, self-esteem, and well-being. *Social and Personality Psychology Compass*, 5(1), 1-12. Retrieved from <http://dx.doi.org/10.1111/j.1751-9004.2010.00330.x>
- Neff, K. D. (2015). The 5 myths of self-compassion. *Psychotherapy Networker*, 39(5).
- Neff, K. D., & Germer, C. K. (2013). A pilot study and randomized controlled trial of the Mindful Self-Compassion Program. *Journal of Clinical Psychology*, 69(1), 28-44. doi:10.1002/jclp.21923
- Neff, K. D., Hsieh, Y.-P., & Dejitterat, K. (2005). Self-compassion, achievement goals, and coping with academic failure. *Self & Identity*, 4(3), 263-287.  
doi:10.1080/13576500444000317

- Neff, K. D., Kirkpatrick, K. L., & Rude, S. S. (2007). Self-compassion and adaptive psychological functioning. *Journal of Research in Personality, 41*(1), 139-154. doi:10.1016/j.jrp.2006.03.004
- Neff, K. D., & McGehee, P. (2010). Self-compassion and psychological resilience among adolescents and young adults. *Self and Identity, 9*(3), 225-240. doi:10.1080/15298860902979307
- Neff, K. D., & Vonk, R. (2009). Self-compassion versus global self-esteem: Two different ways of relating to oneself. *Journal of Personality, 77*(1), 23-50. doi:10.1111/j.1467-6494.2008.00537.x
- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies, 38*(8), 485-498. Retrieved from <http://dx.doi.org/10.1080/07481187.2014.913454>
- Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies, 28*(4), 309-340. doi:[10.1080/07481180490432324](http://dx.doi.org/10.1080/07481180490432324)
- Nekolaichuk, C. L., Cumming, C., Turner, J., Yushchyshyn, A., & Sela, R. (2011). Referral patterns and psychosocial distress in cancer patients accessing a psycho-oncology counseling service. *Psycho-Oncology, 20*(3), 326-332. doi:10.1002/pon.1765
- Nekolaichuk, C. L., Cumming, C., Turner, J., Yushchyshyn, A., & Sela, R. (2011). Referral patterns and psychosocial distress in cancer patients accessing a psycho-oncology counseling service. *Psycho-Oncology, 20*(3), 326-332. doi:10.1002/pon.1765
- Neukrug, E., & Schwitzer, A. M. (2006). *Skills and tools for today's counselors and psychotherapists: From natural helping to professional counseling*. Belmont, CA: Thomson/Brooks/Cole.
- Niazi, A. K., & Niazi, S. K. (2011). Mindfulness-based stress reduction: A non-pharmacological approach for chronic illnesses. *North American Journal of Medical Sciences, 3*(1), 20-23. doi:10.4297/najms.2011.320
- O'Brien, M., Harris, J., King, R., & O'Brien, T. (2008). Supportive-Expressive Group Therapy for women with metastatic breast cancer: improving access for Australian women through use of teleconference. *Counselling & Psychotherapy Research, 8*(1), 28-35.
- O'Hara, D. (2013). *Hope in counselling and psychotherapy*. London: Sage Publications.
- O'Keeffe, A. (2004). What good the pink ribbon? *New Statesman, 133*, 26-27.
- Odou, N., & Brinker, J. (2014). Exploring the relationship between rumination, self-compassion, and mood. *Self and Identity, 13*(4), 449-459. doi:10.1080/15298868.2013.840332
- Odou, N., & Brinker, J. (2015). Self-compassion, a better alternative to rumination than distraction as a response to negative mood. *The Journal of Positive Psychology, 10*(5), 447-457. doi:10.1080/17439760.2014.967800
- Ogden, P. (2015). *Sensorimotor psychotherapy: Interventions for trauma and attachment*. New York, NY: W.W. Norton & Company, Inc.
- Ohaeri, B. M., Ofi, A. B., & Campbell, O. B. (2012). Relationship of knowledge of psychosocial issues about cancer with psychic distress and adjustment among breast cancer clinic attendees in a Nigerian teaching hospital. *Psycho-Oncology, 21*(4), 419-426. doi:10.1002/pon.1914
- O'Leary, Z. (2014). *The essential guide to doing your research project*. Los Angeles, Calif.: Sage Publications.

- Olson, J. S. (2002). *Bathsheba's breast: Women, cancer and history*. Baltimore, MD: Johns Hopkins University Press.
- Orange, D. M. (2011). *The suffering stranger: Hermeneutics for everyday clinical practice*. New York, NY: Routledge.
- Paek, M.-S., Ip, E. H., Levine, B., & Avis, N. E. (2016). Longitudinal reciprocal relationships between quality of life and coping strategies among women with breast cancer. *Annals of Behavioral Medicine, 50*(5), 775-783. Retrieved from <https://doi.org/10.1007/s12160-016-9803-y>
- Palesh, O., Butler, L. D., Koopman, C., Giese-Davis, J., Carlson, R., & Spiegel, D. (2007). Stress history and breast cancer recurrence. *Journal of Psychosomatic Research, 63*(3), 233-239. doi:10.1016/j.jpsychores.2007.05.012
- Paley, J. (2014). Heidegger, lived experience and method. *Journal of Advanced Nursing, 70*(7), 1520-1531. doi:10.1111/jan.12324
- Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology, 7*(2), 99-121. doi:10.1080/14780880802513194.
- Panjari, M., Davis, S. R., Fradkin, P., & Bell, R. J. (2012). Breast cancer survivors' beliefs about the causes of breast cancer. *Psycho-Oncology, 21*(7), 724-729. doi:10.1002/pon.1949
- Parkin, C. M., & Fernandez, L. M. G. (2006). Use of statistics to assess the global burden of breast cancer. *The Breast Journal, 12*(Supplement 1), S70-S80. doi:10.1111/j.1075-122X.2006.00205.x
- Paskett, E., Herndon, J., Donohue, K., Naughton, M., Grubbs, S., Pavy, M., . . . Bittoni, M. (2009). Health-related quality of life in long-term breast cancer survivors. *Cancer, 115*(5), 1109-1120. doi:10.1002/cncr.24140
- Paterson, L. C., Lengacher, A. C., Donovan, A. K., Kip, E. K., & Toftagen, S. C. (2016). Body image in younger breast cancer survivors: A systematic review. *Cancer Nursing, 39*(1), E39-E58. doi:10.1097/NCC.0000000000000251
- Patsiopolous, A. T., & Buchanan, M. J. (2011). The practice of self-compassion in counseling: A narrative inquiry. *Professional Psychology: Research and Practice, 42*(4), 301-307. doi:10.1037/a0024482
- Pauley, G., & McPherson, S. (2010). The experience and meaning of compassion and self-compassion for individuals with depression or anxiety. *Psychology and Psychotherapy: Theory, Research and Practice, 83*(2), 129-143. doi:10.1348/147608309X471000
- Pearce, S. (2001). Men's experiences of coping with their wives breast cancer involved focusing on the cancer and treatment and focusing on family to keep life going. *Evidence Based Nursing, 4*(1), 31. doi:10.1136/ebn.4.1.31
- Pearson, M., & Wilson, H. (2001). *Sandplay and symbol work: Emotional healing and personal development with children, adolescents and adults*. Camberwell, VIC: Australian Council for Educational Research.
- Pearson, M., & Wilson, H. (2009). *Using expressive arts to work with mind, body and emotions*. London: Jessica Kingsley Publishers.
- Pérez, S., Galdón, M. J., Andreu, Y., Ibáñez, E., Durá, E., Conchado, A., & Cardeña, E. (2014). Posttraumatic stress symptoms in breast cancer patients: Temporal evolution, predictors, and mediation. *Journal of Traumatic Stress, 27*(2), 224-231. Retrieved from <http://dx.doi.org/10.1002/jts.21901>
- Pert, C. B. (1997). *Molecules of emotion: Why you feel the way you feel*. New York, NY: Simon & Schuster Inc.

