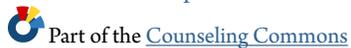

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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in
Western Australian women survivors of breast cancer

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Chapter Seven

Discussion

7.1 Overview

A diagnosis of breast cancer captures women's attention in a way that few other challenging life events have the capacity to do. Fortunately the reality is that some forms of cancer, particularly BC, are no longer considered an inevitable death sentence. The hope held by society is that the medical profession can extend life and continue to find cures for diseases that once brought physical threat, eventual death, and for loved ones that most unwelcome sorrow of loss. Since the 1970's there has been an exponential increase in numbers of survivors amongst women diagnosed with BC (Fallowfield & Jenkins, 2015; Hewitt & Holland, 2006, p. 25). This means the outlook for physical survival has become unignorable optimistic (Alfano & Rowland, 2006; Burke et al., 2012; Fallowfield & Jenkins, 2015). At the same time, however, over one third of those who are classified as 'survivor' will be vulnerable to a cancer recurrence in the years of long-term survivorship (Butow et al., 2015; Hewitt & Holland, 2006). Women diagnosed with BC face challenges on many levels (Wimberly et al., 2005). The experiences of diagnosis, treatment and survival, generate a range of unwelcome and uncomfortable emotions that include depression, anxiety, helplessness, pain, isolation, sexual dysfunction, feelings of vulnerability, and fear of recurrence (Alfano & Rowland, 2006; Hopko et al., 2015; Lu, Man, You, & Leroy, 2015; Montgomery & McCrone, 2010; Pérez et al., 2014).

Not every woman 'meets' BC in a negative way and in this study a small number of participants reported managing their emotions or encountering elevated mood experiences in the immediate diagnosis and treatment phase of their illness (Büyükaşık-Çolak, Gündoğdu-Aktürk, & Bozo, 2012). Some of the terms used by those participants to describe how diagnosis felt included "*a feeling of being blessed*", "*excitement*", "*feeling special*" and "*on a huge high*". However, the long journey ahead meant that reserves of emotional stamina were not an infinite resource for many of the BCS participants in this study. In the process of this study it was

observed, during individual interviews and group sessions, that when the women felt less positive or under some emotional strain there was an increase in the use of self-critical language. Women's reactions to themselves oscillated between the relief of feeling well and coping, and the disappointment on days when they felt unwell. During their participation in the study indications were that positive emotional energy was particularly vulnerable and unavailable in instances when emotional suppression was adopted as a usual coping strategy. In those times, the flow of emotional stamina that seemed to accompany the relief of survival, became less of an exponential curve upwards and more of a roller coaster ride through processes of physical and psychological adjustment re-alignment.

To be the bearer of the label 'BC survivor' means a woman brings focused concentration to the effort of remaining vigilant about monitoring health progress. The focus for many women is to generate and maintain optimism about survival, and the future wellbeing, and at the same time re-establish identity, and reclaim life in its everyday 'ordinariness'. To do this the survivor is required to adhere to a prescribed course of treatment and engage in positive health behaviours to arrest evolution of the disease. However, compliance with treatment has been identified as susceptible to a survivor's psychological state (Manning & Bettencourt, 2011). The beliefs of many of the women in this study were consistent with findings in current literature that encouraged concentration on diet, exercise, and positive thinking as the keys to success in overcoming the hurdles faced in having to live with the legacy of BC (Greenlee et al., 2016; Hamer & Warner, 2017; Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Sabiston & Brunet, 2012).

Alteration to a woman's identity and psychological functioning can happen through physical alterations to her body, and the way her body responds to life-saving chemicals. Cognitive impairment in the form of memory loss, inability to concentrate, and feeling like their mind no longer works as rapidly or as astutely as it was able pre-BC was reported by the women in this study and was consistent with conclusions drawn in research studies (Von Ah, Habermann, Carpenter, & Schneider, 2013).

In addition to changes in the relationship with self, and in relationships with others, change can also take place in other domains such as not being able or willing to return to a pre-BC career. Additionally, advancing age brings with it the inevitability of additional health and psychosocial related factors that will call for closer attention to the way a woman lives into her cancer survivorship (Thavarajah et al., 2015). Physical and emotional resources may be taxed not only by living with the after-effects of cancer, but will be extended by loss of loved ones, changes in cognitive and physical functioning, and other occasions of significant change that come with the passage of time (Hanchate et al., 2010; Mandelblatt et al., 2016). As aging becomes personally more relevant for the woman living with BC, a deeper understanding of the psychological energy expended in the processes of hope, maintenance, and resilience may remain invisible to a social world that can interpret survival as a return to normality marked by the end of a medical emergency.

In contrast to concerns about the potential for ageing to bring with it changes to cognitive and physical functioning, it has been stated that “older women with breast cancer have more positive mental health than younger women with breast cancer” (Colby & Shifren, 2013, p.18). This argument would need to be tested not only against a survivor’s capacity for an optimistic perspective on BC, or their propensity for pessimism about their likely outcome, but the nature of power in relationships with significant others, in addition to their attitudes and beliefs about self. In general, the women in this study espoused optimism about their future health. They talked about the strategies they engaged in to avoid recurrence. During interviews and the OtSC and PRP sessions all but one of the women tended to frame their dialogues optimistically. The study by Colby and Shifren (2013) pointed to prior research by Carver et al., 2006, that argued that optimism positively affects quality of life and mental health for BCS, but not for their physical health. In reality, normality exists as a concept filled with assumptions, expectations, and illusion.

A BC survivor is called to live in an ‘in-between’ space that carries an existential challenge (Hvidt, 2017; Trusson et al., 2016). That challenge comes in the form of an opportunity to explore the limits and potentialities inherent in personal resources to uncover who they had been, reveal who they are and want to be, as well as how they want to ‘be’ for themselves and others. The collective wisdom of the

women participants for this study indicated however, that the most immediate existential issue was firstly a process of clarification of who they are not or who they no longer wanted to be.

A survivor's psychological response to BC has been referred to as co-determined by the event itself as well as a (vaguely or profoundly remembered) background narratives and emotional coping styles (Wendling, 2016). The 'back story' to life is one that can be subtly powerful and therefore implicitly accepted as the belief of 'that's just me'. A cautionary note is relevant here. A survivor's background life narrative is not something that can be pointed to as a direct causal factor in the genesis of BC. Although some research in the 1980's assessed personality factors in relation to BC (Hahn & Petitti, 1988; Thomas, 1988), the debate about any causal link between personality factors and development of cancer has continued for several decades without clear conclusion (Bleiker et al., 2008; Chida, Hamer, Wardle, & Steptoe, 2008; Kruk, 2012; Price et al., 2001).

While personality factors cannot be regarded as a convenient, salient, and therefore excusatory, reason for maladaptive psychological responses to BC (Kruk & Aboul-Enein, 2004), the themes extracted from review of the narratives given in a variety of ways by women participants revealed a psychological legacy from their past that suggested a history of emotional suppression. Suppression of emotional distress has been found to be associated with increased depression, anxiety and anger in women diagnosed and treated for BC (Ando et al., 2011). Learned behaviours and relational styles from their past appeared to have conferred on the women survivors in this study a less than clear idea of their place and purpose in the scheme of human relational interactions. What they had inherited related to beliefs about their role as a woman being one of able to care for others, and be the willing bearer, and repairer, of others distress. Personal value was derived from being of service to others, and this was reflected in the choice of occupation for many of the women. Fields such as nursing, education, and teaching dominated the study population. Their encounter with BC had, however, begun to raise awareness of an internal desire to separate themselves from a perception that being of service was the a primary way to feel good about themselves. To do so would mean inevitable alteration in their self-perception and self-description.

In this study, eleven themes were identified in the narratives of women who had survived BC. Collectively the themes created an overall sense of positive growth and development of a stronger sense of self in most of the women. On the face of it the collection of survivor's themes could be interpreted as demonstration of definite and positive emotional distance having been gained from the initial shock. Such an interpretation would not however tell the full story. There is no denying that the 'first layer' of the stories gives an impression that the women's dialogues were strongly indicative of new life perspectives and changed attitudes toward self. Their dialogues were replete with words of hope and optimism, courage and strength. To be among those who had survived BC yielded significant relief for all but two of the women.

The themes that emerged from those interviews revealed that most of the women who joined the study had not considered that a meaningful life could be specifically about them rather than about them in relation with others. The women in this study who suffered negative disruption to feelings of balance in the emotional physical spiritual and intellectual aspects of themselves as they adjusted to living with cancer, reported feelings of alienation from their authentic self and from others whose lives remained untouched by BC. Living life in an outward 'form' similar to what it was prior to BC can be perceived as convincingly comforting in a socially constructed environment that can carry a well-disguised fear of cancer contagion through conversation. Despite the visibility of being normal again, inwardly the women were no longer the same person and often no longer able or willing to attend to the demands of their previous life. After friends and family had been able to be present to the intensity that came with the medical treatment phase, the women reported that there came a point when the usual support networks were no longer available to invest as much energy and time into offering emotional strength and practical support.

