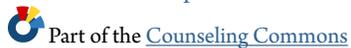

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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in
Western Australian women survivors of breast cancer

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Chapter Six

Findings

6.1 Overview

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

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

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

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

Pseudonyms have been used for direct quotations from all participants.

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

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

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

6.2 Women survivors of BC

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

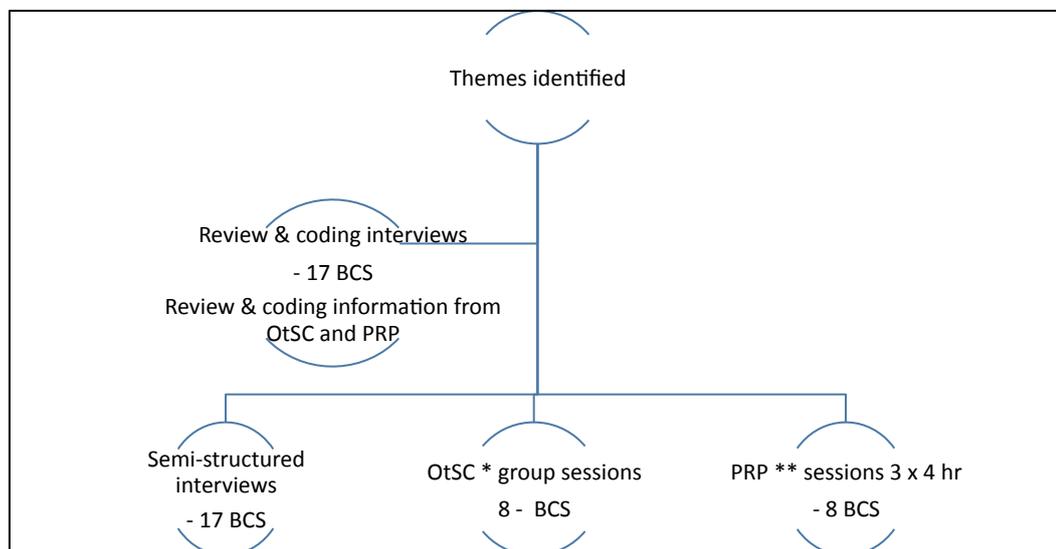


Diagram 7: A 5-step process of theme identification

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

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

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

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

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

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

M = married RS = recently separated

Table 2: Demographic data for PRP group participants

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

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

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

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

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

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

Table 3: Major themes for women participants

6.3 Findings from women survivors of BC

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

6.3.3 Support: “People care in different ways”.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Not all women enjoyed community support. Wendy commented:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Jenny added that:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

second year Lara resigned from a position she had held for many years, and began to involve herself in community activities that were more personally satisfying than her paid employment had been. As a ‘treat’ for herself, Lara said she had begun a daily ‘practice’ of walking by the river and observing pelicans. This was quiet time for her, time to think for herself, and to be by herself.

Stephanie decided that putting herself first meant to no longer worry about whether people in the social world judged her. Stephanie’s post-BC self was someone who felt comfortable to “*go out and wear the most hideous ... my pyjamas, my slippers, whatever ... and I’ve never once thought ‘oh, she’s looking at me’ ...*”.

In terms of putting herself first, a different experience was had by Jenny. Treatment had been completed and Jenny was on extended sick leave from her employment. In our discussion Jenny recalled that she had always found it difficult to prioritise her own needs and this remained the case once the intensive phase of her treatment for BC had ended. Combined with “*my chemo-brain*” Jenny said she felt incapable of returning from extended sick leave and taking up the challenges of her pre-BC work. There were financial imperatives in her life that made it a priority for her to return to work. However, in one way, Jenny was able to put herself first when she acknowledged her inability to pick up where she had left off. Acceptance of the fact that she would not return to work that had given great meaning to her life meant Jenny felt confused and disturbed. She was confused about whether the decision not to return to work was actually hers, or whether her employer had manipulated the opportunity so as to leave no ‘vacancy’ to which Jenny could return. Jenny described that confused state as one that made her feel as though she “*couldn’t believe this was my real life*”.

6.3.6: Emotions and personal growth: “*I’m a more spiritual person now*”.

Adjusting emotionally to the presence of adversity in the form of BC offered the women in this study an opportunity for both new vulnerabilities and new strengths to emerge. Some attempted to reduce negative feeling states and remained focused on more positive thoughts. However, avoidance of negative feelings did not offer a guarantee of a positive outcome. Participants talked about the process of assimilation of the experience of BC into their personal narrative. One way they

seemed to bring a new sense of meaning to BC was to use positive words in their references to BC. The results were, for some, life-changing, but for others fear and anxiety resisted any encouraging rhetoric that did not fit with internal reality.

Spiritual beliefs were experienced as positive, as well as a significant emotional support in their focus on survival, by two participants in the core group. Spiritual beliefs would be regarded as a support when a woman begins the isolating journey of dealing alone with BC. This may mean that women who pre-BC do not cannot draw on cultural resources that religion and spiritual beliefs afford, could struggle and ultimately experience more existential distress as they transition to survivorship.

Terri said she felt as though during the time since diagnosis and treatment she had found it almost impossible to fully process the emotional or psychological adjustment. She admitted that her first priority had been the need to concentrate on physical wellbeing. Emotions for Terri were generally experienced as uncomfortable. However, the spiritual and personal strength drawn from her Christian faith system was what Terri found was a mainstay during difficult times. Participation in this study was a way Terri considered useful in helping to explore any emotional residue. However, she admitted:

dealing with all of that [feelings] ... I have struggled with it ... um, I think I probably bury it rather than deal with it ... but I am thinking you can't carry on like this, you do have to deal with it.

Carole had formed the opinion that “*emotionally ... I don't think people understand how much it wreaks havoc with your system*”. Describing herself as someone who “*usually*” could “*control my emotions*”, Carole's BC coincided with the breakdown of her marriage and it was this combination that she felt contributed to a change from being a person who would “*not say anything, possibly take it in internally*” to someone who “*used to cry very easily*”. Carole admitted that prior to diagnosis her marriage was not flourishing and since having BC she found herself contemplating “*if that contributed to it [BC]*”. In the bigger picture Carole felt that she was now emotionally stronger than the person she had been prior to BC. Although Carole reported that she felt she had found more “*confidence*” in herself

since having BC, she also pointed out that her sense of self-esteem felt “*worse*”. She hastened to add that “*I don’t know whether its because of my marriage break-up ... and whether that’s come into it as well*”.

Beverley felt that emotionally she was “*really quite good*”. This personal evaluation was given from the perspective that she had dealt with significant challenges in her personal life which Beverley referred to as having been more “*emotionally upsetting*” than having BC. However, she talked about her realisation that for her lumpectomy was no longer “*like they’re taking out a mole or something*”. She went on to clarify her comment by saying, “*it’s a little lump yes, but with the surrounding tissue it’s not ... there’s a lot in it*”. She had found that regular reassurances from the breast surgeon that her breast was “*settling down nicely*” were helpful in giving Beverley a clearer sense that she was making progress in her recovery. This was important for her emotionally because she had not realised that physically “*the repercussions went on for so long*”.

Jenny’s emotional adaptation to BC took a distinctly different pathway to the majority of other participants in this study. Initially Jenny found herself experiencing a state that could be described as invincible. During that phase she maintained a tireless routine of creating clothing and quilts for her family, as well as being vigorously supportive of other women with BC through activities such as making bandanas and turbans, and organising a fund-raising event. Despite these efforts, Jenny expressed a deeper feeling that “*people misunderstand me, or are jealous of me*”. She described herself as “*one of the most talented people that I know*” who was a “*give-it-all person*” with a “*full-on approach*” that others may have felt threatened by.

Jenny attributed her ‘give-it-all’ attitude to her response to trauma experienced with the murder of her father some nineteen years prior to her diagnosis of BC. His murder meant that although she had suffered a “*breakdown ... after my Dad got killed*”, she also said that now “*I live every day to the fullest*”. Jenny had not always acknowledged herself as clever or talented despite being creative and musically gifted. She provided a more open description of herself as someone who had previously “*always felt second best because I HAD to get married*”. Jenny

explained that throughout her life feelings of self-doubt and low self-worth generated a drive in her to prove she was not second best. When still a young mother one way Jenny said she had attempted to subdue emotional discomfort of not being good enough was to push herself and achieve outstanding success in all areas of her University degree.