- Petersen, S., & Benishek, L. A. (2001). Social construction of illness. *Women & Therapy, 23*(1), 75-100. Retrieved from [http://dx.doi.org/10.1300/J015v23n01\\_06](http://dx.doi.org/10.1300/J015v23n01_06)
- Petersen, S., Heesacker, M., & Schwartz, R. C. (2001). Physical illness: Social construction or biological imperative? *Journal of Community Health Nursing, 18*(4), 213-222. doi:10.1207/S15327655JCHN1804\_02.
- Petticrew, M., Bell, R., & Hunter, D. (2002). Influence of psychological coping on survival and recurrence in people with cancer: Systematic review. *British Medical Journal, 325*(7372), 1066. doi:10.1136/bmj.325.7372.1066
- Pettiford, J., Felts, S., Wischkaemper, E., Miller, D., Crawford, S. & Rahman, R.L. (2017). A bio-psychosocial intervention program for improving quality of life in breast cancer survivors: Final outcome of a prospective randomized trial. *The Breast Journal, 23*(5), 537-544. doi:10.1111/tbj.12786
- Pidgeon, A. M., Ford, L., & Klaassen, F. (2014). Evaluating the effectiveness of enhancing resilience in human service professionals using a retreat-based Mindfulness with Metta Training Program: A randomised control trial. *Psychology, Health & Medicine, 19*(3), 355-364. doi: 10.1080/13548506.2013.806815
- Pierce, J. P., Stefanick, M. L., Flatt, S. W., Natarajan, L., Sternfeld, B., Madlensky, L., . . . Hajek, R. (2007). Greater survival after breast cancer in physically active women with high vegetable-fruit intake regardless of obesity. *Journal of Clinical Oncology, 25*(17), 2345-2351. doi:10.1200/jco.2006.08.6819
- Pieters, H. (2009). From 'cancer patient' to 'cancer survivor': Older breast cancer survivors in transition. In M. Heilemann (Ed.): ProQuest Dissertations Publishing.
- Pillai-Friedman, S., & Ashline, J. L. (2014). Women, breast cancer survivorship, sexual losses, and disenfranchised grief: A treatment model for clinicians. *Sexual and Relationship Therapy, 29*(4), 1-18. doi:10.1080/14681994.2014.934340
- Piot-Ziegler, C. L., Sassi, S. M., Raffoul, W., & Delaloye, J. F. (2010). Mastectomy, body deconstruction, and impact on identity: A qualitative study. *British Journal of Health Psychology, 15*(3), 479-510. doi:10.1348/135910709X472174
- Pinto, A. C., & de Azambuja, E. (2011). Improving quality of life after breast cancer: Dealing with symptoms. *Maturitas, 70*(4), 343-348. doi:10.1016/j.maturitas.2011.09.008
- Pinto-Gouveia, J., Duarte, C., Matos, M., & Fráguas, S. (2014). The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clinical Psychology & Psychotherapy, 21*(4), 311-323. Retrieved from <http://dx.doi.org/10.1002/cpp.1838> doi:10.1002/cpp.1838
- Poehner, M. E. (2012). The zone of proximal development and the genesis of self-assessment. *The Modern Language Journal, 96*(4), 610-622. doi:10.1111/j.1540-4781.2012.01393.x
- Porroche-Escudero, A. (2014). The 'invisible scars' of breast cancer treatments. *Anthropology Today, 30*(3), 18-21. doi:10.1111/1467-8322.12111
- Pössel, P., Adams, E., & Valentine, J. (2012). Depression as a risk factor for breast cancer: Investigating methodological limitations in the literature. *Cancer Causes & Control, 23*(8), 1223-1229. Retrieved from <http://www.jstor.org.ezproxy.usc.edu.au:2048/stable/23255037>

- Post, S. G. (2002). The tradition of agape. In S. G. Post, L. G. Underwood, J. P. Schloss, & W. B. Hurlbut (Eds.), *Altruism and altruistic love: Science, philosophy, and religion in dialogue*. (pp. 51-64). New York: Oxford University Press.
- Powers, T. A., Koestner, R., Zuroff, D. C., Milyavskaya, M., & Gorin, A. A. (2011). The effects of self-criticism and self-oriented perfectionism on goal pursuit. *Personality and Social Psychology Bulletin*, *37*(7), 964-975. doi:10.1177/0146167211410246
- Price, M. A., Tennant, C. C., Smith, R. C., Butow, P. N., Kennedy, S. J., Kossoff, M. B., & Dunn, S. M. (2001). The role of psychosocial factors in the development of breast carcinoma: Part 1. *Cancer*, *91*(4), 679-685. doi:10.1002/1097-0142(20010215)91:4<679::AID-CNCR1051>3.0.CO;2-W
- Priest, H. (2004). Phenomenology. *Nurse Researcher*, *11*(4), 4-6.
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, *18*(3), 20-24.
- Przedziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: Breast cancer, body image, distress and self-compassion. *Psycho-Oncology*, *22*(8), 1872-1879. doi:10.1002/pon.3230
- Pudrovska, T., Carr, D., McFarland, M., & Collins, C. (2013). Higher-status occupations and breast cancer: A life-course stress approach. *Social Science & Medicine*, *89*, 53-61. Retrieved from doi:<http://dx.doi.org/10.1016/j.socscimed.2013.04.013>
- Ramazanoglu, C., & Holland, J. (2002). *Feminist methodology: Challenges and choices*. London, UK: Sage Publications Inc.
- Rancour, P. (2008). Using archetypes and transitions theory to help patients move from active treatment to survivorship. *Clinical Journal of Oncology Nursing*, *12*(6), 935-940. doi:10.1188/08.CJON.935-940
- Raque-Bogdan, T. L., Ericson, S. K., Jackson, J., Martin, H. M., & Bryan, N. A. (2011). Attachment and mental and physical health: Self-compassion and mattering as mediators. *Journal of Counseling Psychology*, *58*(2), 272-278. doi:10.1037/a0023041
- Rasmussen, J. L. (2014). Expressive arts as a medium for facilitating anger expression in women who self-silence. (Unpublished PhD thesis). Saybrook University, San Francisco, CA.
- Razavi, D., Delvaux, N., Marchal, S., Durieux, J.-F., Farvacques, C., Dubus, L., & Hogenraad, R. (2002). Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomised study. *British Journal of Cancer*, *87*(1), 1-7. doi:10.1038/sj.bjc.6600412
- Reath, J., & Carey, M. (2008). Breast and cervical cancer in indigenous women: Overcoming barriers to early detection. *Australian Family Physician*, *37*(3), 178-182. Retrieved from <https://search.informit-com-au.ipaces.nd.edu.au/documentSummary;dn=354498945991410;res=IELHEA>ISSN:0300-8495>
- Reboussin, B. A., Rejeski, W. J., Martin, K. A., Callahan, K., Dunn, A. L., King, A. C., & Sallis, J. F. (2000). Correlates of satisfaction with body function and body appearance in middle- and older aged adults: The activity counseling trial (ACT). *Psychology and Health*, *15*(2), 239-254. doi:10.1080/08870440008400304