The participant women who realised they wanted to change the dynamics of relating with significant others in their lives post-BC were making attempts to do so through re-arranging external realities such as career change or re-investment in personally enjoyable social activities such as dancing. Interpersonal relating was also amended. An example for one participant was accepting, finally, that there was no possibility of a reciprocal friendship with a close relative despite having provided,

during her own post-BC treatment time, extensive practical support to that person. This shift in acceptance had brought a sense of relief for the participant because she was able to arrest constant rumination about ways in which she might be able to please that person. What remained relatively unexplored was the intrapersonal relationship and the inner directive to keep helping that resulted in constant failure to actually ‘help’.

For many of the women who participated, their narratives presented an invitation into a private world that ‘embodied’ contradiction. Themes that highlighted the relationship with their body, their active concern for others, and their perception of what it meant to be self-compassionate, told a tale of the women having ‘thin’ descriptions of themselves. It was as if the women described themselves on a one-dimensional plane – the dimension of carer – either care-giver or care-taker. While they reported feeling stronger than they had previously experienced themselves, examples of life events given to amplify statements made during participation indicated some inability to disentangle themselves from pre-BC relational structures and patterns that maintained an identity status quo. This was particularly so in regard to their self-relationship. The implication was that long-held beliefs about value and worth coming from tending to others was a legacy learned from traditional social and familial interactional styles.

What this meant was that to embrace SC as a useful and psychologically healthy way to ‘be’ for themselves could stimulate a process of self-discovery and self-management. Three phases could be identified for such a process. The first phase would involve an openness to and engagement with what it means to live in a self-compassionate way. The next phase would be one of observation of one’s internal responses to the way SC guides inter- and intra-personal relating and will call for a willingness to feel inconvenient feelings and relational discomfort of not meeting usual expectations of self. The final process would be integration of self-compassion into the structure of the personality in a way that feels harmonious and congruent within the egoic structure.

The women who began with anticipatory feelings of their diagnosis bringing something “special” to their lives found at times the journey became an arduous one.

Many of the women had previously enjoyed a career in ‘high touch’ fields such as nursing, allied health, and education, in which the needs of others were considered paramount. The encounter with BC as an unwelcome and intrusive ‘agent’ of change had propelled an unanticipated movement to greater awareness of their own needs and wellbeing. Admitting that BC had invited them to a place where they had come, not to die, but, to live they were now motivated to be mindful to include themselves in the picture of life.

7.2 Relationship with self and after-effects of BC

Reconsolidation of the ‘self’ as more than a survivor of BC but as a person who is disease-free, who no longer has BC, was a prime source of emotional and physical effort for participants in this study. In discussing their relationship with themselves and their physical body women openly confirmed that prior to diagnosis the connection with their body had been ignored or put aside for a very long time. The women’s comments established that prior to BC they would more often than not unfailingly surrender concerns about their body’s needs and always attend to the needs of those they loved or as often was the case the needs of relevant others.

The physicality of disease and survivorship had generated intense body awareness. Exercise, healthy eating, and management of weight were the key directions women focused on to redefine themselves as well and cancer free. To concentrate attention on actively doing something that offered outwardly observable results (eg weight management) provided positive feedback of positive physical recovery. Concentration on lifestyle factors such as diet seemed helpful in limiting contemplation on personal emotional challenges. Acceptance and awareness of increased psychological vulnerability was centred primarily on emotional recovery from distress caused by discovery of the disease and subsequent treatment. This meant a paradigm of self-understanding that would include a review of psychological development was not part of their current thinking. Attempts to avoid dwelling on painful emotions meant acknowledgment of BC as a persistent emotional health challenge was eschewed by most participants.

What stood out as significant was that a large proportion of participants did not want to carry a label or be identified as a ‘BC survivor’. The term ‘survivor’ or

‘victim’ was rejected by them. It appeared that these women did not want to be reminded of ever-present realities. The realities for them were twofold. On the one hand there was expressed reluctance to be linked to illness or physical or emotional vulnerability. A concomitant reality was that a recurrence of cancer meant a return to exacting treatment protocols, in addition to presenting a potent reminder of a potentially reduced life-span. Participants reminded me that despite ongoing reliance on pharmacological treatment they regarded themselves as being free of cancer. In discussions throughout the data gathering phase there was expression of cognitive endeavours to negate not just the possibility of recurrence, but any fear of recurrence. My terminology in the interviews initially referred to “women who have had breast cancer” or asking about “living with breast cancer”. The common response from most participants was clear and swift. They were keen to adjust my use of the terminology by saying “*but I don’t have breast cancer - not now*”. Overall, their evidence pointed to a robust resistance to any potential for a newly-located self-identity as a strong person to become subsumed under the label of ‘BC survivor’.

The theme of emotions and personal growth revealed unpleasant outcomes for some of the women who had initially navigated the passage through treatment in a stable emotional state only to suffer a decline in their psychological health in the time after connection with the medical care system had formally concluded. From their reports it was clear those women experienced negative rumination that had gathered strength and persisted intensely after the end of treatment. Feelings of abandonment, dejectedness, and personal rejection were exhibited in different ways. One woman voiced bitter, angry, reflections related to the perceived absence of physical help and emotional guidance that she felt was not forthcoming after completing treatment. This participant referred to BC as yet another injustice with which she had to deal. Outward expression of her anger was directed at her spouse (in my presence during the interview), her medical advisers, as well as directed toward a local government council that she said had not rectified what she considered to be a toxic environmental issue that she believed had caused her BC. To another woman removal of her breast meant loss of a significant aspect of her ‘value’ as a sexual partner. A secondary loss was the unexpected removal of the opportunity to resume the employment role she held prior to BC. The meaning she made of the change BC made in her life was that her most valued and valuable roles had been

unjustly taken from her. Yet another participant continued to experience unpleasant treatment-related complications in her mental wellbeing. This participant had presented at her interview with what could be interpreted as an ‘upbeat’ attitude toward ongoing, post-treatment care, that involved painful medical procedures. However, the ‘mask’ of being able to ‘laugh it off’ fell away, temporarily, when, she acknowledged to me, briefly but it appeared, knowingly, the fear that her medical prognosis meant survival was not yet an assured outcome.

A further three spoke openly of their fear that every body symptom now brought with it some form of ‘confirmation’ of a sinister revival of BC. Those women also spoke of trying to manage feelings of fear related to uncertainty about their future chances of long-term survival. Despite acute awareness of the power of cancer to redefine their future, what was noticeable during the interviews was a hesitancy when negative concerns about their future health was given voice. This happened with broken sentences, retraction of comments that might suggest powerlessness in the face of fear of recurrence, and ambiguity within talk about cancer, their self relationship, and self-compassion.

During conversations about their experience of BC and beyond, the BC survivor participants preferred to replace comments that could have been interpreted negativity with positively-gearred and self-affirming statements. It seemed that this was an important choice for them to uphold a belief that a positive attitude would be some type of safeguard against recurrence. Talking in positive terms about themselves post-BC supported their sense of being free of cancer and in control of life once again.

Instances where fear of recurrence was expressed through physical indicators such as teary-ness, or through occasional inclusion in the dialogue of fear-infused or hope-denying language were followed up with comments that restored a sense of power over emotional distress. What was reflected in the process of their dialogues was the strain of suppression of enduring concerns. The lingering, cumulative effect of unaddressed emotion from both the trauma of diagnosis and treatment as well as unavoidable fear of what the future, collided with pre-existing habits of avoidance of emotions such as fear anger powerlessness that had negative social and personal

connotations. Comments were also made that expressed habits of not thinking well of themselves. An example was when one woman said she did not think of herself as “smart”. In general the women spoke about how having BC had helped them realise they were “stronger” than they had thought. During review of the transcripts, and revision of extracted themes, the question was whether their perception of now being stronger would become captive to learned habits of ‘soldiering on and doing more’ or would it be applied to being strong about self-acceptance and initiating patterns of self-kindness in self and other relating.

Resistance to identification as a victim or a survivor of a life-threatening disease indicated a potential for growth into a self-relationship that would be characterised by feelings of emotional prosperity. The ‘strength’ in themselves that many of the women mentioned finding contrasted with feelings of emotional impoverishment that could be unfailingly generated by negative judgments of them through ‘external feedback’. Conversations with women in this study were characterised by a resistance to acknowledge any lack of ‘specialness’ in their life – they felt special through their service to others rather than ever considering what it might be like to be thought of as special for no other reason than they were who they were. Not every participant followed this pattern of situating themselves outside of BC once they had completed treatment.

In contrast to resistance to a survivor label, at least two participants presented with what might be considered a form of ‘attachment’ to BC as the ‘thing’ that made them feel special. This appeared to be so because having BC engendered close care and support from family, friends, and social networks. These two women also acknowledged feelings of importance - a sense of being admired by others because of their battle with cancer. One of the two participants spoke of her disappointment that she had not received the same level of love and practical support she perceived was given to her sister who had, after a long battle with BC had died from the disease. Another felt that the social and work environments she tried to re-enter post-BC demonstrated little appreciation for the enormity of her struggle and the courage she had to find in order to survive.