Jenny admitted that in the most recent time her sense of self had “*taken a battering over the last six weeks trying to get back into [work]*”. In that statement Jenny was referring to her attempt to return to her pre-BC employment. Her comment confirmed that she was aware her emotional state was not sufficiently stable to make re-entry into a work situation appropriate or advisable. One cause of her distress was that Jenny felt her “*touch with death*” had gone largely unnoticed by others. This had left her with the feeling that “*nobody actually cares*”. She felt alone in her despair at what had happened to her life.

Shirley had a different outlook and talked about feeling “*lucky*” because of her perception that her experience was not as physically or emotionally demanding as that of other women with BC. Her work with BC support groups had provided insight into the struggles of others. Shirley had then offset her experience by comparing it with that of other women with BC. Shirley felt that other women who may have had a sick child, an aging relative, or experienced a range of other environmental demands were not as lucky as she. Shirley said that, emotionally, she felt “*good*” although she admitted to getting “*cranky*” when tired. She now felt able to “*just take it slowly*” and reiterated that emotionally she considered herself in a good place and in the bigger picture considered herself more fortunate than others when she thought about her experience of BC.

Lara was pleasantly surprised by a feeling of being able to access her emotions more easily since having BC. Always able to feel empathic “*with other people’s feelings*” Lara talked about the grief she experienced throughout life through being open to other people’s emotional experiences. “*Now*”, she said, “*it’s come back to me big time*”. With this statement Lara was referring to her understanding that prior to BC she “*didn’t get the teary side of it*”, but used to feel a tinge of enviousness about others ability to express their emotions. She said that she

would think “*aaahhh, look at those people crying*”. Since having BC Lara’s experience of emotions had changed from a focus on what other people were feeling to being in tune and curious about what she was feeling. The shift in Lara happened, she said:

Because of the hormone changes. I’ve become more feminine. I suppose I’ve got more of those hormones or some flooding. But I’ve become a lot more emotional, I cry a lot easier and there’s more empathy [for myself].

Carole was pleased she had grown personally to the point that now “*if I don’t like it ... I better tell*”. Her commentary in the interview revealed a marriage in which she said she “*was probably not happy*” but had stayed with longer than she wanted.

Judy talked about the fact that she:

was always anxious when my husband came home ... what sort of mood would he be in .. I never knew how high to jump, and when I jumped it wasn’t high enough ... or it was too high.

Having separated from her husband Carole said she realised she now had “*a higher meaning in life which I didn’t have before*”. She added that “*deep down I’m much calmer than before I had cancer. I just say “ok, take a deep breath, and it’s ok”.*” Carole commented that through having had BC she had grown personally to the point where she can say “*no*” without feeling as though she needs to make an excuse for refusing an invitation to socialise. Despite her awareness of the threat to her health inherent in BC, Judy said that she was now able to feel excitement in each day. That excitement she said “*it’s like when you remember ... when you were a kid ... on your birthday ...*”.

Gemma was able to talk about now being able to feel the “*big sadness*” in her family; a sadness that had persisted for several generations. She also spoke of her belief in the danger inherent in not being able to let go of hurts and worries, particularly those hurts that happen in relation to the behaviour of loved ones “*because that can eat you up inside and make you more bitter and twisted*”. The description of herself was of someone who had always attempted to keep their emotions in check. Years before being diagnosed Gemma said she had felt clear that if ever she had BC her decision would be to “*just cut them off*”. However, she

confessed that “*its harder ... you’re not quite as flippant as that when it actually happens*”. But Gemma had found that her chosen belief system helped provide a “*sort of guiding thing*” that she felt was needed in order to navigate life without becoming overwhelmed by it. It was important, she said, to have “*some sort of guiding thing, in your head ... to help you to step back, to give you something else to focus on and also to centre yourself back in yourself*”. She referred to herself as someone not likely to “*fall apart*” but to consider things in logical and practical terms and be more interested in what needs to be done rather than what needs to be felt.

A brief comment by Nicole was very poignant. In her understanding of emotions and opportunities for personal growth Nicole felt that “*women are overly critical of other women*”. She was of the opinion that the very people who can show care for another woman were often not the ones to give that care. To highlight her point Nicole had also commented that she often felt more safe and trusting of workers in supermarkets and shopping malls than with people who should care.

Nicole said that optimism had declined significantly because of the fear of recurrence hinted at by a treatment specialist. She described her worsened state in the following way:

I think I’m worse now than what I was during the process, I think during the process ... my husband tells me, I was quite strong and because it is a process and you know what you have to do ... you’re spending your energy doing it and not thinking about it so much in November I had to go back and see the radiation oncologist and he said to me ... how are you coping with your Arimadex ... and I said, ‘oh you know, it stops side effects and goes well’. He replied ‘you know you can always stop it and save it til your cancer comes back and use it then’ ... and I’m like, I beg your pardon? And he says ‘you’re in the top 5% group for this cancer returning’ ... I go, ‘no’ ... I’m thinking am I hearing things ... and he said ‘you should be looking after your body’.

6.3.7 Relationship with my body: “It’s carrying my soul and my heart”.

Treatment for BC takes place in as rapid a time as medical resources can offer. However, survival and living with a changed body is a lifelong process. For the women in this study the time post-treatment brought with it a stark reality of what it was like to live with embodied reminders of BC. Some of those embodied reminders became obvious when they first looked at the scarring from surgery, when they encountered chemotherapy-induced alopecia, a fatigue that refused to accept denial, as well as unpleasant burns and blisters as a result of radiation therapy.

The women wanted to appear to their social world and family environment as though life was back to normal – the often-spoken-about ‘new normal’. While wearing a prosthetic breast was the choice of some participants, others said they were not perturbed by the lack of one or both breasts. Clothing was chosen to enhance the body as a whole rather than focus visual emphasis on the breast area.

Questions about the relationship with their body elicited a range of responses. In particular, when invited to comment, the majority of women in partnered relationships preferred not to comment about restoration of intimacy and sexuality. Perhaps the women felt they were of an age where engagement in an active sex life was either not of particular interest in the bigger picture, or the topic was considered too personal to discuss with me. On the other hand, the topic of sex and sexuality was openly discussed by two of the participants.

One example of openness about sexual intimacy was when a participant talked of her decision to have breast reconstruction because, she said, her double mastectomy would likely mean the end of an active sex life. Another felt frustrated and concerned for her husband because her experience was the surgery meant their experience of foreplay and sexual intimacy was significantly limited. Using the terminology of a baseball game, she commented that:

you’re actually asking your husband to go direct to second[base], or if you want to look at it as third base ... to basically go direct to third, and you have to bypass it because it's not there... that sensory part of you, is not there... so being in the mood is something that doesn't exist...

For a year post-BC treatment Jenny was proactive in improving her relationship with her body. Jenny mentioned that she was now eating better, exercising more, and said “*I am more aware how my body is feeling and I honour my body more*”. To explain this, Jenny said she had moved from a position where she “*didn’t like it[her body]*” and “*used to berate my body*” to a gentler position where she felt able to be kind to herself and say “*what a good body you have*”.

Prior to BC Jenny had struggled to manage her weight. She described her relationship with her body as “*a roller coaster ride of weight gain and loss all of my adult life*”. Since BC Jenny had come to recognise the ways her body reacted to particular drug therapy. She was especially aware that using chemical means to encourage sleep had a detrimental effect on her cognition. Cognisant of the variation in responsiveness to psychopharmacology, Jenny said:

so now I think ... good body ... so I think I look at it in a different way ... it’s carrying my soul and my heart ... it is incredibly responsive to chemicals, and so I kind of say to myself now, I’d better look after this body.

Even though reconstructive surgery had left “*big scars*” Jenny said “*I think I’ll be much happier with my body*”. During the interview she said her overall outlook was that “*there have been some positive changes with my body*”. However, Jenny’s positive outlook at the time of her interview was not able to be maintained. The transition to survivorship had not gone well for Jenny. When she joined the OtSC sessions and participated in the PRP, Jenny had been diagnosed with clinical depression. During the first of the OtSC sessions admitted to the group that she had attempted suicide twice in the several months between her interview with me and this first OtSC session. Jenny said she had used prescription medication in her suicide attempts in an effort to “*stop the pain*”. Initial optimism in the year since treatment, was replaced with a conviction that she had “*completely lost trust and connection*” with her body. Jenny also spoke of her depression as meaning she was no longer able to understand or regulate her emotions.