- Reeve, J., Lloyd-Williams, M., Payne, S., & Dowrick, C. (2010). Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health, 14*(2), 178-195. doi:10.1177/1363459309353298
- Reich, M., Lesur, A., & Perdrizet-Chevallier, C. (2008). Depression, quality of life and breast cancer: A review of the literature. *Breast Cancer Research and Treatment, 110*(1), 9-17. doi:10.1007/s10549-007-9706-5
- Reiche, E. M. V., Nunes, S. O. V., & Morimoto, H. K. (2004). Stress, depression, the immune system, and cancer. *The Lancet Oncology, 5*(10), 617-625. doi:[https://doi.org/10.1016/S1470-2045\(04\)01597-9](https://doi.org/10.1016/S1470-2045(04)01597-9)
- Reilly, M. A., & Cohen, R. (2008). Sowing seeds of social justice through performative pedagogy: Middle school students explore genocide. In T. Huber-Warring (Ed.), *Growing a soul for social change: Building the knowledge base for social justice: Vol. 1. Teaching-Learning indigenous, intercultural worldviews: International perspectives on social justice and human rights* (pp. 383-398). Charlotte, NC: Information Age Publishing.
- Repetto, L., Carreca, I., Maraninchi, D., Aapro, M., Calabresi, P., & Balducci, L. (2003). Use of growth factors in the elderly patient with cancer: A report from the Second International Society for Geriatric Oncology (SIOG) 2001 meeting. *Critical Reviews in Oncology/Hematology, 45*(2), 123-128. doi:[http://dx.doi.org/10.1016/S1040-8428\(02\)00132-4](http://dx.doi.org/10.1016/S1040-8428(02)00132-4)
- Rettger, J., Wall, K., Corwin, D., Davidson, A., Lukoff, D., & Koopman, C. (2015). In psycho-spiritual integrative therapy for women with primary breast cancer: What factors account for the benefits? Insights from a multiple case analysis. *Healthcare, 3*(2), 263-283. Retrieved from <http://www.mdpi.com/2227-9032/3/2/263> doi:10.3390/healthcare3020263
- Reyes, D. (2012). Self-compassion. *Journal of Holistic Nursing, 30*(2), 81-89. Retrieved from doi:10.1177/0898010111423421
- Riba, M. (2006). Breast cancer: What psychiatrists need to know. *Psychiatric Times, 23*(4), 30.
- Robb, C., Haley, W. E., Balducci, L., Extermann, M., Perkins, E. A., Small, B. J., & Mortimer, J. (2007a). Impact of breast cancer survivorship on quality of life in older women. *Critical Reviews in Oncology and Hematology, 62*(1), 84-91. doi:10.1016/j.critrevonc.2006.11.003
- Robles, T. F., Glaser, R., & Kiecolt-Glaser, J. K. (2005). Out of balance: A new look at chronic stress, depression, and immunity. *Current Directions in Psychological Science, 14*(2), 111-115. Retrieved from <http://www.jstor.org/ipacez.nd.edu.au/stable/20182999>
- Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology, 21*, 95-103.
- Rogers, N., Tudor, K., Tudor, L. E., & Keemar, K. (2012). Person-centered expressive arts therapy: A theoretical encounter. *Person-Centered & Experiential Psychotherapies, 11*(1), 31-47. doi:10.1080/14779757.2012.656407
- Romeo, A., Ghiggia, A., Tesio, V., Di Tella, M., Torta, R., & Castelli, L. (2017). Post-traumatic growth, distress and attachment style among women with breast cancer. *Journal of Psychosocial Oncology, 35*(3), 309-322. doi:10.1080/07347332.2017.1289291
- Rosedale, M. (2009). Survivor loneliness of women following breast cancer. *Oncology Nursing Forum, 36*(2), 175-183. doi:10.1188/09.onf.175-183

- Rosenblatt, L. (2006). Being the monster: Women's narratives of body and self after treatment for breast cancer. *Medical Humanities*, 32(1), 53-56.  
doi:10.1136/jmh.2004.000212
- Rothschild, B. (2000). *The body remembers: The psychophysiology of trauma and trauma treatment*. New York, NY: W.W. Norton & Company
- Rowland, J. H. (2008). Cancer survivorship: Rethinking the cancer control continuum. *Seminars in Oncology Nursing*, 24(3), 145-152.  
doi:10.1016/j.soncn.2008.05.002
- Roy-Byrne, P. P., Davidson, K. W., Kessler, R. C., Asmundson, G. J. G., Goodwin, R. D., Kubzansky, L., . . . Stein, M. B. (2008). Anxiety disorders and comorbid medical illness. *General Hospital Psychiatry*, 30(3), 208-225.  
doi:<http://dx.doi.org/10.1016/j.genhosppsych.2007.12.006>
- Rubin, L. R., & Tanenbaum, M. (2011). "Does that make me a woman?". *Psychology of Women Quarterly*, 35(3), 401-414. Retrieved from  
doi:10.1177/0361684310395606
- Ruini, C., Offidani, E., & Vescovelli, F. (2013). Life stressors, allostatic overload and their Impact on posttraumatic growth. *Journal of Loss and Trauma*, 20(2), 109-122. doi:10.1080/15325024.2013.830530
- Russo, M. F. (2005). Play therapy and social constructivism: Seeing the world through a young person's eyes. *Journal of Evolutionary Psychology*, 27(3-4), 24-27.
- Rybak, C. (2013). Nurturing positive mental health: Mindfulness for wellbeing in counseling. *International Journal for the Advancement of Counselling*, 35(2), 110-119. doi:10.1007/s10447-012-9171-7
- Rybak, C., & Decker-Fitts, A. (2009). Understanding Native American healing practices. *Counselling Psychology Quarterly*, 22(3), 333-342. Retrieved from  
<http://dx.doi.org/10.1080/09515070903270900>
- Sabiston, C. M., & Brunet, J. (2012). Reviewing the benefits of physical activity during cancer survivorship. *American Journal of Lifestyle Medicine*, 6(2), 167-177. Retrieved from  
<http://journals.sagepub.com/doi/abs/10.1177/1559827611407023>
- Sachs-Ericsson, N., Gayman, M. D., Kendall-Tackett, K., Lloyd, D. A., Medley, A., Collins, N., . . . Sawyer, K. (2010). The long-term impact of childhood abuse on internalizing disorders among older adults: The moderating role of self-esteem. *Aging & Mental Health*, 14(4), 489-501.  
doi:10.1080/13607860903191382
- Sagar, S., & Stoeber, J. (2009). Perfectionism, fear of failure, and affective responses to success and failure: The central role of fear of experiencing shame and embarrassment. *Journal of Sport & Exercise Psychology*, 31(5), 602.
- Salovey, P., Stroud, L. R., Woolery, A., & Epel, E. S. (2002). Perceived emotional intelligence, stress reactivity, and symptom reports: Further explorations using the Trait Meta-Mood Scale. *Psychology & Health*, 17(5), 611-627.
- Satici, S. A., Uysal, R., & Akin, A. (2015). Early life experiences and self-compassion: a structural equation modelling. *Estudios de Psicología*, 1-23.  
doi:10.1080/02109395.2015.1026123
- Sattman-Frese, W. (2009). Psychosomatic perspectives on cancer. Retrieved from  
[http://goodtherapy.com.au/library\\_flex/psychosomatic\\_perspectives\\_on\\_cancer](http://goodtherapy.com.au/library_flex/psychosomatic_perspectives_on_cancer)