Re-locating themselves back in a world that had moved on while the women 'lived' in the BC world brought challenge in the form of trying to join again workplace and social structures. Some women talked of the strength of family support whereas others felt that friends and work colleagues had 'run away' from them because of their cancer and not knowing how to broach the topic. They felt as though people whom they expected they could count on for support had disappeared. Yet, other people who had not been considered close friends prior to their encounter with BC were the ones who appeared willing and able to offer strength at the times when the woman's own strength was tested to its limits.

For the majority of participants the illness had generated a to-be-expected depletion in physical and emotional stamina. For many of the women their self-perception was that they had been able to find the strength to survive unpleasant physical and cognitive effects that included fatigue, depression, lymphedema, and 'chemo-brain'. Any impairment in physical functioning was something the women expected to subside within the characteristic 5-year window of survival. 'Chemo-brain' allied to the negative effects of chemotherapy was a state they anticipated would resolve itself as their recovery progressed.

The findings suggested that understanding of psychological health in relationship was framed by previously-enculturated socially-endorsed norms for females. Those norms centred on the importance of caring, offering empathy, listening and attempting to understand as best they can what the 'other' needs or wants. The outcome from this way of relating was that the women tended to ignore - or were not able to hear - their own body-voice. This was especially apparent in regards to warning signs from their bodies. Subtle internal processes that may carry a template of learned experiences and emotional events have been said to have potential to become disguised in the 'language' of the body (Pert, 1997). The implication from Pert's theorising is that unprocessed emotional experiences remain stored in the body. Somatic psychotherapy theorises there is correspondence between physical and emotional dysfunction (Broom, 1997). Unresolved traumatic or emotionally wounding experiences are regarded as those that can negatively influence the physiological functioning of the human body (Rothschild, 2000; van der Kolk, 2014).

The relationship with self and with one's own emotional needs was regularly subsumed by a characteristic desire to maintain relationship with significant others through being able to anticipate what was needed by others. The process of considering and anticipating others need was accompanied by giving attention to others needs. The willingness to meet others needs was not, however, consistently provided from a position of love and care. An accepted – and unquestioned – sense of duty and fulfilment of the expected role of women in their social world was pervasive. The boundaries between the multiple roles the women fulfilled regularly became blurred, and it appeared that what was surrendered was attention to self-care (Mackenzie, 2014).

For some participants, being a woman meant they had absorbed a constructed expectation to feel responsible for helping people work through their feelings. Penny talked about her relationship with her husband as being characterised by his upset when Penny was not in a positive state herself. In response to Penny's concern for her partner on receiving a BC diagnosis she made reassuring comments to her husband that she would survive, everything would be OK. From comments Penny made this appeared to be done so as to rescue him from feeling any distress. Penny was not alone in that shift from having an awareness of her own feelings to the process of care-taking feelings of fear and alarm in significant other's. Several participants reported decisions not to cancel holiday plans because others would be disappointed or because the woman felt that if she announced her BC diagnosis this would spoil festive season enjoyment for other family members. When asked to recall a time when she had been self-compassionate one participant commented that she had indeed been self-compassionate in taking a rest which then meant she had energy to cook her husband a meal.

Shirley commented about times post-BC when she was feeling depressed, stating that her husband's standard response to times when she felt in a less-than-happy mood was to remind her to take some medication to restore a more congenial mood. Her husband's comments served to reinforce for Shirley that his perception of her was a stereotypical one of her as 'woman'. To Shirley this indicated he regarded women as emotionally fragile and irrational in their moods. His 'remedy' for this was medication as a way women could restore their sense of balance. It seemed that

being able to resort to medication also offered Shirley's husband inoculation against his own feelings of helplessness when witnessing her as emotionally distressed. In short, medication helped him rescue himself from the threat of unpleasant, uncomfortable emotions.

When first interviewed, a majority of participants subscribed, some more, some less, to an accepted societal belief that in general women automatically take on an expected role of loving care-takers of a family (Mackenzie, 2014). The comments from the women indicated that they never expected to put themselves first and never questioned when they were not. As their connection deepened with others in the OtSC sessions and PRP a more authentic exuberance for life was, temporarily, more freely available in a safe and trusted environment with other women. The result was that acceptance of 'conditions' to their living - conditions such as care-taking, being aware of others needs, putting their needs down the 'list' - began to move forward in their awareness. In conclusion, despite decades of liberation from stereotypical roles for women in general, what had persisted in women participants was benign acceptance of their role, as wife, mother and/or partner, as the one to offer assistance, care, kindness and generosity to others when need arises. Breast cancer had begun a process of these women enjoying who they are and releasing what they are not – or who they do not want to be.

Treatment to manage or arrest the physiological threat and relief from symptoms that persist as a result of treatment is one part of the health care process. The field of care for the person living with cancer is now much broader than it would have been half a century ago. Recognition of there being layers to personal meaning-making in addition to awareness of what it is that holds potential for healing for human beings has brought about changes in care for the cancer survivor. Banded together under the collective term of complementary and alternative therapies/medicine (CAT/CAM) a cancer survivor now has access to a suite of supportive activities such as counselling, yoga, mindfulness, art therapy, and music therapy. Each of these activities as well as an extended range of creative-arts-based approaches to healing have the potential to support proactive moves the person makes to move beyond an identity as survivor.

The labels of ‘BC survivor’ or ‘woman survivor of BC’ may become ones that can obscure the person’s larger reality. That reality is that a person with cancer – who may survive or who does not survive – is a multidimensional being with a range of physical emotional intellectual and spiritual needs and desires who exists in a range of differing contexts. This means as a multidimensional being a survivor of BC would likely respond well to a multidimensional empowering and growth-focused approach to emotional support. A multidimensional approach invites the person who has survived to be proactively engaged as an integral element in their own healing process.

7.2.1 Restoration of emotional functioning: The psychological self.

Reports from some participants confirmed a revitalised interest in life had been catalysed by their close encounter with death. That encounter had brought an often unpleasant, unwelcome, but necessary surrender to an essential, but temporary, shift in their psychological structure. There were a number of participants however, who maintained a pre-BC model of relating with themselves, family and with others. For them, enjoyment of life remained heavily influenced through shaping and maintaining harmonious relationships with significant others in their family and social environments.

Therefore, a not-so-surprising realisation was that the post-BC ‘self’ continued to ‘house’ significant elements of the psychological structure that had been in place prior to diagnosis. In other words, persistent in the psychological self were the shadows of negative childhood injunctions such as driven-ness, need to excel, low self-worth, and insistent self-criticism. For participants, thoughts, actions and ways of relating with self and others, continued to subtly mirror, or repeat, remnants of an earlier imposed blueprint for responding to emotions. Therefore a psychosomatic ‘network’ of embodied remembrances of BC continued to be unattended to. Those embodied remembrances of BC were able to be masked by the relief that came with survival and the confirmation of their strength in enduring the treatment regime.

The perspectives of the women in this study gave credence to the assumption that if a woman speaks up about things they are not happy or not satisfied with, then

they risk being regarded as being a selfish person. This appeared to be particularly so in negotiating relationships. The result was self-imposed restriction to being self-loving or self-compassionate. From their reports and my observations in the OtSC and PRP, the women were very capable of experiencing 'bad moods', able to feel angry, to grieve, or to be upset and sad. In the group of participants in this study there seemed little restriction on their ability to feel, However the retraction on self-kindness that would pave the way for a regular, natural, flow to self-expression seemed inhibited specifically so as not to appear self-centred. This was a persistent finding in the life stories shared for this study.

The interview process supported a hypothesis of the enduring, and depleting, power of cultural expectations and the results of trivialisation (and self-trivialisation) of women's concerns about themselves. The perseverance of past habits of self-value and self-relating was especially reflected in the first two themes – "I never said why me" and "I don't have a Plan B". In both themes participants reported an optimistic stoicism from which they made a deliberate and conscious choice not to outwardly express feelings of shock or fear on hearing their diagnosis.

One outcome of a tendency for procedural memory to regulate the relationship with themselves was that women in this study continued to hold close an expectation that preserved their 'role' as responsible and loving caregiver in their family, and to continue to be so, even in the encounter with a life-threatening disease. This meant staying focused on finding the energy to be optimistic about survival while keeping a mind for the 'suffering' of significant others in their life. was one source of distraction from the workings of their interior world. For example, concern for others emerged in a strongly conveyed desire to support women diagnosed with BC in the future. Self-concern would mean taking time to reflect on a deeper purpose and meaning to their life and their experiences. Self-concern might also bring an invitation to review what it was a BC survivor would like to encourage and create in their life for the foreseeable future.

Commentaries from the women about their BC experiences were couched in an overall expressed hope that what they disclosed could potentially help ease the suffering of others. Their compassion for the suffering of women diagnosed with BC

was beyond question. The concerns and hopes for others wellbeing reflected concerns and hopes they also had for themselves. This meant that the complex construct that emerged with compassion toward others was that on another level what was given to others was the very thing the women would have enjoyed receiving. The complicating factor was that many of the women found it more acceptable to give than to receive.