Some women disclosed that the relationship with their body prior to BC was one characterised by lack of awareness and lack of attention to the physical self. Some participants commented that looking after their body had not been a

“conscious choice” whereas post-BC there was a clear consciousness to focus on nutrition and weight control. For example, in talking about her relationship with her body Nicole said that prior to diagnosis:

I probably wasn't extremely respectful of it ... yeah ... I would work hard. I played hard ... I did have an awareness of it because I had hypertension ... but I didn't really respect it that much ...

Nicole went on to explain that prior to BC she was a person who, when her hypertension was at its worst would “*just take my tablets and get on with it ...*”. The experience of BC had changed her relationship with her body, primarily because of the onset of menopause. Menopause was a very challenging experience for Nicole who stated that on the ‘bad days’ her emotional state was like “*killing yourself because you don't want to do it anymore*” and “*you wish you were dead*”. Eventually Nicole emphasised that since having BC she now talked with her body. BC had brought to her awareness the need to be more considerate of the limits for her physical being.

Wendy talked about her post-BC vigilance about aches and pains that she would normally have dismissed:

I've always not had to worry about my body, I've been very fortunate I've never had to worry about my weight, I've never had to carry negative body image before, but now it's probably ... I am very in tune with it and ... I will even think I really feel like a certain vegetable or a juice, and I'll go and do it ... I'll listen to [it] ...

Prior to having BC Geneva said that she “*probably didn't give ... much thought*” to her relationship with her body. She admitted that the relationship with her body was one in which she would not worry too much about it and was “*probably taking it for granted*”. Post-BC her awareness had been raised so that Geneva felt more aware of those aspects of life that “*impinges on your body*”. She now was aware of the need to monitor and maintain nutrition and exercise. However, she indicated that “*I still don't look at myself very much*”. As a woman married, with adult and teenage children, a grandchild, and the responsibility for daily care of an aging relative, Geneva hinted at not having time to devote to a relationship with her

body. It was only some time after treatment had been completed that she felt able to take time to focus on her body. Opening up more about her physical wellbeing Geneva did say that because she knew other women whose BC had resulted in a mastectomy, she was easily able to “*rationalise*” the fact that one of her breasts was “*half the size of the other one*”. However, she was aware that “*I still don’t look at myself very much*”. Geneva felt she had not yet reached the point of feeling as though she was in a positive, healthy relationship with her body:

I’m still not there but I understand the impact much more I think, even though beforehand, you know, theoretically, that all of these things are good for you it’s only now that ... I actually have the time to myself because other things have been going on in my life ... to actually start to think about things ... whereas ... other people have done [things] that way, you know, almost from diagnosis. But I don’t feel like I could’ve done that.

The relationship Shirley had with her body was connected to how she felt she looked. When her body looked good Shirley felt good about herself. She “*liked to watch my weight and make sure that ... and I always had good bras, and ... so I... I knew that I looked ... good. I just knew I was OK*”. Shirley echoed Geneva’s comments about not feeling as though there was time to look after her body. She explained that with children and then grandchildren “*I didn’t really have time to think ... is my body ok, or, do I look glamorous*”. Shirley talked about the need, in the past, to “*always ... look nice*” at business functions for her husband’s employment. “*And now*” she said in a final comment about her body, “*I think, well, I’ve been through this little crisis. Now we’re going to get on with life. And that’s what I think ... I’m getting on with life.... and I’m making the best of a bad body. Well... It’s not a bad body (laughs).*

Lara was a slightly built person, and, similar to Shirley, talked about the clothes she wore and the pleasure she experienced when she lost a significant amount of weight in the year prior to diagnosis. She said losing weight meant she “*felt better about myself that I’d lost the weight and I felt better about having photos taken because I hated photos taken when I was much heavier*”. In discussion about her relationship with her body Lara said, “*I get angry with it sometimes because it can’t do the things it used to do*”. Physical endurance and strength was important to Lara

as with a husband who was often away with his work for extended periods of time, she had taken on responsibility for household repairs and maintenance. She commented that in times of doing hard physical work around her house she had felt exhausted but then unable to sleep. Those times of physical exhaustion coupled with insomnia left her feeling unsettled emotionally. Lara talked about being the one in the household who had always done the painting, paving, fixing the pump for the water supply, as well as mowing the lawn, although she admitted that since having BC she no longer mowed the lawn.

Overall, Lara was pleased with her body's capacity to still have a "*massive spurt*" every now and then when she could undertake maintenance work around the house. Some tasks involved her climbing "*up on the roof*", "*moving bricks*", and "*shovelling gravel*" and she talked about feeling angry with her body when "*it can't do the things it used to do*". Mental determination was highly valued by Lara and she clarified this by saying that "*the determination to get things done gets me through, and then I fall in a heap*".

Weight loss was also a topic Beverley spoke about although her determination was channelled in to a different focus to Lara's. She had undergone a hysterectomy six months prior to diagnosis. Prior to that surgery she felt "*I really was in a very good condition*". After abdominal surgery she felt that her body was no longer "*in tune*" and when diagnosed with BC she believed her body had not yet regained its pre-surgery healthy form. Beverley talked about the challenges she felt in relating with her body since BC. The experience of "*a period of ignoring it and just not looking in the mirror*" because of physical changes post-BC was a time when Beverley said she "*didn't want to have to worry about*" her body. She explained that her focus was "*more concerned with my mind and meditating and being able to cope mentally and emotionally*". Maintaining a weight loss, healthy eating, and exercise regime was something that Beverley was aware "*you're supposed to do*", however, she added that "*sometimes it's just too hard to do everything*". She made it clear, however, that her prime concern was to be able to function well mentally.

Terri stated clearly that she said she did not have a relationship with her body. And yet, attention to wellbeing and what was necessary for physiological wellness

was of particular interest to her. She laughed as she explained that her self-perception was that she was not “*pretty ... sexy or gorgeous*”. Instead, her perception was she was someone who had been “*ugly*”, “*fat*”, “*short*” and who “*never had any boobs, and still haven’t*”. As someone who “*stopped growing at about ten and a half*” when she went to boarding school, and who had neither the small waist nor generous breasts she desired, Terri carried the legacy of feeling that, when growing up “*it was always the pits having no boobs*”. She then talked about a less than adequate diet for a growing girl in boarding school, and that during those years she “*just had lots of medical sort of things*”. As a consequence Terri did not like “*feeling sick*” and credited her school experience with leading her “*more into a healthy way of living*” in her adult life. She talked about feeling extremely sick after chemotherapy, but then countered that comment with an assurance that not every experience of treatment was negative:

that was probably the worst ... just the sick feelings ... I didn’t really bother about my hair falling out ... it was the least of my problems, I had a lovely wig ... my sister had jazzed me up with all these scarves and I actually felt better than when I had my own hair ... (laughter) ... the hair was never a problem because I knew it would come back one day.

Since completing treatment for BC Terri felt that her relationship with her physical self had not changed. Her most important consideration was “*as long as I feel well in myself ... then the rest doesn’t matter so much. But I just don’t want to not feel well*”.

6.3.8 Self-worth, self-blame and BC: “*We’re over-generous givers*”.

There was a strong link between the evaluation the women in this study had of themselves and the self-worth derived from being helpful to others. Several participants hinted at the challenge in ever making a commitment to a life-long caring and respectful relationship with themselves. They suggested their self-talk was more often than not linked to what they should or could be doing for others – children, partners, close relatives, friends. An interesting finding was that the interviews with Significant Others also featured the notion that women held a very strong commitment to care for others that was life-enhancing for those others, but less so for themselves. A summary of the eighth theme would be that women in this

study were willing givers with recognition that they were over-generous givers. They drew attention to their perception that while women saw themselves as ‘givers’, men did not experience themselves in the same way.

Beverley voiced a clear opinion about socially-condoned beliefs she felt were unfair and unjust for women. She used the term “*over-generous givers*” to describe her observation that women, generally speaking, think of others first, tend to seek approval through doing, and seek to avoid self and other criticism. Beverley’s observation seemed to highlight the core of this eighth theme. She talked about the women with BC whom she had met:

I think from all the women I’ve met with breast cancer they seem to be the most loveliest women and they seem to be downtrodden ... you know ... they are the women that are too nice, they don’t stick up for themselves, they do too much ... you know ... they are looking after everybody else instead of looking after themselves.

Beverley had realised that she experienced a feeling of tension in her body when she was attending too much to others’ needs. Post-BC she now called it “*that cancer feeling*”. It felt uncomfortable for her and it was this tension that was a warning sign for her. Beverley wanted to eliminate the that cancer feeling from her bodily-felt experiences because:

My body let me down, because the way I’d been living was ... that was ... gave me ... That’s just my little ... what’s it called, my theory ... I’ve met lots of women. They all say I’ve done too much and I’m not looking after myself. Many ... not all of them ... And living their lives for their children.