- Schaefer-Schiumo, K., & Atwood, J. D. (2009). Kirstin's journey through breast cancer: A social constructionist perspective. *The American Journal of Family Therapy, 37*(4), 318-335. doi:10.1080/01926180802705649
- Schapira, L. (2014). Handling uncertainty. *Supportive Care in Cancer, 22*(3), 859-861. doi:10.1007/s00520-013-2086-y
- Schellekens, M., Tamagawa, R., Labelle, L., Specia, M., Stephen, J., Drysdale, E., . . . Carlson, L. (2017). Mindfulness-Based Cancer Recovery (MBCR) versus Supportive Expressive Group Therapy (SET) for distressed breast cancer survivors: Evaluating mindfulness and social support as mediators. *Journal of Behavioral Medicine, 40*(3), 414-422. doi:10.1007/s10865-016-9799-6
- Schellenberg, B. J. I., Bailis, D. S., & Mosewich, A. D. (2016). You have passion, but do you have self-compassion? Harmonious passion, obsessive passion, and responses to passion-related failure. *Personality and Individual Differences, 99*, 278-285. doi:10.1016/j.aid.2016.05.003
- Schernhammer, E. S., Haidinger, G., Waldhör, T., & Vutuc, C. (2009). Attitudes about the use of complementary and alternative medicine in cancer treatment. *Journal of Alternative & Complementary Medicine, 15*(10), 1115-1120. doi:10.1089/acm.2009.0083
- Schmidt, J. E., & Andrykowski, M. A. (2004). The role of social and dispositional variables associated with emotional processing in adjustment to breast cancer: An internet-based study. *Health Psychology, 23*(3), 259-266. doi:10.1037/0278-6133.23.3.259
- Schmidt, S. D., Blank, T. O., Bellizzi, K. M., & Park, C. L. (2012). The relationship of coping strategies, social support, and attachment style with posttraumatic growth in cancer survivors. *Journal of Health Psychology, 17*(7), 1033-1040. doi:10.1177/1359105311429203
- Schreiber, J. A., & Edward, J. (2015). Image of God, religion, spirituality, and life changes in breast cancer survivors: A qualitative approach. *Journal of Religion and Health, 54*(2), 612-622. Retrieved from <https://doi.org/10.1007/s10943-014-9862-y>
- Schulman-Green, D., & Jeon, S. (2014). A psychoeducational intervention for women with breast cancer improves self-management. *Psycho-Oncology, 23*(S1), 58. doi:10.1002/pon
- Schulz, J. (2006). Pointing the way to discovery: Using a creative writing practice in qualitative research. *Journal of Phenomenological Psychology, 37*(2), 217-239. doi:10.1163/156916206778876290
- Scoglio, A. A. J., Rudat, D. A., Garvert, D., Jarmolowski, M., Jackson, C., & Herman, J. L. (2015). Self-compassion and responses to trauma: The role of emotion regulation. *Journal of Interpersonal Violence, December 16, 2015*, 1-21. doi:10.1177/0886260515622296
- Sears, S. R., Stanton, A. L., & Danoff-Burg, S. (2003). The yellow brick road and the emerald city: Benefit finding, positive reappraisal coping and posttraumatic growth in women with early-stage breast cancer. *Health Psychology, 22*(5), 487-497. doi:10.1037/0278-6133.22.5.487
- Seegerstrom, S. C. (2010). Resources, stress, and immunity: An ecological perspective on human psychoneuroimmunology. *Annals of Behavioral Medicine, 40*(1), 114-125. doi:10.1007/s12160-010-9195-3
- Segrin, C., Badger, T. A., Meek, P., Lopez, A. M., Bonham, E., & Sieger, A. (2005). Dyadic interdependence on affect and quality-of-life trajectories among women with breast cancer and their partners. *Journal of Social and Personal*



- Relationships*, 22(5), 673-689. Retrieved from <http://dx.doi.org/10.1177/0265407505056443>
- Seligowski, A. V., Miron, L. R., & Orcutt, H. K. (2015). Relations among self-compassion, PTSD symptoms, and psychological health in a trauma-exposed sample. *Mindfulness*, 6(5), 1033-1041. doi:10.1007/s12671-014-0351-x
- Seok, J.-H., Kim, L. S., Hong, N., Hong, H. J., Kim, S.-J., Kang, H. J., & Jon, D.-I. (2010). Psychological and neuroendocrinological characteristics associated with depressive symptoms in breast cancer patients at the initial cancer diagnosis. *General Hospital Psychiatry*, 32(5), 503-508. doi:10.1016/j.genhosppsych.2010.06.001
- Seppala, E., Rossomando, T., & Doty, J. R. (2013). Social connection and compassion: Important predictors of health and well-being. *Social Research: An International Quarterly*, 80(2), 411-430. doi:10.1353/sor.2013.0027
- Shah, A. (2017). Ethnography? Participant observation, a potentially revolutionary praxis. *HAU Journal of Ethnographic Theory*, 7(1), 45-59. doi:10.14318/hau7.1.008
- Shahar, B., Szepsenwol, O., Zilcha-Mano, S., Haim, N., Zamir, O., Levi-Yeshuvi, S., & Levit-Binnun, N. (2015). A wait-list randomized controlled trial of loving-kindness meditation programme for self-criticism. *Clinical Psychology & Psychotherapy*, 22(4), 346-356. Retrieved from <http://dx.doi.org/10.1002/cpp.1893>
- Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), 1153-1166. Retrieved from doi:<http://dx.doi.org/10.1016/j.socscimed.2005.07.010>
- Sharpley, C. F., Bond, J. E., & Agnew, C. J. (2004). Why go to a counsellor? Attitudes to, and knowledge of counselling in Australia. *International Journal for the Advancement of Counselling*, 26(1), 95-108. doi:10.1023/B:ADCO.0000021552.13762.dd
- Sheppard, L. A., & Ely, S. (2008). Breast cancer and sexuality. *The Breast Journal*, 14(2), 176-181. doi:10.1111/j.1524-4741.2007.00550.x
- Sheridan, M. A., Sherman, M. L., Pierce, T., & Compas, B. E. (2010). Social support, social constraint, and affect in spouses of women with breast cancer: The role of cognitive processing. *Journal of Social and Personal Relationships*, 27(1), 5-22. doi:10.1177/0265407509347836
- Sherman, K. A., Woon, S., French, J., & Elder, E. (2017). Body image and psychological distress in nipple-sparing mastectomy: The roles of self-compassion and appearance investment. *Psycho-Oncology*, 26(3), 337-345. Retrieved from <http://dx.doi.org/10.1002/pon.4138>
- Sheikh, S., & McNamara, M. E., (2014). Insights from self-blame and victim blaming. *Psychological Inquiry: An International Journal for the Advancement of Psychological Theory*, 25(2), 241-244. doi:10.1080/1047840X.2014.904138
- Shinebourne, P. (2011). The theoretical underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis*, 22(1), 16-31.
- Sieff, D. (2008). Unlocking the secrets of the wounded psyche: Interview with Donald Kalsched. *Psychological Perspectives*, 51(2), 190-207. doi:10.1080/00332920802454197
- Siegel, D. J. (2003). An interpersonal neurobiology of psychotherapy: The developing mind and the resolution of trauma. In M. F. Solomon & D. J.