During the most intense phase of their treatment they had been able to experience and receive the concern care and love of others. However what remained evident in their personal narratives was that once life returned to something that equated with pre-BC normality, unconscious habits of self-exploitation re-entered their daily living. It seemed there was a self-protective function in treating themselves harshly. Self-protection in the form of an inner critical ‘voice’ seemed to offer respite from the emotional strain of anticipated self- and other judgment. The women’s stories told of an internal dynamic tension between care and concern for others and care and concern for themselves. In giving to others they were in a way giving to themselves and protecting against judgment. Therefore, in being compassionate to others there was an accompanying sense of creating a sense of self-worth through positive and helpful contributions made to other people’s lives.

Gaining a positive sense of self from being concerned for others provided only temporary relief from the absence of an abiding sense of self-worth. The evidence for this came to light in comments from the women about self-compassion. Asked to recount a recent time when they had been self-compassionate their comments often related to putting in place boundaries about how they wanted to be treated. However, there was more often than not a lack of being able to direct kindness toward themselves without some form of external catalyst. At the same time as the women were able to push back against previously unconscious habits of concern for others what persisted was the lack of conscious expectations of ‘receiving’ in return for care and concern given to others. There was also limited conscious awareness that caring and supportive attention to their own emotional state by themselves or by others could be tolerated for any extended time.

For the most part there was subtle, active, but seemingly unaware, resistance to receiving kindness from self or others without giving or returning the ‘favour’. The need to return kindnesses shown seemed to emerge from fear of being found to be selfish, or their needs being regarded as an imposition or too dominant. Kindnesses extended to the women during their treatment and transition to ‘survivor’ had been accepted during the time in which they felt ill and were unable to attend to daily living in their usual way.

Evidence from the interviews and group sessions for this study indicated that the indelibly physical nature of treatment for cancer had forced greater awareness of the interrelationship between illness wellbeing and self-nurturance. It had taken a diagnosis of cancer for women’s self-awareness and self-acceptance to begin to ‘open’ their mind to a larger version of themselves. That larger version of self was one of being a valuable and worthy human being not because of what she could do for others. That larger version was one in which a sense of wholeness and joy about self could be experienced. Tender self-comfort and self-reassurance could become part of a normal way of relating with self in the everyday, not just when they felt sick, or in need of help.

The personal strength the women survivors summoned in order to survive had aided a post-BC shift to make changes in previous unconscious willingness to overlook the importance of their own needs so as to accommodate others’ needs. However, while positive changes had taken place, positive change had not been universally integrated through all ‘dimensions of the self’. What remained unobtrusively embedded in participant narratives were disclosures that indicated the psychological ‘self’ post-BC still contained a residue of aspects of the ‘self’ that had been in existence prior to diagnosis. Restoration of emotional functioning post-BC so they were able to include themselves as important and deserving of nurturance was often challenged by the absence of physical symptomology and a belief that medical treatment had ‘fixed’ the disease. This meant concern and care for their own bodies, their minds - and their destiny - was still being unavoidably and unconsciously prejudiced by the legacy of a past construal of self as being of value most when in the process of being helpful to others.

What remained was an internal psychological orientation that was still subject to societal rules, values and expectations even of themselves as BC survivors. Rather than the rules, values and expectations relating to ‘women’ in general, their life as a BC survivor now had rules, values and expectations about how to ‘be’ as a cancer survivor. For example, one already-discussed dominant narrative that remained intact was fear of being selfish or being judged as ‘emotional’. Emotional ‘strength’ to ‘soldier on’ as a survivor of cancer was considered valuable. Family members and co-workers encouraged a return to a non-ill self. Supportive as such encouragement may seem, vulnerability to emotions or emotional intimacy with themselves was therefore something regarded as a form of submission to negative psychological remnants of the disease – an indication of weakness – and something to be recovered from or put aside.

Contradiction was inherent in the BC-saturated stories related by the women – a contradiction that at some level seemed implicit although not expressed. The women’s interpretation of their journey through BC was of their tolerant acceptance of an inevitable process to enable survival with a specific focus on taking positive action to remedy the physiological problem. However fixing the most obvious immediate problem through effectively and efficiently removing BC had cured a disease for the women but had not in a larger sense brought ‘healing’ for their psyche.

BC had affected the women’s attitudes towards themselves and their bodies in a way that had challenged awareness of a tendency to put their own needs aside to cater for the needs of others. The evidence was that a process of psychological evolution was underway. Changes that were not so visible had occurred in their conscious psychological self. Their stories told of personal change that meant an openness and willingness to listen to themselves and evaluate situations in relation to how they wanted to live post-BC rather than what they believed was expected of them. They had begun to perceive life differently and had begun to re-imagine their future self in a way that would not have been possible pre-BC. BC had presented the women with a ‘refurbishment’ of the self they thought they were. There was also intangible, but explicit, demonstrations of a shift in valuing their capacity for

relationship-tending as opposed to that capacity being devalued because of the expectation that it is what women do by virtue of their ‘nature’.

More conscious self-guidance of the direction of that re-interpretation began to happen when, in a psychologically safe environment, with no cultural expectations of how to be as a survivor, they had the freedom to begin reconstruction of their life narrative. Through embarking on a process of deepening self-discovery the women began to feel free enough to experiment with re-shaping their psychological self in relation to others and the world around them.

7.3 Emotional and personal growth

The theme of emotional and personal growth revealed, in general, that participants had not moved outside recommended conventional treatments for BC. The interpretation of BC most commonly held was of it as a disease harboured in the body. Therefore, fixing the body was considered to as a medical matter. What followed the completion of the medical process was a decision that positive thinking and an optimistic attitude along with development of coping strategies would create a ‘savings account’ of evidence of personal effectiveness at staying well. The belief was these strategies afforded greater potential of personally defeating BC.

The majority of women in this study had not participated in BC support group activities other than as a way to seek short-term, immediate post-treatment psychological support. While many of them had been involved as a participant in a research study, or had brief encounters with cancer care groups, comments made indicated that for the most part, prior to the BC experience they had not consciously thought of engaging in personal exploration of their inner world. None of the women participants, nor the significant others, had engaged in in-depth personal development processes such that compassion-focused therapeutic activities or psychotherapeutic techniques might employ.

What had not been sought prior to participation in this study was a regular contemplative practice or process that would seek to foster self-exploration and re-evaluation of their post-BC sense of themselves. A commonly held view amongst participants was that BC was one of two things: it was either incurable or, in the

case of this study's participants, able to be 'cured' by application of medical treatment. A small number had engaged in short-term conventional verbal counselling that had provided much needed emotional comfort. Emotional comfort had been used as a means to increase their sense of personal control and take care of the body through external means such as massage. This form of support had helped them regain mind over matter by using distractions, by placing a positive interpretation on what was happening to them now as well as maintaining a positive vision of the future. In general participants were not clear about what exact purpose would be served if they were to engage in additional emotional support.

In terms of their personal growth, at the end of their participation in this study two of the women who had completed all three phases of involvement remained unclear about how to reconcile a dynamic inner tension between the concept of being self-compassionate and the deep desire to avoid being thought of by others and by themselves as selfish. This was not to imply that they had not grown personally.

The consensus amongst participants that their life was very different as a result of BC. This led me to wonder whether self-compassionate communication could be a conduit through which women and their significant others could be supported to emotionally take a step back from their disease. A step backward supported by counselling that included the work of finding self-nurture and self-love in contrast to work that might focus on problem resolution could allow enough time to develop self-compassion. The focus would be to herald a shift to a refreshed relationship with themselves and the world. This could mean stepping aside from thinking primarily about treating psychological symptoms of the after-effects of BC to a position that prioritised assessment and inclusion of ways to develop a long-term self-harmonious balance in emotional functioning.

One significant other had taken this step backward after his wife's death when he reached a state of feeling his life without her was pointless and meaningless. His 'rock bottom' moment, when thinking of his children were no longer an anchor to his human life, led to a subsequent review of his potential. He talked about his decision not to continue existing in a colourless world, but to acknowledge and allow himself to feel his emotional pain and at the same time open to living life more fully.

This significant other chose to investigate aspects of himself that had been ignored until BC arrived as the unwanted intruder in his marriage.

In the process of getting to know themselves these particular participants encountered an internal struggle as they attempted to reconcile loving kindness for self and a more tender internal commentary with a deep imprint about the negative implication of being selfish. Self-love self-nurture as kindness toward themselves began to emerge through the process of participation. This happened as the women became more open and less concerned about others reactions to their talking about losses, fears and concerns in a forum that offered deep listening and silent compassion. This type of environment offered time for gestation and ‘birth’ of new insights about themselves and revised relationships with others.

As the times of meeting as a group continued for the 8 women, there was permission from within themselves to become absorbed in ‘experimentation’. Having time to experiment with ideas about relating with themselves and others in the PRP sessions, as well as experimentation with creative tools, created acceptance of compassionate silence as a valid response rather than automatic entrance into someone else’s world by way of offering a remedy. Spontaneity and their capacity to enjoy was clearly demonstrated as their experimentation in the group sessions lessened the control of their thinking by collective assumptions of what being woman, being middle-aged, and a BC survivor meant to them. What replaced the collective assumptions was collective wisdom.