Extending her description of characteristics of what she called an over-generous giver, Beverley clarified her reflection by saying she felt that women were more willing and capable than men of:

over-generous giving and denying themselves ... and their life and their needs, basic needs, they are very important. And not feeling worthy enough to speak out ... and have their needs met, you know, in an unequivocal sense.

Beverley added a caution to her expression of concern about the ways women relate with themselves. She commented that:

it's so easy to fall back into the role of looking after everybody else ... it can happen in a discussion or in a telephone call ... you can do it without knowing, it's so ingrained ... in your psyche ... very scary.

Jenny described herself as a person who was “*so hard on myself*” and sometimes driven by “*perfectionism*”. Jenny talked about “*still trying to do all that I used to do*”. As an example, Jenny mentioned a number of projects she had embarked on, one of them being “*making pyjamas for all my grandchildren*” during her radiation treatment. She stated that she had sewn turbans for other women with cancer, and created handmade Christmas gifts for family and friends. When it came time to consider a return from sick leave, Jenny said she felt “*in no fit state*” to return to work. By this time her all-over body pain levels had increased.

During Wendy’s interview she talked about the way that BC had affected her children. Her comments echoed those from other women, especially those who had taken part in all phases of participation. When talking about the impact of BC on her children, her comments indicated that there was no ‘safety net’ for her to fall in to when things went wrong. BC meant that Wendy had the experience of isolation from any support:

I was the person in the family who always held everything together ... I crumbled [because of BC] ... so there was no one there to pick up the pieces, really ...

Stephanie talked in very certain terms about self-blame. With the following words she made it clear that she did not blame herself for having BC:

My sister-in-law ... said to me that if I didn't fix my mindset that my cancer would come back ... she said that it was my it was my ... connection with my mother ... that gave me cancer in the first place ... and I was sitting there and I thought to myself you're nuts ... if I thought for one minute that I gave myself cancer in any way I'd go crazy, I would go nuts.

Gemma held a similar view to Beverley, and also raised concerns from her experience that women were the ones who *“will often just ... it’s the serving everybody else ... it’s our make-up is like that”*. Gemma emphasised that her comments were *“very generalist ... I’m talking very much in general”*, however, highlighted *“but men: it’s me first and then I’ll look after everybody else”*. Growing up under the influence of a grandmother who *“had very strong beliefs”* and a personality Gemma described as *“very rigid and sort of very emotionally ... almost uptight”*, Gemma had finally reached a stage in life where she felt *“I’ve developed a bit more of a healthy self-esteem”*. Emotion was expressed through tears and long silence when Gemma spoke of her own growth and the realisation that her values and beliefs were worth fighting for, and that her opinion did matter:

... and just learning you’ve actually got to stick up for yourself because if you keep trying to do something for someone else you totally can compromise yourself ... so I’ve actually had to learn to fight ... which is a big thing, because it would be the last thing ... I would never want to confront or fight. But then, I think what I’ve realised is ... there are things worth fighting about ... fighting for.

Additionally Gemma was aware that she had grown personally to the point where *“I try not to be judgmental about other people’s good things and bad things, and just go ... it’s all ok”*. What concerned her from that statement was that *“I don’t say that to myself enough”*. Her commentary continued with a statement that women, in her view, tended to be nurturers who were more often than not inclined to regard the needs of others as more important than their own needs. As she spoke, Gemma acknowledged her impression that when a woman has a *“great”* need to do what she called the *“noble thing”* and relentlessly attend to others’ needs, then an external *“expectation”* can be unconsciously activated in the minds of others. In recognition of what she had just said, Gemma added what seemed a comprehensive perspective on life. In talking about the potential for resentment to Gemma stated that *“you’ve got to actually let some things go”*. Her idea was that being a little more philosophical about life and embracing a set of guiding principles was important *“to help you to step back, to give you something else to focus on, and also to centre yourself back in yourself”*. Gemma offered a sense of her own values and beliefs when she said:

What I think I've learned is ... I didn't judge this before ... you can't totally blame ... if something doesn't work out and your expectations aren't fulfilled it may not all be your fault ... there's way more variables occurring that could have had something to do with that.

6.3.9 Unexpected benefit: The gift of cancer: “It’s probably been more positive than negative”.

The perspective that BC could be a ‘gift’ to the life of the person treated was spoken about by several participants. Of the 8 women who completed all three components of participation in this study, 6 had worked post-BC to create lifestyle changes that would bring health-related benefits. The ‘gifts’ they spoke about were improved diet, increased exercise and making more conscious choices around care for their physical body. Additionally, women in this study used the word “*gift*” when talking about their journey of self-discovery that had begun from having had BC. Even though each of the women had expressed challenges in adapting to their changed lives as a result of diagnosis and treatment, all but one found their experience of cancer presented an unanticipated opportunity for personal growth.

Geneva reported that in terms of her physical wellbeing as a survivor of BC, “*funnily enough its probably been more positive than negative*”. Geneva felt that overall her experience “*personally*” of BC was not a negative one. The entrance into her life of BC was the event that interrupted her regular routine, and:

what its done is give me permission to do what I need to do to get myself into a better place. And a lot of people don't ever have that opportunity or that incentive. And so even though I'm not there yet, I still don't look on [BC] as a negative experience.

Geneva admitted that a positive outcome was the loss of her hair, and this, she said, was “*fantastic*”. To clear up any misunderstanding about her comment, Geneva went on to say that “*now its grown back grey, and it's a nice grey, and I don't have to dye it anymore*”. Eliminating the need to continue to dye her hair was not the only ‘gift’ of cancer for Geneva. “*Being able to take time out for myself*” had given Geneva the opportunity to reach the conclusion that she was “*allowed to be there and listen to people*” without necessarily needing to have or express an

opinion. For Geneva, the realisation that *“I can just listen”* was *“really important”*. She talked about the internal struggle to give herself permission to step aside from being the person who could provide an answer for an emotional dilemma, or being the one to provide comfort for someone in distress. Geneva had the view that *“people aren’t static ... people are dynamic and they’re changing all the time”*. Her comment related to her own growth; she was growing and changing from who she was prior to BC. Geneva talked about being uncomfortable and comfortable with the changes in her attitudes and values.

Beverley did not use the term ‘gift’, however, she referred to a personal discovery from her time with BC that *“my closest relationship is with my husband”*. She felt their experience as a couple going through BC had helped her shift to a position of greater acceptance *“that he is who he is, why he is, and that’s just how it is, and he might never change”*. Beverley said she had discovered that to keep hopefully expecting something different from a long-term relationship than what is on offer is *“a definition of insanity”*. Instead, she felt that having BC had helped her to discover that the relationship with her husband is *“there to stay if I choose to want to continue”*. With emphasis she repeated *“... if I choose”*.

An unanticipated benefit for Beverley was the awakening of her spirituality. Being confronted with the prospect of death had brought her to the place where she was able to say *“I’m a more spiritual person now, and I’ve got a good understanding. I’m really very happy that I had that ... that I’ve gained that”*. The opportunity for Beverley to open to becoming a more spiritual person was an aspect to life that she said *“I think is really important”*.

Although she said her statement sounded like *“a cliché”*, Gemma said that she realised since having BC she was *“a bit stronger than you think”*. She spoke also of her recognition *“maybe that I can actually get through a lot ... and perhaps actually that I was a lot more practical than I would’ve thought”*. The ‘lens’ through which Gemma viewed life was one that drew her attention to wondering whether having BC would mean *“you’re gonna fall”* into a distressed emotional state in which she would become *“a mess”*.

Gemma was also thoughtful about not judging any other person's emotional expression. She advocated a *"non-judgmental approach"* before making a decision that someone *"is appearing to fall apart"*. Emotional expression she considered as *"maybe that's a good thing because they are expressing themselves and that is actually quite appropriate for what's just happened to you"*. In terms of her future, Gemma's characteristic philosophical approach to life helped her *"just go la la la"* and at the same time apply personal, internal wisdom to her situation. Her attitude was to find out *"everything you can"* but then to have *"the wisdom to go ... don't go there"*. From this thinking she had made a decision not to find out a prognosis for her BC, however, still felt confident that she was not ignoring reality completely:

I might not be in that statistic ... you can't live your life what if, what if. You just have to go – I haven't got it right now. I just say I haven't got it, I don't have cancer and I'm not going to have cancer. So I don't even think [about] whether I'm gonna make five years.