- Siegel (Eds.), *Healing trauma: Attachment, mind, body, and brain* (pp. 1-56). New York, NY: W.W. Norton & Company, Inc.
- Siegel, D. J. (2009). Emotion as integration: A possible answer to the question, What is emotion? In D. Fosha, D. J. Siegel, & M. F. Solomon (Eds.), *The healing power of emotion: Affective neuroscience, development & clinical practice* (pp. 145-171). New York, NY: W.W. Norton & Company
- Silva, S. M., Moreira, H. C., & Canavarro, M. C. (2012). Examining the links between perceived impact of breast cancer and psychosocial adjustment: The buffering role of posttraumatic growth. *Psycho-Oncology*, 21(4), 409-418. Retrieved from <http://dx.doi.org/10.1002/pon.1913>
- Sinclair, S., Beamer, K., Hack, T. F., McClement, S., Raffin Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2016). Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliative Medicine*, 31(5), 437 - 447. doi:10.1177/0269216316663499
- Singer, T., & Klimecki, O. M. (2014). Empathy and compassion. *Current Biology*, 24(19), R875-R878. doi:10.1016/j.cub.2014.06.054
- Sirois, F. M. (2013). Procrastination and the priority of short-term mood regulation: Consequences for future self. *Social and Personality Psychology Compass*, 7(2), 115-127. doi:10.1111/spc3.12011
- Sirois, F. M., Kitner, R., & Hirsch, J. K. (2015). Self-compassion, affect, and health-promoting behaviors. *Health Psychology*, 34(6), 661-669. doi:10.1037/hea0000158
- Skinner, N., & Fox-Francoeur, C. (2013). Personality implications of adaption-innovation: VI. Adaption-innovation as a predictor of disease proneness. *Social Behavior and Personality*, 41(2), 223-227. doi:10.2224/sbp.2013.41.2.223
- Skovholt, T. M., & Trotter-Mathison, M. J. (2014). *The resilient practitioner: Burnout prevention and self-care strategies for counselors, therapists, teachers, and health professionals*. Retrieved from <http://ebookcentral.proquest.com/lib/usc/detail.action?docID=646574>
- Sloan, R. P. (2011). Virtue and vice in health and illness: The idea that wouldn't die. *Lancet*, 377(9769), 896-897. doi:10.1016/S0140-6736(11)60339-5
- Smeets, E., Neff, K., Alberts, H., & Peters, M. (2014). Meeting suffering with kindness: Effects of a brief self-compassion intervention for female college students. *Journal of Clinical Psychology*, 70(9), 794-807. Retrieved from <http://dx.doi.org/10.1002/jclp.22076>
- Smith, J. A., Larkin, M., & Flowers, P. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, UK: Sage Publications Inc.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London, UK: Sage Publications Inc.
- Smith, L. C., & Shin, R. Q. (2014). Queer blindfolding: A case study on difference “blindness” towards persons who identify as lesbian, gay, bisexual and transgender. *Journal of Homosexuality*, 61(7), 940-961. doi:10.1080/00918369.2014.870846
- Smith, S., Singh-Carlson, S., Downie, L., Payeur, N., & Wai, E. (2011). Survivors of breast cancer: Patient perspectives on survivorship care planning. *Research and Practice*, 5(4), 337-344. doi:10.1007/s11764-011-0185-7

- Snyder, C. R., Pedrotti, J. T., & Lopez, S. J. (2011). *Positive psychology: The scientific and practical explorations of human strengths* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.
- Sohl, S. J., Levine, B., Case, L. D., Danhauer, S. C., & Avis, N. E. (2014). Trajectories of illness intrusiveness domains following a diagnosis of breast cancer. *Health Psychology, 33*(3), 232-241. doi:10.1037/a0032388
- Sotelo, J. L., Musselman, D., & Nemeroff, C. (2014). The biology of depression in cancer and the relationship between depression and cancer progression. *International Review of Psychiatry, 26*(1), 16-30. doi:10.3109/09540261.2013.87589
- Sousa, D. (2008). From Monet's paintings to Margaret's ducks: Divagations on phenomenological research. *Existential Analysis, 19*(1), 143-155. Retrieved from <http://hdl.handle.net/10400.12/1881>
- Sousa, D. (2013). Validation in qualitative research: General aspects and specificities of the descriptive phenomenological method. *Qualitative Research in Psychology, 11*(2), 211-227. Retrieved from <http://dx.doi.org/10.1080/14780887.2013.853855>
- Souza, B. F. d., Moraes, J. A. d., Inocenti, A., Santos, M. A. d., Silva, A. E. B. d. C., & Miasso, A. I. (2014). Women with breast cancer taking chemotherapy: depression symptoms and treatment adherence. *Revista Latino-Americana de Enfermagem, 22*(5), 866-873. doi:10.1590/0104-1169.3564.2491.
- Sperry, L. (2010). Breast cancer, depression, culture, and marital conflict. *The Family Journal, 18*(1), 62-65. doi:10.1177/1066480709356228
- Spira, J. L., & Reed, G. M. (2003). *Group psychotherapy for women with breast cancer*. Washington, DC: American Psychological Association.
- Springham, N. (2016). Description as social construction in UK Art Therapy research. *International Journal of Art Therapy, 21*(3), 104-115. doi:10.1080/17454832.2016.1220399
- Springham, N., Thorne, D., & Brooker, J. (2014). Softer: Looking for oxytocin in Art Therapy. *International Journal of Art Therapy, 19*(1), 31-42. doi:10.1080/17454832.2014.882366
- Stang, H. (2016). Compassion and loving-kindness meditation. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Assessment and intervention*. (pp. 161-164). New York, NY: Routledge.
- Stanton, A.L. (2012). What happens now? Psychosocial care for cancer survivors after medical treatment completion. *Journal of Clinical Oncology, 30*(11), 1215-1220. doi:10.1200/JCO.2011.39.7406
- Stergiou-Kita, M., Grigorovich, A., Tseung, V., Milosevic, E., Hebert, D., Phan, S., & Jones, J. (2014). Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Research and Practice, 8*(4), 657-670. doi:10.1007/s11764-014-0377-z
- Stinckens, N., Lietaer, G., & Leijssen, M. (2013). Working with the inner critic: Process features and pathways to change. *Person-Centered & Experiential Psychotherapies, 12*(1), 59-78. doi:10.1080/14779757.2013.767747
- Sturdy, A., Schwarz, M., & Spicer, A. (2006). Guess who's coming to dinner? Structures and uses of liminality in strategic management consultancy. *Human Relations, 59*(7), 929-960. doi:10.1177/0018726706067597
- Subnis, U. B., Starkweather, A. R., McCain, N. L., & Brown, R. F. (2014). Psychosocial therapies for patients with cancer. *Integrative Cancer*