7.3.1 Emotions and wellbeing.

A significant number of the women in this study regarded their encounter with BC as a commonly experienced source of temporary, but profound, personal disempowerment. Collaboration with the biomedical system in their quest for survival brought compromise to emotional wellbeing (EWB). The women’s experience of the disruption to EWB is reflected in the literature on the effects of BC. Although eagerly anticipated, a return to EWB was not enjoyed as an automatic by-product of survivorship by all women who took part in this study.

EWB was something the women had found they needed to give effort to, just as their body had been the primary source of effort to join the medical system in accomplishing their physical healing. With increasing distance from being a cancer sufferer to adjustment to life as a survivor, there came the risk of easefully settling back into unaddressed and habitual routines of intra-personal and interpersonal communication, social exchange and social discourse. The women in this study demonstrated a growing awareness that the stress they reported to me as integral to the decline in their health was not something they wanted to have as a life ‘companion’.

Anecdotally, a significant number of women participants in the study reported in this thesis, held a personal belief that unaddressed, extraordinarily intense levels of unresolved stress in the year or two leading up to diagnosis had compromised their immune system and precipitated the generation of illness in their body. Another woman survivor of BC, consulted as part of personal-experience ‘reference’ sources for the study, was asked about her perception of whether there was any connection between stress and BC. Her response to me was emphatic. While this survivor believed stress was not the actual cause, she did regard stress as a highly significant contributor to her development of the disease.

The concern was that conditioned thinking about needing to care for others or about others would reclaim primacy in their emotional functioning. Those ways of thinking and behaving were ones that sadly reflected acceptance of socially constructed stereotypical ideals. Having faced a fear and shock of diagnosis and treatment, survivorship presented them with the challenge of finding emotional sustenance from within themselves. This meant stepping away from limits placed on their self-expression either by themselves so as not to appear powerful, dominant or selfish, or by others for the same reasons. In this regard, the women reported BC as the life event that brought with it a relaxation of their previous acceptance of ‘norms’ about women’s roles. They spoke about feeling less bound by nagging concerns that they should think and behave in ways expected of them by significant others.

Engagement in personal discovery became the important intermediary that initiated a re-fashioning of the women’s attitudes towards themselves and their

bodies. Time to engage in a mindful but relaxed and ‘playful’ growth-focused approach to fostering emotional awareness, wellbeing, and personal vitality, was one way the women encouraged in themselves gently-paced movement towards exploration of unfamiliar ways of being. After the trauma of diagnosis and treatment, BC had become the indisputable agent of change. Autonomy of choice to go with the change or to return to life as usual belonged to the women.

7.3.2 A different perspective.

In an entirely different direction Myss (1997) has taken a position of there being a tendency in humans who have suffered adverse life events (excluding trauma), to steadfastly maintain a position of being in need of care and support. This author points out that a façade of needing to be taken care of is a coping strategy adopted to avoid active engagement in a personal change process that would ultimately lead to separation from unresolved emotional pain that feels familiar and has been an habitual way to get some needs met. The possibility of being their own agent of change would, according to Myss, be carefully but usually unconsciously, concealed beneath a belief of being unable to be psychologically stronger than they know themselves to be. The view of Myss is one that seems to sit in contradiction to the principles of being self-compassionate.

Contrary to the social commentary put forward by Myss (1997) participants in this study spoke of their newly tested strength as something they regarded as bringing enhanced personal coherency to their emotional landscape. The term ‘strength’ seemed to represent an opening of a door to discovery of a collection of previously untapped resourcefulness. The resources waiting to be fully discovered offered the capacity to evaluate choices from a broader and more authentic self-perception – a perception that provoked self-reflection increased self-knowledge and considered self-determination through their relevance to qualities of self-kindness, self-nurturance.

7.4 The desire for self-nurturance

Self-nurturance is a desired by people and is sought in many forms. In this theme the women’s comments were a reminder about the caustic effect of judgment from self and others. They felt that having another person listen to them in a non-

judgmental way offered a way to speak their own 'truth'. It appeared as though there had been much unsaid about themselves, not just about their BC experience but their whole of life experience. The chance to speak openly without fear of judgment or correction meant that the women had not had opportunities to hear themselves. What had been missed then was time and space to listen to their innermost 'being' and in doing so become aware of their innermost potential.

In the Western social world women are often assumed to be and depicted as nurturers of others, care-givers for others, reproducers, and sexual partners of others. Since the latter part of the 20th Century half they have also been depicted as being able to do anything that a male person can do. A dominant social portrayal of the roles of women as carers and nurturers of others was confirmed by participants. Referred to by Beverley as the ones who are over-generous givers, participants talked of themselves as the ones in the family who maintained relationships and an overall sense of peace and calm.

Self-nurturance had been accepted pre-BC as being primarily derived from creating and maintaining connections with family members, guiding relationships between family, and taking responsibility to ensure enjoyment for others during special events for family. Part of that 'responsibility' included support for aging and emotionally unwell family members in addition to attending to handy-person jobs around the house. Women BCS in this study commented on the perception that without their intervention relational disharmony within the family may be likely to extend beyond a bearable point, and practical tasks around the home would be likely not to be completed in a timely fashion. Some of the women commented about feeling a general lack of appreciation for and an invisibility of the contributions they made to family harmony.

Post-BC the women felt they gained nurturance from their connection with other women survivors. The group connection was most effective in reducing feelings of emotional isolation and mediating contact and sharing experiences with other co-survivors (Cozaru, Papari & Sandu, 2014).

7.5 Unanticipated benefits: The gift of cancer

A paradox for a large number of the women was that their cancer experience temporarily isolated and alienated them from those who were healthy - family, work colleagues and social contacts - and yet those women also had the experience of becoming acutely aware that BC offered an undeniable opportunity for change. The women's comments confirmed a heightened desire to live a meaningful life. New-found strength was cited as an emergent 'gift' from traversing BC. This 'gift' was manifest in the theme of appreciation for their own resilience and ability to be 'strong' throughout the trials of the life-saving medical treatment regime.

An outcome of having a serious illness has been found to be a greater appreciation for life as well as for close personal relationships (Sears, Stanton, & Danoff-Burg, 2003). One specific area of unanticipated benefit, reported in comments from a large number of participants in this study, was that they had come to appreciate how emotionally and physically strong they felt as a consequence of having had BC. Several went so far as to say that having the disease had saved their life. They reported that realisation of their inner strength came from successful endurance of the immensely potent rigours of treatment for BC. That strength appeared to have come, in part, from the lived experience of having been able to exert some personal power over the outcome of the disease. In part, the emotional disturbance wrought by BC seemed to act as incentive to catalyse dormant psychological processes that would, of necessity, override fear and distress, and privilege survival.

Participants felt that their survival was positively affected by their adherence to the initial treatment process, to medication regime, and loyalty to a healthy lifestyle. They were clear that they would not want to have a recurrence of cancer as a way to gain personal growth. However, their interpretation of having received a benefit for their life echoed findings from literature on Post-Traumatic Growth and BC (Casellas-Grau et al., 2016; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009). The feeling of having received 'benefit' from BC came from having received support from their medical team, from BC care professionals, from family, friends, and from others who may not have been part of their life up until the time of diagnosis. The majority of participant survivors in this study had children who were

teenaged, or early adulthood, rather than children who were infants. One important finding was that all the women who participated in this study would likely be assessed as being in a reasonably stable financial position. This was evidenced by the fact that most of the women were able not to return to paid employment unless they chose to do so for their own wellbeing.

Overall, participant interviews signalled that a significant number of the women had come to accept BC as a valuable opportunity to reinterpret their minds and their bodies in ways that felt more empowering for their life. To capitalise on that sense of empowerment, self-compassion-focussed psychosocial interventions could be routinely included in post-BC treatment care. To do so could bring a way to circumvent any tendency to return to pre-BC habits of self-relating.

7.6 Personal Reflection Program sessions

The PRP sessions offered the women a space in which a different relationship with themselves could be explored and entertained. In those sessions the disease was not afforded power to define who they were. Observations of their engagement in the PRP sessions indicated the women welcomed curiosity about who they were as a whole person. In particular they were able to recognise social pressure related to gendered appearance of the female body. Of the women in the PRP sessions whose BC resulted in a mastectomy, only one had made the decision to have reconstructive surgery.

There was an overall awareness about maintaining fitness and good health. BC had meant taking charge of their wellbeing and their lives. From the group discussions came growing awareness of ways in which they had not exerted their own authority before BC. Curiosity about what being a woman would mean from this moment in time forward was something they laughed about, discussed, pondered, and reflected on in the PRP. Curiosity that was related to their suspicions about precursors to their BC, the disease progression, and what external ‘add-ons’ would indicate power over BC was discussed. There was an expressed desire to step forward into a renewed self physically, emotionally and spiritually.