Carole's 'gift' was that she discovered *"I'm a fairly strong person"*. Because her marriage was breaking down at the same time as her encounter with BC she felt *"determined to get through this and be healthy again ... and I am determined to do that"*. Doing some of her own research about BC: *"what causes it, and what could possibly be the cause ... and so on"* became Carole's ally during her experience. She said, *"I did a lot of research"* and often found herself wondering why other people with cancer did not *"get out there and try"*. In addition, BC had *"made me a lot closer with my children"* Carole said. In particular she highlighted the relationship with her son who had changed from rarely making a phone call to Carole to calling her twice a day post-BC. An emphatic statement from Carole was *"I'm gonna beat this"*. As if to underscore the depth of her intention, this statement was repeated, and after a pause, was followed up with the words *"That's all"*.

Wendy spoke of developing *"deeper friendships with people who were not in my social group"*. She followed up this statement with a *"Yee-hah"* – a way of indicating that Wendy felt satisfied that her social connections were supportive for her. Two women Wendy had previously known but had not been friendly with, had become, post-BC her closest confidantes. She said she valued their honesty, openness, and capacity to talk with her about her feelings and her health in a

straightforward manner. Wendy intimated that since having BC she did not want to be forced, or convinced, to step out of a reflective, and sometimes melancholy, state. She found herself drawn to spend time with people who could acknowledge and accept that *“I still feel ... still sad in myself ... and I don’t feel happiness ... I really struggle with it [happiness]”*. Wendy had found herself avoiding social situations where there was *“all this positive stuff going on”*. For Wendy, self-nurturance was to be able to stay with her feelings and not try to divert herself from her emotional life no matter how challenging those emotions were.

Terri felt as though BC had led to developing closer connections with some friends *“who were really, really helpful”*. She spoke in a softer tone when referring to new friends made when attending a BC recovery group. In particular she talked about one younger woman she had developed a strong emotional bond with, saying *“if I hadn’t had cancer I would never have known [her]”*. The friendship and support received from others was something Terri regarded as *“precious”*. She also talked about the relationship *“between me and my sister”* as *“just wonderful ... absolutely wonderful”*. *“It [BC] changes how you relate to people”* she said. Terri associated the fact that people *“will open up more”* to someone who has had cancer with her observation that people in distress may be able to identify more closely with someone else whom they perceive has had to go through *“something that’s hard”*.

BC served not only to deepen and extend Terri’s personal connections with friends and family. Terri disclosed that she now realised the *“importance of listening to people”*. Listening was something Terri had recognised she *“never did before ... because I didn’t have time”*. BC had also had a positive influence on the relationship with her husband. Not only were there changes in a positive way in how her husband related with Terri. She said that because of her BC *“I really got to see that I was precious to my husband”*.

Lara’s sense of humour helped her talk about what she had discovered from her experience of BC. Even though there were *“annoying”* aspects of recovery and survivorship, Lara smiled when she said *“I sort of think, I look at it, and think ... and I think ... I’m above ground anyway”*. She pointed out that over the last twelve months she had started to express herself more assertively and be more vocal in

situations where what someone else was doing, such as smoking in a no smoking zone, was the cause of discomfort for her. Lara said that in relation to the way she would think about or judge situations she was *“starting to turn things around”*. She now was able to see *“there is another purpose and sometimes there is a reason things didn’t work out and sometimes it’s for the better”*. She continued by saying *“I look at cancer ... though it’s a stupid thing to say ... as a gift”*. Lara referred to cancer as *“the wake-up call I needed to have to change things in my life”*. She talked about BC as generating a *“major shift”* in her thinking. The major shift Lara experienced had helped decrease a tendency to ruminate and then empowered her to change aspects of her life that were unsatisfying and worrying. Lara had recognised that she was prone to investing significant amounts of energy to things that did not warrant such a substantial amount of her time and focus. Describing her time with BC she said *“for me it’s actually been a blessing. I’ve relished this time on my own”*. She felt that *“I sort of found myself, basically, in this last year”*, and had been able to recognise *“parts of me that I like and ... parts of me that I didn’t like”*. Lara expressed feeling more relaxed about life in general, as well as commenting that she felt more able to see life events and their purpose in a bigger picture.

Jenny echoed the comments made by other women, that *“I’m stronger than I thought”*. However, Jenny extended her comment by saying that through BC she had also discovered she was *“weaker”* than she believed herself to be. She became emotional when talking about feeling vulnerable and realising that a key task for her was not to push her body so hard, and to develop a kinder self-dialogue than in the past. Her father, she said, had represented the *“perfectionist”* in her family of origin, and Jenny had worked hard to emulate and meet her father’s standards. Having BC had confirmed for Jenny that she was accepted, completely, just as she was and that *“my husband loves me”*. She intimated also that her four adult children had demonstrated, in practical ways, their willingness to support her in any way possible. An example of this was their decision to shave their heads, wear pink and attend a social event Jenny organised to raise funds for cancer research.

Shirley felt lucky to be alive and felt grateful for the changes to her life since being diagnosed. By way of example Shirley commented that she and her husband had travelled more since her BC. She referred, in general, to life being too short to

use time and energy concentrating on aspects of life that had no meaning for her. Importantly, Shirley commented about a feeling she now enjoyed of being very capable to manage her own life. *“I do more, I stand up for myself more than I used to”*.

Participants in this study were determined in their resoluteness to acknowledge new-found personal resources and ‘strength’ as a positive additive to their life and their relationships. As one participant commented:

I think what it does ... a little bit ... is it makes a little bit of you permanently grown up ... you know ... you’ve got this really grown up thing you have to deal with.

6.3.10 Self-compassion – “Learning to say no”

The concept of self-compassion was responded to by participants in two ways. One way of responding was from an understanding of the emotional implication of being self-compassionate. For instance, women talked about not treating themselves kindly. They voiced their concerns that being self-compassionate would mean selfishness, or facing an awareness of not having received compassion from those who could have or should have given it, and not knowing how to be kind to themselves. The second way of responding emerged from an intellectual understanding of the concept. In those instances the responses given gave a rhetorical comment that to be self-compassionate, that is, to think well of yourself and be kind to yourself, was considered a helpful resource for living well.

Self-compassion as an automatic aspect of the self-relationship was not an entirely welcomed, or open, topic for discussion. Fear and uncertainty about self-compassion, as well as fear of receiving too much kindness from others, found its way into interviews and group discussions. While the women welcomed support during the active phase of their disease, once treatment was completed and they felt as though life ‘should’ return to normal, there seemed a tendency to return to a state of being unconsciously less than kind to themselves albeit in subtle ways. The paradox that faced this research was that while SC has been found in research to be positively associated with relief from depressive symptoms, could SC be expected to

automatically decrease psychological distress through awareness of and practice of self-kindness and mindfulness.

Overall, however, the responses given by the women participants, meant this theme could be summed up as commentary on a process of the BCS learning to say ‘no’ to others in their lives. Despite this positive change, it seemed that the women were not yet able to say ‘yes’ to themselves. The commonalities in the participant’s experiences revolved around the capacity for self-criticism to be the source of motivation and suffering. Uncertainty about how they would feel about themselves if they eased their concern for others was another commonality in the reports from the women. The discussions about the meaning they made of the term self-compassion appeared to stimulate reflection on BC as a place to begin to know and understand themselves, maybe for the first time.

When asked for what the term self-compassion meant to her, Carole said that she thought “*some people might think it’s a woman thing*”. She continued by saying that she because her children were now older, being kinder to herself was more possible. Carole commented it would be very hard for her to be self-compassionate “*with children who were younger*”. Carole talked about thinking well of herself only since having BC. She said self care was “*something that I’ve learned to do ... I never understood any of that before*”. Prior to having BC, Carole said she thought taking care of oneself was “*a whole lot of hotch-potch and baloney, whereas now I strongly believe it*”.

Shirley’s translation of the term self-compassion was “*not to be too hard on yourself*”. With a loud sigh, she explained what she meant. “*I’ve always thought I had to do things, you know, I had to ... had to be the mainstay of things in the family*”. Shirley stated clearly that “*mothers do that*”, and recalled a time pre-BC when she had been hospitalised for several days with hepatitis. On returning home she was surprised when one of her adult children offered to cook the evening meal. Shirley’s immediate internal response to the offer was “*but ... I’m home ... it’s expected of me*”. However, she went on to state that she was able to accept the offer of help even though it did not feel ‘right’ to do so.