- Therapies*, 13(2), 85-104. Retrieved from <http://journals.sagepub.com/doi/abs/10.1177/1534735413503548>
- Sulik, G. A. (2007). The balancing act. *Gender & Society*, 21(6), 857-877. Retrieved from <http://dx.doi.org/10.1177/0891243207309898>
- Sulik, G. A. (2011). *Pink ribbon blues: How breast cancer culture undermines women's health*. New York, NY: Oxford University Press.
- Surbone, A., Annunziata, M. A., Santoro, A., Tirelli, U., & Tralongo, P. (2013). Cancer patients and survivors: Changing words or changing culture? *Annals of Oncology*, 24(10), 2468-2471. doi:10.1093/annonc/mdt229
- Svensk, A. C., Öster, I., Thyme, K. E., Magnusson, E., Sjödin, M., Eisemann, M., . . . Lindh, J. (2009). Art therapy improves experienced quality of life among women undergoing treatment for breast cancer: A randomized controlled study. *European Journal of Cancer Care*, 18(1), 69-77. doi:10.1111/j.1365-2354.2008.00952.x
- Tacon, A. M., & McComb, J. (2009). Mindful exercise, quality of life and survival: A mindfulness-based exercise program for women with breast cancer. *The Journal of Alternative and Complementary Medicine*, 15(1), 41-46. doi:10.1089/acm.2008.0255
- Takahashi, M. (2014). Psychosocial distress among young breast cancer survivors: Implications for healthcare providers. *Breast Cancer*, 21(6), 664-669. doi:10.1007/s12282-013-0508-9
- Tallman, B. A., Altmaier, E., & Garcia, C. (2007). Finding benefit from cancer. *Journal of Counseling Psychology*, 54(4), 481-487. doi:10.1037/0022-0167.54.4.481
- Tal-Margalit, M. (2013). 'Who is afraid of research?' Report and review of the Israeli Association of Creative & Expressive Therapies conference, January 2012. *Body, Movement and Dance in Psychotherapy: An International Journal for Theory, Research and Practice*, 8(2), 121-124. doi:10.1080/17432979.2013.774188
- Talwar, S. (2007). Accessing traumatic memory through art making: An art therapy trauma protocol (ATTP). *The Arts in Psychotherapy*, 34(1), 22-35. Retrieved from <https://doi.org/10.1016/j.aip.2006.09.001>
- Tan, H., Wilson, A., & Olver, I. (2009). Ricoeur's theory of interpretation: An instrument for data interpretation in hermeneutic phenomenology. *International Journal of Qualitative Methods*, 8(4), 1-15. doi:10.1177/160940690900800401
- Tang, Y., Hölzel, B. K., & Posner, M. I. (2015). The neuroscience of mindfulness meditation. *Nature Review*, 16(4), 213-225. doi:10.1038/nrn3916
- Taylor, S., Harley, C., Absolom, K., Brown, J., & Velikova, G. (2016). Breast cancer, sexuality, and intimacy: Addressing the unmet need. *The Breast Journal*, 22(4), 478-479. Retrieved from <http://dx.doi.org/10.1111/tbj.12614>
- Tedeschi, R. G., & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks, CA: Sage Publications Ltd.
- Terry, M. L., & Leary, M. R. (2011). Self-compassion, self-regulation and health. *Self and Identity*, 10(3), 352-362. doi:10.1080/15298868.2011.558404
- Terry, M. L., Leary, M. R., Mehta, S., & Henderson, K. (2013). Self-compassionate reactions to health threats. *Personality and Social Psychology Bulletin*, 39(7), 911 – 926. Retrieved from doi:10.1177/0146167213488213
- Teyber, E., & McClure, F. H. (2011). *Interpersonal process in therapy: An integrative model 6th ed.* Belmont, CA: Brooks/Cole.

- Thavarajah, N., Menjak, I., Trudeau, M., Mehta, R., Wright, F., Leahey, A., . . . Szumacher, E. (2015). Towards an optimal multidisciplinary approach to breast cancer treatment for older women. *Canadian Oncology Nursing Journal*, 25(4), 384-408. doi:10.5737/23688076254384395
- Thomas, S. P. (1988). Is there a disease-prone personality? Synthesis and evaluation of the theoretical and empirical literature. *Issues in Mental Health Nursing*, 9(4), 339-352. doi:10.3109/01612848809140936
- Thompson, B. E. (2014). Meaning making and the art of grief therapy. In B. E. Thompson & R. A. Neimeyer (Eds.), *Grief and the expressive arts: Practices for creating meaning* (pp. 3-13). New York, NY: Routledge.
- Thompson, B. L., & Waltz, J. (2008). Self-compassion and PTSD symptom severity. *Journal of Traumatic Stress*, 21(6), 556-558. Retrieved from <http://dx.doi.org/10.1002/jts.20374>
- Thompson, K. (2006). What people need to write. In G. Bolton, V. Field, & K. Thompson (Eds.), *Writing works: A resource handbook for therapeutic writing workshops and activities* (pp. 141-157). London: Jessica Kingsley Publishers.
- Thorne, S. E., & Murray, C. (2000). Social constructions of breast cancer. *Health Care for Women International*, 21(3), 141-159. doi:10.1080/073993300245221
- Thornton, H. (2003). Battling breast cancer: Review of: Lerner, B.H. The breast cancer wars: Hope, fear, and the pursuit of a cure in twentieth-century America. *Journal of the Royal Society of Medicine*, 96(10), 516. PMID: PMC544643
- Tiggemann, M. (1992). Body-size dissatisfaction: Individual differences in age and gender, and relationship with self-esteem. *Personality and Individual Differences*, 13(1), 39-43. doi:10.1016/0191-8869(92)90215-b
- Tomita, M., Takahashi, M., Tagaya, N., Kakuta, M., Kai, I., & Muto, T. (2016). Structural equation modeling of the relationship between posttraumatic growth and psychosocial factors in breast cancer. *Psycho-Oncology*, 26, 1198-1204. doi:10.1002/pon.4298
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. doi:10.1093/intqhc/mzm042
- Trusson, D., Pilnick, A., & Roy, S. (2016). A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Social Science & Medicine*, 151, 121-129. Retrieved from <https://doi.org/10.1016/j.socscimed.2016.01.011>
- Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixsmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher*, 20(6), 17-20. doi:10.7748/nr2013.07.20.6.17.e315
- Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *Journal of Cross-Cultural Gerontology*, 31(2), 157-172. Retrieved from <https://doi.org/10.1007/s10823-016-9287-z>
- Urcuyo, K. R., Boyers, A. E., Carver, C. S., & Antoni, M. H. (2005). Finding benefit in breast cancer: Relations with personality, coping, and concurrent well-being. *Psychology & Health*, 20(2), 175-192. doi:10.1080/08870440512331317634