The expressive-creative arts activities which supported the PRP, helped women detach a cloak that may have previously covered any silent, inner identification of self as a cancer survivor. Therefore, the group quickly assumed an identity other than that of helping each other through the defining life event of BC (Husebo, Karlsen, Allan, Soreido, & Bru, 2015; Spira & Reed, 2003). In the small group context it seemed the eight women began to redefine themselves as lively and interesting women first and foremost. Additionally, meeting as a group that discussed a range of facets of life – other than illness - helped locate and contemplate future directions they wanted life to take. As a group they took time to experiment with ideas about how they wanted to design their future from this current point in time. This redefining of themselves as a person was a central topic rather than the discussion remaining recovery-oriented or problem-focused.

Research into creative psychological interventions such as Supportive-Expressive Group Therapy that included hypnosis had been used to explore pathways to relief from emotional distress and pain for women BCS (Butler et al., 2009). In addition, Art Therapy (Svensk et al., 2009), Mindfulness-Based Art Therapy (Jang, Kang, Lee, & Lee, 2016) as well as group exercise and supportive group psychotherapy (Martin, Bulsara, Battaglini, Hands, & Naumann, 2015), Music Therapy (Lesiuk, 2015), and Dance and Movement Therapy (DMT) had been found to provide relief from emotional distress. The PRP sessions devised for this study involved experiential creative-arts-based exercises as a way to cultivate and practice self-acceptance within a group setting where receptivity to the other was intentional and non-judgmental (Aguirre-Camacho et al., 2017). Experimentation with flexibility in their attitudes towards self, while experientially making close ‘contact’ with their innermost thoughts and feelings was met with intensive listening from the group. The support experienced in the group provided a path to integration of physical, psychosocial and spiritual needs. The group process facilitated opportunities to explore and revise ways to effectively cope with stress (Koraleski, Ryan, & Carlson, 2014).

What this meant for participants who completed the PRP was that they came to the initial group without prior understanding of how expression of their emotional state, or their hopes for the future could take place through an imaginative, creative

process. As could be expected, participants had not previously had any introduction to the concept that their personal artistic expression could so easefully produce information about an envisioned or hoped-for autobiography. Awareness was low that painting or drawing something, or creating an image with miniatures, could spark self-interest and nurture hope and encouragement. Over the course of the group interactions there appeared to be reduction in the avoidance of emotion-laden cancer-related content in their thoughts and feelings. Cancer did not dominate the conversation, nor was it avoided; the topic of cancer had a place in discussions but was not the topic that captured most of their emotional involvement during the group sessions.

The women who engaged in the PRP sessions seemed to be those participants who exhibited the strongest desire to be of help to other women diagnosed. Their motivation to be a help to other women connects to the theme of giving support and emerged from their own move to make their lives more meaningful in which needs of self and needs of others could be relativised. This meant that needs of self and others were weighed up from a place in which self-knowledge and awareness informed decision-making about any course of action. Reciprocal 'actions' for support received was a hallmark of their discussion about life in the immediate post-BC phase of life. The comments about helping others related to the theme of giving and receiving support. Once they no longer regarded themselves as having BC, the women continued to find comfort in being able to give back rather than to allow themselves to continue being the receiver of kindness. Allowing themselves to receive without an urge to repay a kindness was being cultivated, however, to completely re-position themselves as able to accept kindness, without feeling some guilt or fear, was not yet realised.

In those reflection sessions the expressive arts activities meant the women were able to be free to be with each other in a natural way and enjoy each other. They came to experience mutual trust and respect through the inevitability of being vulnerable as they talked about their hopes, dreams as well as short and long-term plans. Rather than critical self-judgment that might have resulted in a reluctance to openly discuss feelings and ideas for their life for fear of being considered irrational, over-emotional, or selfish, participants in the PR sessions expressed openness to

wanting to be more creative, to a desire to be more self-caring, and motivation to feel more empowered about their lives.

In the time spent together in the PRP sessions what became apparent was a mutual trust and respect that was obviously solidified by a shared history of surviving BC. Beyond that initial trust and respect their group sharing indicated the relationships that mattered most to the women were those in which there was a sense of emotional freedom and reciprocity, natural openness, and an easeful giving and receiving of loving care.

Interviews with the women participants, the OtSC sessions, PRP sessions, as well as interviews with the significant others, revealed aspects of themselves that had the potential to impair or interrupt a coming to terms with women's patterns of self-relating. Participants in the OtSC and PRP spoke in terms of lifelong habits of 'veiling' their needs. These themes were also characteristic of interviews with women participants who attended an interview only. Self-care strategies were often related to regaining a sense of external physical attractiveness along with reduction in the fear of recurrence rather than revising an intrinsic state of self-valuing.

One of the women in the group had attempted suicide post treatment as her only way to relieve desperation at no longer feeling as though she fitted into a world that seemed not only to have forgotten her but rejected her attempts to reclaim a place of value and meaning. Her expression was of very real and genuine emotional pain and suffering. Her depression was profound and was experienced almost viscerally by others in the group. In the final PRP session, while her depression appeared not to have lifted significantly since the first OtSC session, a drawing created during the final PRP session was interpreted by her as an indication of new growth and hope for the future. Many of the images this participant created as her response to the experiential activities could be interpreted as depicting growth, colour, optimism and courage. Yet, the descriptions used when she shared the meaning of her drawings seemed not to have reached a sustainable conscious awareness. Positive self-statements in her responses to expressive activities were short-lived and, as would be anticipated in a state of depression, any feelings of optimism were constantly overwhelmed by hopelessness and negative rumination. In

response, the group was caring and supportive, and offered a safe, listening space in which she could openly express intensely experienced feelings without fear of judgment, expectation, or invalidation.

Each of the women became able to nurture a greater sense of self-kindness by focusing attention on her unique response to the activity-based exercises. Group sharing following an activity meant each person could talk about their values, their attitudes, what mattered to them, and their beliefs about life and what life meant for them. Simultaneously, for those listening as each person's shared those personal insights, there was a modelling of being able to contain difficult feelings and be comfortable in the discomfort that engendered.

One participant who at the start of her involvement in the process for this study felt confident she would not be a person who would engage in or need emotional support gave a telling comment on the last day of the final PRP group. On that day she mentioned to me that if we had 'done' the groups and expressive therapies activities at the very start of the project more extensive and even deeper reflection would have been forthcoming. Unfortunately the limited number of times we were able to meet in a group context within the confines of this study meant the growth that had begun could have used more time to flourish. At the end of participation in this study five of the women continued to meet monthly to offer emotional support and nurturance to each other.

What the women were able to nurture in themselves was a greater sense of balance about the meaning and importance of things. They realised that they neither needed to conform with or rebel against the status quo they had been faced with as young adult women. The result of the shift was that rather than being the nurturers - the ones who gave nurturance to others and took on the role of providers of love and care for their families and significant others - BC brought with it an unanticipated impetus to relinquish that role.

7.7 Participant observation from the OtSC and PRP

The role of participant observer was adopted for the OtSC group sessions in addition to the PRP group sessions. Participant observation as a methodological

framework for these two aspects of this study was chosen because of the insider-outsider role the researcher played as facilitator for both of these phases of participation. The 'insider' role allowed feelings of connectedness to develop between participants and myself as researcher. The assumption was that given the sensitive topics being discussed the feeling of connection, trust, and being emotionally 'held' would be critical for meaningful dialogues to be shared. My professional background is in counselling, and this meant relationships between the women, and between the women and myself could be managed without my becoming over-involved or over-identifying with feelings expressed. The outsider stance was maintained through non-participation in any of the experiential activities. My role as facilitator, and one of standing 'outside' of the women's in-the-moment experiences, allowed me to stay separate from emotional engagement generated by the experiential activities. During the group sessions my background in counselling was surrendered as much as was possible, and the role of naïve observer adopted, so as to facilitate from a flexible and reflexive space.

The method of gathering data involved observing and participating (as a facilitator) in the group sessions allowed access to more explicit insight into the lived experience of participants. Observation in this instance was not the major source of data generation but provided an otherwise unobtainable insight into the beliefs, attitudes and behaviours of the participant survivors. Facilitation and observation of the processes gave a sense of being able to 'stand in their shoes' for a brief time (Alase, 2017). While it had been anticipated that video-taping and audio-recording would be possible, survivor participants were explicit in their request that the sessions not be recorded in any form apart from some notes I could make along with photographs of the images they created in response to activities offered.

7.8 Relevance of self-compassion: Finding self, saying no

The relevance and benefits of a kinder more nurturing relationship with oneself, in the face of the challenge of BC, becomes evident when considering the potential to be proactive in developing adaptive responses to living with this disease (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2014).

Shifting from placing others first to thinking of self did not mean that the women came to ignore or deny the needs of others. On the contrary, they reported continued care that nurtured family and friends in the ways they had always done. The only change was that their choice to actively give to others was one that was now a more conscious choice. This shift to conscious choice stood in contradiction to previous giving as a way not to be judged as selfish, unkind, or feel helpless in the face of someone else's stated needs.