Shirley described being “*very critical of myself at times*”, and said she was a person who liked things to be “*right*” and liked things “*to be perfect*”. Locating her thinking to life post-treatment, Shirley said, “*but now, blow it ... if it doesn't get done, it doesn't get done. I've learned I can't do everything*”. At the same time, Shirley laughingly referred to herself as a person who was “*not very bright*”, and yet, when faced with a challenging task, Shirley said she found it helped to simply keep telling herself “*you can do it*”. The subtler self-talk in what Shirley said was that even though she may not be very smart, she could still achieve something or complete a task.

Shirley described a prevailing attitude in her earlier life as one where she “*always thought everything had to be perfect, and people always expected it of me*”. When talking about her relationship with her husband, Shirley recognised the feeling that she now had to be a perfect wife who could “*be there for him*”. She saw her role as being able to alleviate fears he had about her survival. Advised by a friend that her husband's concern and control of her was only because he loved her, Shirley responded with “*but that's not loving. I don't think that's loving. I think that's possessing*”. Shirley did not want to be regarded as someone who was now permanently unwell and yet this was a perception of Shirley carried by her husband. “*Smothering*” was a state that Shirley referred to as the thing “*I can't cope with*”. Specifically, she felt that her husband's permanent state of concern and worry about her wellbeing and her capacity post-BC to handle life was not helpful to her. Shirley said, “*I don't have to be looked after. I don't have to be told. I'm a big girl now. I can work it out for myself*”. Shirley was strong and clear when she spoke about the effect controlling behaviour can have on relationships. She did not like the feeling of being controlled and said, “*Why should I give up my life ... I just got it back... I've just got my life back!*”

To illustrate ways in which she had been able to treat herself in a kinder, gentler way in recent times, and work life out for herself, Shirley talked about now taking extra time to read a newspaper in the mornings, or giving herself time to complete a project. She mentioned allowing herself more time to complete tasks, and to illustrate her point, talked of Easter eggs for her grandchildren saying, “*I've still got the Easter eggs to give them ... and it'll be the middle of June and they'll get the*

Easter eggs". She also gave an example of being able to push back against internal, an external, criticism when on a recent weekend away with long-term friends. Shirley decided to take on the task of cooking breakfast for the group of friends each day. When challenged by her husband that Shirley was not preparing breakfast in the same way as had been done by another group member (someone who had been the group's breakfast cook for many years), Shirley simply said "*Well, X is not here, I am, and this is how I do it*". This comment marked a significant milestone in Shirley's willingness and capacity to step forward into a stronger sense of self. Shirley's comments to her husband indicated that she was able not to take on criticism, but to be more self-compassionate and appreciate her way of doing things.

Gemma interpreted the idea of self-compassion as "*sort of like ... putting yourself first ... but also being a bit more ... well, perhaps its understanding ... of your faults and strengths maybe ... being a bit more forgiving of yourself perhaps*". Gemma also said "*and I still don't think I do that very well*". She described herself as a work colleague always willing and able to get things done. Since having BC Gemma had observed changes in the way she related with her work and with workplace colleagues. She noticed that she was "*starting to say 'no' in the workplace a bit more often in small ways*". Gemma tempered that statement with "*I don't mean a big ... NO*". But change was not easy, and Gemma explained that although she was making small changes "*I always fall back into the yes, yes, yes ... yes, I'll do this for you and I'll do that for you*". What stood out for Gemma was that falling back into old habits and doing things for others only resulted in increased levels of stress for her. To her, self-awareness meant that:

Recently, I'm standing back from it and seeing that you can sometimes be taken for a ride by people, and you don't realise that you're being led down a garden path. And you all of a sudden realise you're in a stressed heap of mess in the corner, and you wonder how I got there. And you realise I should've said 'no' right at the beginning.

As she talked, Gemma recalled the example set for females in her family. She felt that the pattern of caring for others' needs had been "*hugely*" influenced by the example set by female members in her family of origin. "*There's a bit of a thread ... but ... my Nanna to my Mum, to me, not so much my daughter I think it will finish*

with me ... she's a different personality actually ... but you know my Nanna and my Mum and to a degree my Auntie". Gemma felt the example of being of service to others, particularly men, was, to some extent, gender specific and explained: "It's women who will often just ... it's the serving everybody else that you ... it's our make-up is like that". She was able to clarify her comment when she said, "I definitely think there's a family thread and it's almost hard to unlearn ... its almost like an accumulation of a family trait ... not even just your own nuclear family". Gemma went on to talk about the ways in which relationships and experiences of traumatic loss within her family had a negative influence on patterns of relating that had then been passed on to successive generations. Gemma became quite emotional when talking about deaths and losses that had shaped her grandmother's and mother's worldviews. She felt that self-compassion had been non-existent in her mother's and grandmother's time. Gemma did not want to be specific about the details of her comments about family tragedies. She simply wanted to make the point that she was convinced overwhelming grief from sudden and catastrophic loss for her female ancestors had robbed those women of being able to think of nurturing themselves:

I've talked about this a lot with [a relative] ... and what relationship she had with her mother who's my Nanna ... my Nanna lived with my family for about 34 years after ... so I've had a close relationship with [her] ... and when you hear everyone's life story ... there were things ... in different generations that influenced how that person is in their life and ... that consequently influenced that person and also what was happening at the time ... I'm talking like big world events ... like wars. and people being lost in wars ... and the threads of the families after that.

With laughter and chuckles Beverley expressed a philosophical view of self-compassion being dependent on self-worth:

it's sort of all screaming around in my head How nicely you treat yourself ... and I think that I haven't been really self-compassionate. I'm more compassionate to other people than I am to myself ... I think that's tied in with where I'm at with my feelings of worthiness, you know, if I'm feeling more worthy then I'm likely to be more compassionate to myself.

Beverley talked about recent fluctuations in her sense of self-worth and highlighted that her participation in counselling had helped enhance her overall capacity to regard herself as of value. However, Beverley identified that her sense of self as valuable and worthy was not yet stable. She illustrated this point by saying that after initially doing well, *“then I hit a wall with all these other life situations. So that’s kind of plummeted a bit, and now I’m coming back up with that”*. For Beverley there was a certain and physically obvious discomfort with the idea of giving emotional support and compassion to herself. With lots of pausing, reflecting and searching for the right words, she said:

If you start thinking about being compassionate to your self, then you might end up in tears ... because ... it might be seen as being sorry for yourself, you know, once you get a bit too close, and its ... oh ... being a bit nice to you.

Beverley felt that having BC had changed the way she made decisions. She felt less critical of herself and *“less hard on myself”*. However, even though she had engaged in a personal counselling process to recognise and overturn a habit of not considering her own needs, she said, *“but I wouldn’t really call that self-compassion”*. A couple of moments later, after another long pause, Beverley said, *“... but then maybe it is...”*. Despite her willingness and capacity to review the basis for her decision-making, there was, for her, risk linked to being self-compassionate. Beverley’s concerns about what being self-compassionate might mean for her related to self-awareness. She realised that if she became aware of what she needed in life then by default she would also become acutely aware of what she was not getting from life. To willingly expose herself to emotional suffering by acknowledging the absence of self and other care for her, meant she would be challenged to take action to remedy or adjust her circumstances. Beverley commented in the following words:

Then you know what you need, and you know what you are not getting ... and then that can make you feel very vulnerable. And if you feel too vulnerable then it might be too much ... then you can’t carry on with what you know, with what you have to do so, in a way, maybe ... that might be why I’m squirming when you say self-compassion.

Comment from Wendy indicated that BC had forced her to question the way in which she prioritised outer demands. She indicated this with the following comment when she responded to a question about her understanding of self-compassion. In this comment Wendy acknowledged that before being diagnosed with BC she was a ‘giver’ who was a willing helper to others:

I know possibly before I was unwell I would've probably given so much more to others than to myself ... [I'm] a very compassionate person ... but when you go through something like that [BC], if you don't have self-compassion I think you would struggle ... really struggle with your sense of who you are, just making yourself feel at ease.

Wendy then said that on reflection, she had never regarded her needs as important. For her, parenting was paramount, particularly with a child with special needs. However, she was aware that self-care was important to enable her to care for her son:

I think possibly that I didn't spend enough time with myself, prior to breast cancer ... I didn't really spend the time it took to nurture my body and my mind, like ... I felt I spent a lot of time parenting ... so what I learned about myself was yes, it's ok to go and exercise and the children will be fine ... and it's ok to go and do this ... it's giving myself permission to ...

