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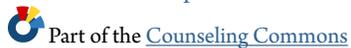
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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in  
Western Australian women survivors of breast cancer

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## **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.

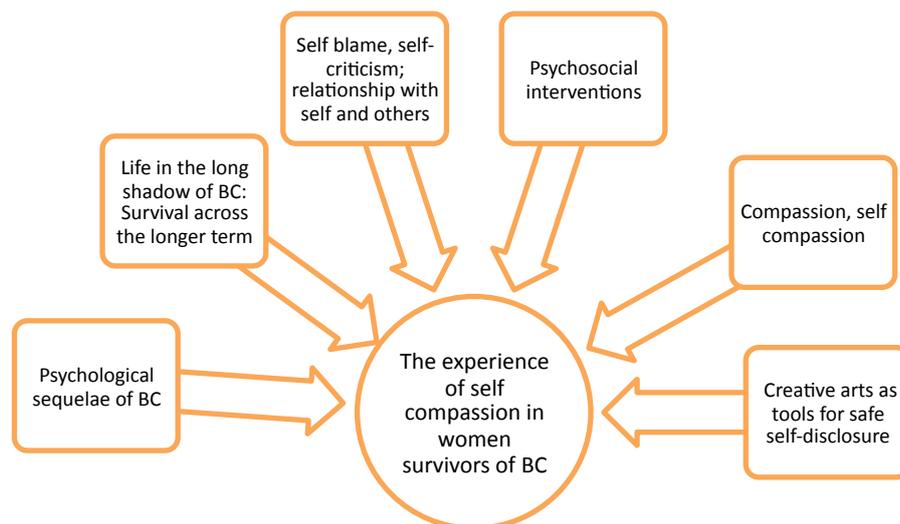
Research into the concept of self-compassion (SC) has been reviewed to identify the potential of an association between the experience and practice of SC, and amelioration of psychological distress for those women who experience negative after-effects from treatment for BC. Examination of the personal 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 of 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).

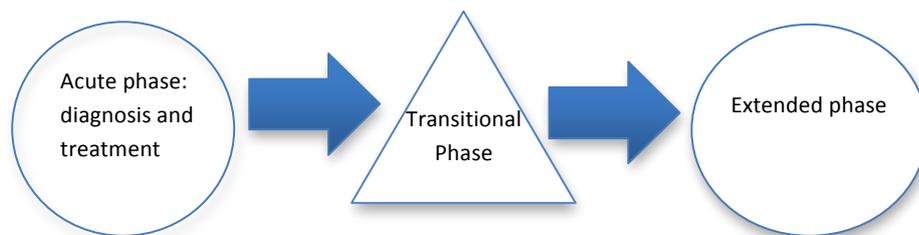
Reports from Norwegian women participants in the study by Drageset et al., (2010) indicated they processed emotional distress in one of two ways: to deal with [emotions] either by openness or by holding back (p. 149). What the study also uncovered was a tendency in participants to be aversive to feeling 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)

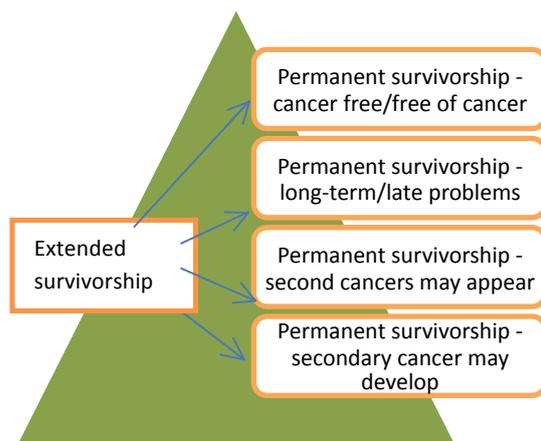
Mullan’s (1985) original model of survivorship was expanded to include a variety of states of longevity that survivors would encounter. The next figure (Diagram 3) illustrates an expansion of Mullan’s (1985) originally hypothesised seasons of survivorship. In this model, devised by Miller, Merry and 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

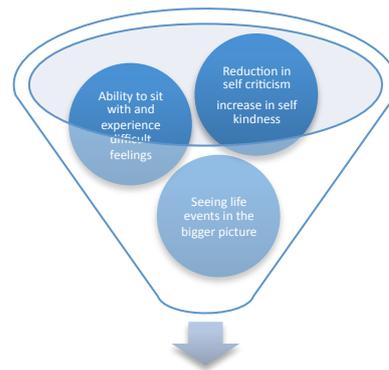
allowing compassion or kindness from others. That negative self-perception would therefore likely mean higher vulnerability to depression (Joeng & Turner, 2015).

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.