The women talked about how they now felt more able to give voice to their particular needs and more often attend to their needs without grief or guilt. In essence, they had begun to put themselves 'in the picture'. BC had removed some of the fear that had previously influenced their relationships with self and others. One way in which the women had begun to relate differently was in acceptance of themselves no longer being the person who would repair relational disharmony for their loved ones. To achieve this many of the women found that they had begun to set limits on the extent to which they would advise, support, and extend themselves. From comments made during interviews it was understandable that, as with physical healing, it was taking time to live into a revised personal post-BC narrative with the vision of themselves as independent of pre-BC patterns of behaviour. To do so meant acceptance of the opportunity for change in self-awareness and self-love, as they embraced the new vision of themselves as a BC survivor.

While the challenges experienced in adaptation were spoken about by each of the women, it was helpful to remember they were situated within wider family, social and cultural contexts. This meant that some women talked about their experience and their understanding of SC through the filter of what being self-compassionate would mean for their family. Some needed time to think about and reflect on the implications of being self-compassionate before they felt ready to share their interpretation of the term. Others openly admitted to not knowing what the term meant. Mention of SC exposed acknowledgment of the interest and desire for change, that paradoxically for many of the women was mixed with a pervasive concern about being judged as selfish. To be labelled as 'selfish' was anathema for women survivors.

7.9 Significant others and the shared journey

The men who participated in this study found that BC brought a state of psychological unrest to their lives. There is evidence to suggest that it is important for men affected by cancer to receive counselling support (Banks, Pearce, French, Lloyd, & Lewis, 2017; Chronopoulou, Sakkas, & Damigos, 2016; Love, Thompson, & Knapp, 2014). In order to be able to provide optimal assistance to couples it is helpful to understand the ways in which men react and adjust to women's BC (Baucom et al, 2012). To understand women's adjustment to BC it is also critical to understand the interactivity between their emotional state and the emotional response of their partner.

A range of themes extracted from interviews with 3 men indicated that a significant other (SO) in the life of a woman BC survivor faces an exponential rise in the complexity of their relationship with the survivor (Love et al., 2014). In the first instance the men in this study told of the shock absorbed by themselves and their wife with the diagnosis of BC. They experienced intense, sudden grief, but also felt as though they had to accept a role reversal when it was apparent they would become, temporarily, the primary caregiver in the relationship. It was clear from the men's stories that they too had experienced significant emotional disturbance with feelings of grief, fear, anger and anxiety. However, they each talked about their first focus being "getting my head around" what was happening and what practical aspects of life needed attention. The desire to keep family life as functioning normally was a key drive in two of the husbands and this was reflected in the theme of disorganisation and unrest.

Despite an acute awareness of the perilous situation confronting their partner, the SOs had not sought, or not thought to seek, counselling support for themselves as a way to alleviate the significant strain they were under as a couple. In line with the second theme of 'being the strong one', the SOs support-seeking beliefs and behaviours that they should be the strong one to offer help to their wife were heavily influenced by cultural expectations of what it means to be male. This finding was consistent with the results of a study by Love, Thompson and Knapp (2014) that found men whose lives are affected by cancer found it difficult to ask for help.

The eighth theme summarised the men's comments about emotions – theirs and their wives'. Consistent with the conviction about staying strong (Theme 1), keeping things normal (Theme 3), and paring life back to the basics post-BC (Theme 11), the absence of finding opportunities to openly express their emotions meant SOs felt the only remaining choice was to internally enclose their feelings and carry on. This meant the men in this study identified no acceptable avenue for them to speak about their experience as a way to facilitate their own adjustment to BC. The men's emotional reactions to their wives' BC also interacted with the way in which their wife responded emotionally to the diagnosis and treatment (Baucom et al., 2012). The wellbeing of the partnership was subsequently tested when their wives' physical symptoms were at their most intense.

Each of the men became hastily aware of the disorganisation BC would bring to their partnership and to family life. The specific tensions and worries the men did not reveal to others combined with fear of what the future might hold meant they experienced high levels of stress and anxiety. Comments about initially feeling chaotic and disorganised as the SOs tried to restore some sense of order in daily living is consistent with the findings in a study into Iranian men's adjustment process to their wives' BC (Nasiri, Taleghani, & Irajpour, 2012). However, despite elevated levels of stress the men opted to rely on their usual strategies for coping with stress. What stood out from data that emerged from interviews with SOs was the way in which each of them drew heavily on their professional training to help them navigate the complications that BC had brought. This was interpreted as their most available resource to regain a sense of control over life that their wife's diagnosis had temporarily denied them.

Women with BC generally have positive interpersonal relationships that help them cope with the effects of the disease (Kayser, Feldman, Borstelmann, & Daniels, 2010). Husbands talked about their fear that the cancer would return at some future point, about adapting their work life, doing a juggling act to meet and prioritise the needs of their wife, the family, work, and caregiver tasks with their own needs. Many of these tasks were familiar to their wives but highly unfamiliar to their husbands. The SOs talked about putting their particular emotional needs on hold in order to concentrate on maintaining a sense of normality.

In this study Theme 5 highlighted that the husbands were highly supportive of their wives. They had enjoyed a positive relationship with their partner. It was therefore understandable that BC was regarded by the SOs as a shared journey, not one person's journey. This experience of constancy and commitment in their relationship during the BC experience has previously been found to be a buffer against poor emotional adjustment in women BCS (Kayser et al., 2010). The men in this study wanted to be present to their wives' illness and wanted to be supportive. This attitude was in line with one of the findings in a study by Pearce (2001).

One challenge posed for the male partners in this study was how to 'stay with' the ambiguity and uncertainty they realised they were likely to face over many years of their wives' survivorship. Their comments reflected the absence of prior 'training' that would help them feel better prepared to provide emotional support to their wife and to themselves across the long term. Communication within families about BC was a new challenge for the SOs. They developed plans for action as a mechanism for coping with the pressure of the unfamiliar role they now fulfilled. In concert with the findings by Pearce (2001), two of the SOs in this study temporarily suspended maintaining their focus on the family as a way to keep going. Although they soon returned their 'gaze' to the family, the strain they felt during the first months of their wife's illness left them overwhelmed and unsure of how they would manage if the worst happened.

BC brought one couple closer together whereas for another husband and wife, the depth of her depression post-BC introduced unanswerable questions about how the future might unfold for them as a couple. The death of his wife - for the third couple - led one husband into acute contemplation of ending his own life and ultimately to a questioning of his construction of self-identity. Theme 10 discussed SC and what it meant for the men. Similar to the women in this study there was the suggestion of concern about SC because of the myth that to be self-compassionate was akin to selfishness. The male participant whose wife had died from BC was the one who seemed to have a clearer understanding of SC. He talked about SC as being "authentic" in his relationship with himself as well as in his connections with others.

Several questions confront a socially constructed Self when reflecting on living with authenticity. Those questions revolve around what it means to be authentic, and what, for each individual, would it mean to live an authentic life. The self the SO's 'knew' of themselves and their wives was deconstructed by BC. In the interviews they each talked of an inevitable confrontation with the question of who they would become as a result of changes to the self known up until this point. The turning point of a life-threatening illness had sowed the seed of doubt about whether the life lived up until that moment was in right order for them to flourish, or was it an egoic fabrication, or wasted time.

Fear of compassion from others, fear of self-compassion and fear of importance to others has been highlighted in research by Joeng, Turner and Tracey, (2015). These authors pointed out Gilbert's (2009) assertion that "people fear compassion because they are afraid they will relive painful childhood experiences wherein they did not feel the compassion they so desperately needed" (Joeng et al., 2015, p. 454). Fear of being self-compassionate has been linked to habits of self-criticism and a fear of diminished motivation to achieve (Joeng et al., 2015). The inner struggle between treating oneself with kindness as opposed to a stern and often contemptuous attitude toward one's own actions and feelings was an issue highlighted by two of the husbands. For both men there was a concern that echoed the perspective held by a significant number of the women interviewed. Their concern was that SC could become a useful pretence - a way to conceal selfishness. The fear of being judged as selfish presented the greatest roadblock to embracing the idea of self-kindness, or acknowledgment of the usefulness of bearing witness to unpleasant or difficult feelings.

Interviews with SO's indicated that their experience of BC meant each of them had unintentionally adopted a more compassionate stance towards themselves. Each of the SO's had initially felt challenged and confronted by the changes that came with BC. Their intimate contact with the disease and the domain of cancer survivorship led to eventual changes that each of them regarded as positive for their life post-BC. Without specifically focusing on the need or desire to be kinder to themselves, exposure to the emotional overload from that potentially traumatic event

had mediated a more moderate, mindful, and accepting relationship with themselves and others as they adapted to and met the challenge of BC.

Despite attempts to keep life normal they had each surrendered to the unanticipated power of BC to heighten their awareness of their unique interpretation of life. They began to question and release previous apprehension about emotionality being a sign of weakness. There was permission to surrender a certain amount of objectivity about relationships. Each of them had come to a turning point where a heightened awareness of their capacity to make informed choices became a strong guiding influence on their thoughts and actions. Any previously held fear that being authentic for themselves might result in lack of control over life, or separation from valued connections with people already in their lives, was able to be re-conceptualised. There was a re-evaluation of what had previously been prioritised, had held value, and been privileged. Qualities such as focus, control, and discipline had made way for their interactions to be equally informed by relational warmth and tending to self-nurturance. The conversations with the SOs pointed to previously unrecognised resources that could help them have greater tolerance for emotional distress. Rather than use busy-ness to avoid it, or alienate themselves from their own emotional responses to life events, the men came to a position of reshaping their relationship with their wife and therefore reshaping the way they related with themselves and others.