Geneva's understanding of self-compassion was linked to her decision to give herself additional time to decide whether to return to her pre-BC occupation. She was aware that no one else could either give her permission or refuse her the right to stay away from a career that she knew was both physically and emotionally demanding. To be self-compassionate for Geneva meant:

Basically loving yourself for who you are, and having an understanding of how life works so you're not too hard on yourself ... and just being able to forgive myself the way I forgive others is another thing, I guess.

When the interview drew attention to times of self-compassion, Lara asked what the term self-compassion meant. Her interpretation of the term was that compassion meant “*how you feel about yourself, whether you can do the self-nurturing side of things*”. The term ‘self’ to Lara meant something related to “*how*

you pamper yourself". Her decision not to return to work, despite the fact she said she had *"fought heart and soul"* to continue with her career post-BC, was a situation Lara looked upon as being self-compassionate. Lara also talked about the point she had now reached where she had told her husband and family she was not willing to be the person to prepare and present *"a full-on English Christmas, you know, turkey, the whole works"* every year. She mentioned the Christmas season as her most *"physically exhausting"* time of the year because *"I'm doing the shopping, I'm getting the house decorated, I'm cleaning, I'm cooking"*. Confessing that *"I'm sick and tired of doing Christmas"*, Lara pointed out that since having BC she had found herself able to retreat from being the one whose efforts make Christmas a special event for everyone in the family. She mentioned that although it had not happened yet, *"I expect one of my children to take over ... because I did for my mother"*. She also indicated that she no longer felt guilty about shifting her focus at Christmas, from others, to herself. Self-compassion for Lara meant taking a step back from feeling responsible for others' wellbeing.

Carole said she had *"not thought of the word self-compassion"* and highlighted that some people might interpret self-compassion as being self-indulgent. She talked about self-compassion in her life in terms of her focus on healthy eating and taking care to look after her physical needs. She commented that physically, BC had *"taken ... years to get over"* and that it had *"taken a lot out of my heart"*. This comment was Carole's way of saying that all her energy had been spent in recovery. Physical stamina was important to Carole and five years post-treatment she said after-effects were only then beginning to diminish in ways noticeable to her. Fatigue was one of the residual concerns for Carole. From her comments, it seemed that being self-compassionate would have been difficult to integrate into daily life up until the time of Carole's participation in this study. It seemed as though Carole had only enough energy to manage day to day tasks without what might have appeared to be an 'add-on' to the work of survival. Towards the end of her participation Carole announced to the PRP group that she had decided to take an overseas holiday on her own – something she would not have previously imagined having the energy to do. For Carole this was self-compassion; to trust herself and her body, and to reclaim joy.

Self-compassion was something Jenny said *“hasn’t been very high because I’ve been caring for everybody else”*. She emphasised that with her diagnosis she felt other family members *“didn’t know how to cope with it”*. The result was that Jenny said she was the one to take care of other people’s feelings. She indicated that throughout her diagnosis and treatment she was the person who supported other family members through their distress.

Jenny’s internal dialogue left her somewhat confused about her emotional experience. At times when she felt there was minimal feedback from those around her to let provide evidence of their awareness of what she had been through, self-compassion was obscured by self-doubt. Jenny would query her reaction and ask herself *“how can you be so upset [by] how other people feel, it’s not about them”*. She admitted she would then internally question herself and engage in self-criticism for feeling the way she did:

Then I start thinking, oh, maybe it’s not as bad ... maybe I’m overreacting, and what’s happening to me isn’t that significant, maybe just overreacting ... and I shouldn’t have these feelings. I’m fine ... build a bridge and get over it.

When self-compassion was mentioned Stephanie said honestly that *“I’m not quite sure what that is”*. She then defined self-compassion as *“how I think about myself, or do I blame myself, or do I look after myself”*. She felt that she could be self-compassionate by making sure:

I’m thinner, fitter healthier ... that I don’t drink alcohol, that I don’t smoke and that I live the rest of my life to the fullest, so that however many years I’ve got left - 5 minutes or 50 years - I get to the end of my life ... and go, yep I did that, I lived my life the way I wanted to, rather than get to the end of it, and go, uggh, didn’t quite do that.

Nicole responded to the term self-compassion by defining it as *“giving yourself a break ... allowing yourself to feel upset, or accepting whatever ... about your health and your body”*. After an extended pause in the conversation as she began talking about her love of going shopping and her peace of mind that her husband was supportive of her being *“a bit of a mall-hopper”*. We came back to the

question of self-compassion and Nicole used that as an entry point to talk about her main concerns prior to BC had been her teeth and her weight. The topic of self-compassion was clearly one that had made Nicole feel a little uncomfortable. The topic was not raised again. When Nicole resumed the conversation she talked about judging herself for not getting better quicker. She commented that she had expected that she would recover more rapidly and be able to “*get back to work and contributing*”. While not talking about self-compassion Nicole also talked about having had 5 children, moving house and having a “*meltdown*” that resulted in her taking two weeks off work and making changes to her work hours. While the formal term self-compassion may have activated some vulnerability, Nicole’s story did indicate her capacity to stop when things were not right and make necessary adjustments to ease any stress.

6.3.11 What women need.

What women participants found to be helpful for themselves, and what they felt women, in general, needed was one and the same thing. Their ideas emphasised the value of interpersonal aspects of relational experience. What they felt women with BC needed was a way to remain consciously connected to self, one’s body, loved ones, family life, and even their workplace as they move through an experience that could generate a state of chronic disconnection from self, the body and others. As a group, the women highlighted the socialisation that had happened in their life. That socialisation led to a sense of responsibility for taking care of others in practical ways as well as caring for others’ emotional life. The result was an inclination to engage in relationships where they were the ones to provide empathy and emotional nourishment. Counting on others for help was, in general, not the preferred model for living life pre-BC. Therefore, a capacity and willingness to allow themselves to receive care and empathy brought the opportunity for growth and development.

Beverley had a background in nursing and prior to her own diagnosis had nursed in an oncology ward. She remembered carrying out suture care on the staples used in mastectomies and felt that the women needed psychological care. Her observation was that what the women needed most was time to talk about their experience with someone who could listen. Beverley’s impression was that “*I think women do like to speak, they like to be heard*”. However, as a nurse, when caring for

women with BC she said *“there was no time to sit down and have a chat”*. Beverley felt strongly about not *“pointing the finger [of blame]”* and expressed caution about any suggestion to a woman *“you’ve got breast cancer because you haven’t been looking after yourself”*. Beverley’s opinion was that society was quick to *“put the cart before the horse”* and, in general, was slow to accept that BC was not a by-product of failure in women to take better care of themselves. Beverley suggested that what was needed was change to societal attitudes about women’s illnesses *“that’s a very big thing to change, isn’t it ... because this is the way it always is”*.

Lara regarded *“support-type groups”* for women with BC as *“just the best thing”*. Her idea was that it was highly beneficial for women to be able to get together and share their experiences. Lara also highlighted the difficulty for a person to talk honestly and openly about their cancer experience *“with someone who hasn’t been on that journey”*. She felt that no matter how understanding and supportive other people wanted to be, a depth of connection was really only able to be encountered with another person who had gone through BC and could say *“yes, this happened [and] I found this invaluable”*. Counselling groups, and self-help or personal-growth groups where women could share their realities, particularly the highs and lows of their journey with BC were avenues Lara said could be helpful for women. However, she also highlighted Australia’s geography and the ‘tyranny of distance’ when she remarked that for some women to travel any distance further than 20 kilometres to participate in support groups could mitigate against regular involvement.

Carole had come to recognise that her interpretation of the often-heard statement about ‘losing the battle with cancer’ meant, for her, the fact that *“the disease has taken over so much of your body that it’s very hard to fight it”*. The wisdom of her personal experience was that *“you do have to fight it, you do have to get in there and ... you have to work at it ... and you’ve gotta eat well...”*. Overall, Carole felt that what would help women with BC was *“mainly just someone there to listen [and] not to be judgmental”*. She went on to say that *“some days are bad, some days are not so bad”* and, that ideally, *“society”* should have a more comprehensive understanding of the process and time needed for recovery from BC.

“But” she said, “I don’t think people really, really understand what its like. They have no idea”.

Referring to the women she had met through a BC support group, Shirley said that *“treatments were all different, our cancers are obviously all different, and we’ve all coped differently”*. She talked about feeling *“close”* to the other women in the BC exercise group she participated in for 8 weeks. In addition, she talked about women understanding practical aspects of BC that impact on their wellbeing such as burns from radiation, finding a post-treatment medication most appropriate for the individual, eating well, and checking vitamin D levels. But, Shirley said, *“what I really would like to do ... go to a .. getaway thing for women and just be pampered and not be told you must eat this and you musn’t eat this”*. Shirley commented that women with BC would benefit from taking time to *“walk in the bush”*. She felt that any support should not be given in a regimented or rigid way and that women would feel more supported if they were encouraged to *“be gentle”*.