- Vahdaninia, M., Omidvari, S., & Montazeri, A. (2010). What do predict anxiety and depression in breast cancer patients? A follow-up study. *Social Psychiatry and Psychiatric Epidemiology*, *45*(3), 355-361. doi:10.1007/s00127-009-0068-7
- Vance, V., Campbell, S., Mccargar, L., Mourtzakis, M. & Hanning R. (2017). The voice of experience: Diet and weight change in women with breast cancer associate with psychosocial and treatment-related challenges. *Canadian Journal of Dietetic Practice and Research*, *78*(2), 74-80. doi:10.3148/cjdpr-2016-034
- Van Dam, N. T., Sheppard, S. C., Forsyth, J. P. & Earleywine, M. (2011). Self-compassion is a better predictor than mindfulness of symptom severity and quality of life in mixed anxiety and depression. *Journal of Anxiety Disorders*, *25*(1), 123-130. doi:10.1016/j.anxdis.2010.08.011
- van de Wiel, H., Geerts, E., & Hoekstra-Weebers, J. (2008). Explaining inconsistent results in cancer quality of life studies: The role of the stress–response system. *Psycho-Oncology*, *17*(2), 174-181. doi:10.1002/pon.1214
- van der Kolk, B. (2015). *The body keeps the score: Brain, mind, and body in the healing of trauma*. New York, NY: Penguin Books.
- van der Wiel, R. (2013). “ I am happy with one”: Re-evaluating the relationship between gender, breast-cancer surgery, and survival. *Agenda*, *27*(4), 55-64. doi:10.1080/10130950.2013.855526
- Verrill, M. (2009). Chemotherapy for early-stage breast cancer: A brief history. *British Journal of Cancer*, *101*(S1), S2-S5. doi:10.1038/sj.bjc.6605268
- van Londen, G., Beckjord, E. B., Dew, M. A., Cuijpers, P., Tadic, S., & Brufsky, A. (2013). Breast cancer survivorship symptom management: Current perspective and future development. *Breast Cancer Management*, *2*,(1), 71-81. doi:10.2217/bmt.12.63.
- Vianna, D., Mendes, A. A., & Bucci, D. A. (2013). Infusion of Life: Patient perceptions of expressive therapy during chemotherapy sessions. *European Journal of Cancer Care*, *22*, 377-388. doi:10.1111/ecc.12041
- Vigliotti, A. (2010). Forming a trauma narrative: The impact of emotion regulation on well-being in a population of breast cancer survivors. In F. Conway (Ed.): ProQuest Dissertations Publishing
- Vineburgh, N. T. (2004). The power of the pink ribbon: Raising awareness of the mental health implications of terrorism. *Psychiatry*, *67*(2), 137-146. doi:10.1521/psyc.67.2.137.35962
- Virgo, K. S., Lerro, C. L., Klabunde, C. N., Earle, C., & Ganz, P. A. (2013). Barriers to breast and colorectal cancer survivorship care: Perceptions of primary care physicians and medical oncologists in the United States. *Journal of Clinical Oncology*, *31*(18), 2322-2336. doi:10.1200/JCO.2012.45.6954
- Vitry, A. (2010). The imperative of happiness for women living with breast cancer. *Canadian Woman Studies*, *28*(2-3), 30-33. Retrieved from
- Volpintesta, E. J. (2011). Compassion. *Hastings Center Report*, *41*(6), 7-7. doi:10.1002/j.1552-146X.2011.tb00148.x
- Von Ah, D., Habermann, B., Carpenter, J. S., & Schneider, B. L. (2013). Impact of perceived cognitive impairment in breast cancer survivors. *European Journal of Oncology Nursing*, *17*(2), 236-241. Retrieved from doi:<http://dx.doi.org/10.1016/j.ejon.2012.06.002>

- Vos, J. (2015). Meaning and existential givens in the lives of cancer patients: A philosophical perspective on psycho-oncology. *Palliative and Supportive Care, 13*(4), 885-900. doi:10.1017/S1478951514000790
- Vuong, D., Simpson, P., Green, B., Cummings, M., & Lakhani, S. (2014). Molecular classification of breast cancer. *The European Journal of Pathology, 465*(1), 1-14. doi:10.1007/s00428-014-1593-7
- Walker, C. A. (2015). Social constructionism and qualitative research. *Journal of Theory Construction & Testing, 19*(2), 37. Retrieved from web.b.ebscohost.com.ipacez.nd.edu.au/ehost/pdfviewer/pdfviewer?vid=1&sid=efa27348-c48c-4241-8a04-5bd69f6792ee%40sessionmgr104
- Wang, Y., Yi, J., He, J., Chen, G., Li, L., Yang, Y., & Zhu, X. (2014). Cognitive emotion regulation strategies as predictors of depressive symptoms in women newly diagnosed with breast cancer. *Psycho-Oncology, 23*(1), 93-99. doi:10.1002/pon.3376
- Weaver, K., Llabre, M., Lechner, S., Penedo, F., & Antoni, M. (2008). Comparing unidimensional and multidimensional models of benefit finding in breast and prostate cancer. *An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 17*(5), 771-781. doi:10.1007/s11136-008-9348-z
- Wegdan, H. (2012). *Benefits of self-forgiveness on well-being and self-forgiveness facilitating factors*. (Doctor of Philosophy Electronic Thesis), University of Windsor, Windsor, Ontario.
- Wei, M., Liao, K.Y-H., Ku, T-Y., Shaffer, P. A. (2010). Attachment, self-compassion, empathy, and subjective well-being among college students and community adults. *Journal of Personality, 79*(1), 191-221. doi:10.1111/j.1467-6494.2010.00677.x
- Weihs, K., Fisher, L., & Baird, M. (2002). Families, health, and behavior: A section of the commissioned report by the Committee on Health and Behavior: Research, Practice, and Policy, Division of Neuroscience and Behavioral Health and Division of Health Promotion and Disease Prevention, Institute of Medicine, National Academy of Sciences. *Families, Systems & Health, 20*(1), 7-46. Retrieved from <http://dx.doi.org/10.1037/h0089481>
- Welfel, E. R., & Patterson, L. E. (2005). *The counseling process: A multitheoretical integrative approach* (6th ed.). Belmont, CA: Thomson Brooks/Cole.
- Wendling, C.-A. (2016). Adverse childhood experiences, breast cancer, and psychotherapy. *Psycho-Oncologie, 10*(3), 221-226. doi:10.1007/s11839-016-0588-9
- Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology, 52*(2), 167-177. doi:10.1037/0022-0167.52.2.167
- Westrhenena, N. v., & Fritz, E. (2013). The experiences of professional hospice workers attending creative arts workshops in Gauteng. *Health Education Journal, 72*(1), 34-46. doi:10.1177/0017896911430545
- Wilberg, P. (2004). *The therapist as listener: Martin Heidegger and the missing dimension of counselling and psychotherapy training*. Eastbourne, UK: New Gnosis Publications.
- Wilkinson, S. (2008). Focus groups. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 186-206). London: Sage Publications.