In summary, the reflections from the men on their experience of their wives' experiences pointed out the importance to include compassion-focused counselling interventions for couples who live with BC. The comments from the men also highlighted that in some partnered relationships there can be a deep but unspoken understanding of the suffering wrought in their partner through their partner's self-criticism. It appeared in the three men in this study that BC was the catalyst for them to accept their importance in their wives' lives. Importantly BC also brought an ability and willingness to re-prioritise life and to communicate to their life partner her contribution and importance in their lives.

7.10 Willing witnesses: Counsellors' perceptions

Counselling for emotional distress has been found to be useful as a way to help dis-empower self-criticism and to improve psychological distress (Banks et al., 2017). The results from counsellors participating in this study supported the claims made by Banks and his colleagues that counselling was beneficial for the person affected by cancer. There was limited current research available that discussed the reflections of counsellors about the psychological needs of women post-BC or the perceptions BCSs held about self-compassion. A significant amount of research was devoted to counselling for risk factors such as genetic family history, or alternatively discussed the benefits derived from specific interventions, as well as discussing survivor's needs for counselling interventions.

The reflections revealed in discussions with the counsellors was consistent with research that found poor body image was more closely linked to mental distress and impairment in the quality of life for BCS (Falk Dahl et al., 2010). The counsellors' comments were also allied to findings in research from Crompton (2003) about the importance for women to be provided with a safe 'space' in which they can be supported to reconceptualise their relationship with their body. However, comment was made that with the older BCS body image was not observed as particularly significant for mental wellbeing. This could be taken to refer to the physical attractiveness that women survivors may surrender as they age. In relation to body image concerns, the counsellors perspective was not supported by ideas from current research that outlined a broad array of personal responses woven into the concept of 'body image' for BCS and the critical need to monitor, assess and evaluate body image concerns (Fingeret, Teo, & Epner, 2014). Working to help decrease a tendency to cope with BC through disengagement with their emotional life meant the counsellors paid attention to finding ways to manage intrusive negative thought patterns and ways to support the integration of head, heart and reason was observed in comments made in several of the themes. The process of reconstruction of life was highlighted in the final theme extracted from counsellor interview transcripts. Statements made in relation to finding what held significance for a survivor and how they rebuild a meaningful life post-BC were related mostly to the perceptions of challenges faced by younger BCS as they negotiated return to

work, family commitments, and life stressors (Pudrovska, Carr, McFarland, & Collins, 2013).

One of the most important themes to emerge from conversations with counsellors interviewed for this study was their positive sense of the intrinsic value of offering psychological support for women survivors of BC. In addition to voicing their concerns for women's wellbeing in survivorship, the quest to provide quality counselling for BCS meant that the counsellors sought to understand the deeper psychological effects of BC. The counsellors expressed an existential issue that was reflected in the first theme – that of their professional desire for survivors to find a way to openly express their cancer-related concerns without an overriding concern for others' reactions.

Related to that first theme was the significant finding that the counsellors considered their work a privilege in a profession that afforded them the opportunity to bear witness to another person's life-death struggle post-BC. The counsellors wanted their work to activate and inspire women survivors to re-examine long-held beliefs and attitudes towards themselves. For example, in the second theme one counsellor talked about not wanting to 'band-aid' the emotional difficulties breast cancer generates. The devotion to providing for the psychosocial wellbeing of BCS Although all three counsellors interviewed supported women BCS with differing foci, each reported motivation, enthusiasm, and passion for their work.

Themes overlapped and presented an overview of the interactivity between counsellors dedication to their work, their robust commitment to helping BCS, awareness of the existential issues facing BCS, and the work of self-care. Self-care was particularly pertinent for facing the varying dimensions of distress exhibited by BCS. The counsellors were tasked with being able to sit with a survivor and manage their own reaction to a narrative shared by a client. The counsellor herself may have had BC, or a close relative may have died from the disease. These possibilities could mean feelings of vulnerability in a counsellor would be heightened. Being with survivors who talked of repetitive cycles of fear, negative self-evaluation, and feelings of disempowerment was discussed by the counsellors who admitted to experiencing personal challenges to their values and beliefs. This was especially so

when confronted by a terminal diagnosis in one of their clients. In addition, balancing the different needs of family members who attend for counselling, as well as finding language to communicate with survivors and their families about cancer in ways that were appropriate, sensitive, but clear, were discussed as needing focused attention from the counsellor.

Counsellors perceptions of their clients understanding of the difference BC made to their body and their life was reflected in the theme about a process of emotional healing and physical recovery taking time. Reflecting on the impact of physical changes as a result of either surgical treatment and scarring, loss of hair, or other after-effects of BC, the counsellors spoke of the contradictions inherent in survival. The theme about 'being real' highlighted the psychological relief women felt, and the rapid movement to feeling physically well once again when treatment was completed. That same theme exposed the torment some women experience at the loss of their breast/s, and the trauma inherent in visually reviewing the surgical scars to a precious part of their body.

The counsellors comments about their reflection of BCS limited understanding, or integration into their personality, of self-compassion, echoed findings about the desire for, and fear of, SC (Pauley & McPherson, 2010). The counsellors reflections included wondering about whether the fact that the idea of SC may initially run contrary to pre-existing ideas a BCS has about the advantages such a 'construct' would have for emotional wellbeing and reclaiming of personal vitality, as well as the disadvantages from being thought of as selfish or self-centred. Reports from their conversations with BCS indicated that the difficulty lay, to some extent in the women's grief and guilt that having once been the source of happiness for their family, they were now the source of stress and [implied] unhappiness.

Overall, the counsellors reflections were able to provide significant insight into and reinforce findings from interviews with women participants in this study. While not referred to using the same linguistic terminology, both counsellors and women participants spoke in general and in specifics about the hopeful search for a personally meaningful life in survivorship, and the accompanying disturbing conflicts that come from living with BC.

7.11 Chapter summary

In this study each of the participants was the narrator of their experience of BC from the point of view of experiencer, significant other/observer, and supporter. As a researcher the opportunity to uncover their descriptions and peer into the interpretations given by each participant allowed me a sense of being able to enter into each of their worlds and experience it from what Carl Rogers (1951) referred to as an ‘as if’ experience. The themes identified in each of the three groups of participants lead firstly to an improved understanding of strategies that had been adopted as self-regulatory mechanisms. Secondly, deeper exploration of the themes provided insight into the potential for SC to be included as a therapeutic intervention to support survivors of BC to maintain awareness of, safely explore, and understand their emotions.

The ‘place’ of beginning this discussion was the intention to explore and identify the current situation regarding self-nurturance prior to BC and whether that resource had been activated in BC survivorship. The intention was not an attempt to identify personality factors as a significant factor in the development of BC. The ‘ending place’ has been to identify a) how participants related with themselves in the past, that is, the stage from which they are emerging, b) their present relationship with self, and c) the stage toward which they are moving. A review of all three stages was believed to help distinguish the style of self-communication and whether SC could be a relevant support for BCS. The influence of unresolved personal issues was reflected in comments made by all three groups of participants. Self-compassionate communication was identified as something desired because it carried personal ‘rewards’ that might foster gentle, mindful attention to physical sensations and psychological adjustment. However, that same resource was viewed cautiously, in part, because of implicit memories of rejection of individuality by self or another. SC was identified as a resource that would likely move forward with personal growth through the existential challenge for BCS of finding who I am and who I am not.

With the intention to explore what it meant to live as a survivor of BC, relevant research questions were posed to women survivors of BC, significant others and counsellors who worked with women with BC. The questions called for reflection and consideration of what clinical practice might contribute to enhanced

emotional wellbeing (EWB) for women survivors as they age. The experiences reported by all three groups of participants highlighted the relevancy and usefulness to continue to explore how the practice of, and training in, SC for the profession of counselling can reach out, and into, women's experiences of living with the after-effects of the disease. The discussion of the findings question whether integration of the aspects of SC such as noticing and staying present to difficult emotions, could help BCS enjoy feeling more contented and connected within themselves, and endow a positive, nurturing effect on the self-relationship. The findings bear out that effort and practice is needed to adopt a caring orientation toward self, to stay present to oneself, be accepting of self, and see life in a bigger picture.

This research has been one way of aiding evolution of current authoritative knowledge about a well-reported and well-researched public health issue that can define the identity of a survivor from initial diagnosis until the end of life. Between the beginning and ending points for this study the 'adventures' of philosophical discovery and psychological realities also promoted clarity about the ways therapeutic interventions can provide extended emotional support for people faced with the immensely potent rigours of treatment for BC that is followed, for many, by the perseverance required to navigate survival.