- Williams, A. M., & Irurita, V. F. (2005). Emotional comfort: The patient's perspective of a therapeutic context. *International Journal of Nursing Studies*, 43(4), 405-415. doi:10.1016/ijnurstu.2005.06.004
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed.). Berkshire, UK: Open University Press/McGraw Hill Education.
- Willig, C. (2015). "My bus is here": A phenomenological exploration of "Living-With-Dying". *Health Psychology*, 34(4), 417-425. doi:10.1037/hea0000176
- Wimberly, S. R., Carver, C. S., Laurenceau, J.-P., Harris, S. D., & Antoni, M. H. (2005). Perceived partner reactions to diagnosis and treatment of breast cancer: Impact on psychosocial and psychosexual adjustment. *Journal of Consulting and Clinical Psychology*, 73(2), 300-311. doi:10.1037/0022-006X.73.2.300
- Woldarsky Meneses, C., & Greenberg, L. S. (2014). Interpersonal forgiveness in Emotion-Focused Couples' Therapy. *Journal of Marital and Family Therapy*, 40(1), 49-67. Retrieved from <http://dx.doi.org/10.1111/j.1752-0606.2012.00330.x>
- Wolf, B. M. (2015). Do families cope communally with breast cancer, or is it just talk? *Qualitative Health Research*, 25(3), 320-335. doi:10.1177/1049732314549605
- Worden, J. W. (1989). The experience of recurrent cancer. *Journal of Psychosocial Oncology*, 39(5), 305-310. doi:10.3322/canjclin.39.5.305
- Wu, S. M., Yang, H. F., Thayer, J. L., & Andersen, B. (2014). Association of the physiological stress response with depressive symptoms in patients with breast cancer. *Psychosomatic Medicine*, 76(4), 252-256. doi:10.1097/PSY.0000000000000060
- Yang, Y., Zhang, M., & Kou, Y. (2016). Self-compassion and life satisfaction: The mediating role of hope. *Personality and Individual Differences*, 98, 91-95. doi:10.1016/j.paid.2016.03.086
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 235-251). London, UK: Sage Publications.
- Yarnell, L. M., & Neff, K. D. (2013). Self-compassion, interpersonal conflict resolutions, and well-being. *Self and Identity*, 12(2), 146-159. Retrieved from <http://dx.doi.org/10.1080/15298868.2011.649545>
- Ye, M., Du, K., Zhou, J., Zhou, Q., Shou, M., Hu, B., Jian, P., . . . Liu, Z. (2018). A meta-analysis of the efficacy of cognitive behavior therapy on quality of life and psychological health of breast cancer survivors and patients. *Psycho-Oncology*, 02 March, 2018. doi:10.1002/pon.4687
- Yoo, G. J., Levine, E. G., Aviv, C., Ewing, C., & Au, A. (2010). Older women, breast cancer, and social support. *Supportive Care in Cancer*, 18(12), 1521-1530. doi:10.1007/s00520-009-0774-4
- Yoo, G. J., Sudhakar, A., Le, M. N., & Levine, E. G. (2017). Exploring coping strategies among young Asian American women breast cancer survivors. *Journal of Cancer Education*, 32(1), 43-50. Retrieved from <https://doi.org/10.1007/s13187-015-0917-x>
- Young-Eisendrath, P. (2008). The transformation of human suffering: A perspective from psychotherapy and Buddhism. *Psychoanalytic Inquiry*, 28(5), 541-549. doi:10.1080/07351690802228864



- Yun, M. R., Song, M., Jung, K.-H., & Yu, B. J. (2017). The effects of mind subtraction meditation on breast cancer survivors' psychological and spiritual well-being and sleep quality: A randomized controlled trial in South Korea. *Cancer Nursing, 40*(5), 377-385. doi:10.1097/NCC.0000000000000443
- Zessin, U., Dickhäuser, O., & Garbade, S. (2015). The relationship between self-compassion and well-being: A meta-analysis. *Applied Psychology: Health and Well-Being, 7*(3), 340-364. Retrieved from <http://dx.doi.org/10.1111/aphw.12051>
- Zhang, H., Watson-Singleton, N.N., Pollard, S.E., Pittman, D.M., Lamis, D.A., Fischer, N.L., Patterson, B., Kaslow, N.J. (2017). Self-criticism and depressive symptoms: Mediating role of self-compassion. *Omega - Journal of Death and Dying. doi:10.1177/0030222817729609.*
- Ziebland, S., & Hunt, K. (2014). Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *Journal of Health Services, 19*(3), 177-182. doi:10.1177/1355819614524187
- Zimmerman, T., Scott, J. L., & Heinrichs, N. (2010). Individual and dyadic predictors of body image in women with breast cancer. *Psycho-Oncology, 19*(10), 1061-1068. doi:10.1002/pon.1660
- Ziv, M. (2006). Creativity and assertiveness in advancing the fight against breast cancer. *European Journal of Cancer Supplements, 4*(2), 86-86. doi:10.1016/s1359-6349(06)80170-9
- Zozulya, A. A., Gabaeva, M. V., Sokolov, O. Y., Surkina, I. D., & Kost, N. V. (2008). Personality, Coping Style, and Constitutional Neuroimmunology. *Journal of Immunotoxicology, 5*(2), 221-225. doi:10.1080/15476910802131444
- Zunszain, P. A., Hepgul, N., & Pariante, C. M. (2013). Inflammation and depression. *Current Topics in Behavioral Neurosciences, 14*, 135-151. Retrieved from [https://link.springer.com/chapter/10.1007/7854\\_2012\\_211](https://link.springer.com/chapter/10.1007/7854_2012_211)
- Zuroff, D. C., Mongrain, M., & Santor, D. A. (2004). Conceptualizing and measuring personality vulnerability to depression: Comment on Coyne and Whiffen (1995). *Psychological Bulletin, 130*(3), 489-511. doi:10.1037/0033-2909.130.3.489