Geneva’s recent participation in a brief counselling and exercise program for women with BC had led her to believe *“people wanted to talk about things ... and go into more depth”*. Her understanding was that to feel as though you were being listened to and heard was an important way to support women. She added, however, that human beings are not predictable nor one-dimensional, and that one person’s experience *“isn’t always the way [other]people go through things”*.

Jenny had worked hard to support BC care groups. She had made turbans, had held fund-raising activities and in general, was positively motivated to be *“involved in support groups”*. However, she had experienced the cancer support groups as *“very challenging”*. Jenny said she felt mentally and emotionally confronted by being in a group with women who had recurrent BC, or women whose diagnosis was terminal. The open nature and changing membership of BC support groups was uncomfortable for Jenny, especially when the group *“was just coffee”*. She found it difficult to connect with others she said, when the approach to the group was *“casual and not having some sense of purpose”*. Her comments referred to Jenny’s desire that BC support groups be more proactive in their supportive role. Her unsatisfactory experience had led Jenny to undertake training to become a group

facilitator for BC support groups. Despite attending training and despite having a strong desire to facilitate recovery groups for women with BC, Jenny reported that *“that really dark time”*, when she attempted to return to her usual employment, had left her feeling intensely vulnerable. She said she had come to the realisation that the time was not yet right for her to offer to facilitate BC support groups. This lack of taking active involvement in facilitation had a negative psychological impact, and had led Jenny to *“feel like a failure though”*. She said she felt *“like I’m not achieving what I set out to do ... I feel like it’s something God gave me, and I’m not being good by not doing it”*.

Terri had a vision of offering weekly groups where women with BC could do specific exercise classes that were matched, at commencement, with the state of their post-BC health, with consideration for their physical capacity to engage. Having taken part in an 8-week BC recovery program involving exercise and group counselling, Terri had the beginning experience of feeling uncertain of the extent of her physical strength. Through extending herself each week at exercise class she was able to move through to recognition of feeling much stronger in her physical body. Her vision for helping women with BC was something she felt both excited about, and, at the same time, felt somewhat downhearted. Her vision was of *“Terri’s exercise class every week”* that could include *“some raw food cooking”*, and she said, *“I reckon we would just have a ball”*. Terri said *“I would love to do it, but I’ve got no qualifications and so I can’t”*. Terri explained that what she had in mind was time to come together to enjoy, share, and to encourage each other; a time that also *“would just lift your whole spirit”*. Her idea was to create a group that would foster strong inter-personal connections where women with BC could *“build up a link to someone who you can then go to when you need to”*. Terri’s sense of humour helped her enjoy her excitement, and also take herself lightly, rather than feel contained and restricted by not yet being able to materialise her vision.

6.3.12 Section summary

Women who contributed their BC narratives to the findings in this study held the view that women were the relational givers and the ones who would strive for harmonious balance in family relating. This finding was consistent with research findings that highlight that in a gendered society women tend to put the needs of the

family above their own needs (Mackenzie 2014). Mackenzie (2014) found that after BC women felt tension between wanting to live into the ‘new’ self, and feeling as though they needed to continue to meet the expectations of their role as a mother, a wife and person with extended family. Meeting gendered expectations was a persistent theme in the women participating in this study. While they reported feeling psychologically stronger and able to redefine some boundaries in their home life, or to relinquish their paid work, putting themselves first remained difficult. The tasks they had performed within the family prior to BC continued after their treatment. While they had changed, family members were still to ‘grow into’ the new normal.

Being self-compassionate and having a capacity for self-compassion seemed dependent on a range of pre-existing factors. Those factors included issues that are not the province of this thesis. For example, the issue of insecure attachment (Joeng et al., 2017), a history of childhood maltreatment (Barlow, Goldsmith Turow & Gerhart, 2017; Boykin et al., 2018), or lack of parental warmth (Kelly & Dupasquier, 2015).

Across all interviews women expressed a strong desire to help other women who would be diagnosed with BC. There was an expressed desire to give compassion to those who were presumed to need it during the journey through treatment for BC. An implication from what could be regarded as an urge to help other women, and perhaps provide to other women what they may not always provide to themselves, is that their participation in this research could be regarded as part of that desire to make meaning and to have a sense of purpose about what they had experienced.

6.4 Findings from Significant Others

Thirteen major themes from semi-structured individual interviews with three males who were a significant other in the life of a woman with BC were identified through the strength of focus.

Prior to interviews with three significant others (SO), the researcher had no personal or professional contact with Chris, Rob and Garrett (pseudonyms used). Aged between 40 and 55 years of age, they were recruited by the researcher using professional networks as well as in response to the question of recruiting an SO from

amongst the women participants. At the time of the interviews, Chris was working as a medical practitioner, and Rob was unemployed, although prior to his wife’s BC he had enjoyed an extensive career as a teacher and high school principal. At the time of interview, Garrett was changing careers. Currently he was completing the second year of a three-year undergraduate degree in counselling. Garrett had previously worked for a number of years in middle management within the finance industry. One couple had no children. The two other couples had children who were between 18 and 30 years of age. Relevant demographic data of the participant significant other is presented at Table 4.

Name (pseudonym)	Partner’s name (pseudonym)	Relationship to BC survivor	Outcome of BC for Partner
Rob	Jenny	Married	S
Chris	Terri	Married	S
Garrett	Louise	Married	NS

S = Survivor NS= Non-survival

Table 4: Demographics of Significant Others

For Garrett, the journey with BC had resulted in his wife’s death. Our conversation about BC was then related to the more immediate experience of her journey from diagnosis to death. Rob’s wife Jenny had initially emerged from treatment optimistically. However, over several months post-treatment Jenny’s earlier positive psychological adjustment declined and she developed clinical depression which resulted in Jenny making several attempts to end her life. At the time of writing this study, Jenny and Rob had begun to emerge from the impact of depression, and Rob indicated that Jenny was willing to engage in life once again.

Chris and Terri were a couple who were noted by Chris as being willing to engage in meaningful cancer conversations from the outset. They made the decision together to navigate diagnosis and treatment with an optimistic outlook and, when interviewed for this study, were looking forward to maintaining the changes they had made post-treatment to ensure physical and emotional well-being.

Interviews lasted from an hour and a half and two and a half hours. The following extracts from the interviews provide a narrative of experiences and perceptions of three SO of three women treated for BC. The focus of the interviews was to discover the perception SO had of their loved one’s experience of BC, her self-image, their understanding of self-compassion, and their experience of their wife’s self-compassion as she navigated the challenges of a life-threatening illness.

The thirteen themes were identified from the interviews with three significant others are listed in Table 5 (p. 248).

Major Themes from Significant Others	
1 Confrontation with the disease: <i>“Like having the ground fall away from under you.”</i>	2 Being the strong one: <i>“I really needed to be as strong as possible for her.”</i>
3 Disorganisation and unrest: <i>“She was very keen on things being as normal as possible.”</i>	4 Turbulence and treatment: <i>“If its tough stuff, you may not hear it.”</i>
5 Caring for ourselves: <i>It’s a shared journey.</i>	6 Self-image: <i>“I’d say - the place just lights up when you walk in”</i>
7 Intimacy, sex and sexuality: <i>“We’ll find other ways of connecting.”</i>	8 Emotional support: <i>Support for me, support for us as a couple.</i>
9 Grief and talk of death and dying: <i>Making every moment count.</i>	10 Self-compassion: <i>Living an authentic life.</i>
11 Back to basics: <i>“Its letting go of projects, plans, activities and thinking more in terms of the people.”</i>	12 The future: <i>“It doesn’t stay dark forever.”</i>
13 What might help: <i>“The medical side is needed but the psycho-oncology is really needed too.”</i>	

Table 5: Major themes from interviews with significant others

6.4.1 Confrontation with the disease: “Like having the ground fall away from under you”.

For each of the men interviewed, the memories of receiving confirmation of their wife’s diagnosis was firmly etched in their memory. Hearing the diagnosis was a particularly confronting time for each of the SOs. Garrett expressed a sense of

shock and a type of speechless dread when receiving the diagnosis. He referred to that moment as:

it was like having the ground fall away from under you or having the rug pulled from under you or something, you know ... where its just that feeling of everything's just changed.

Garrett spoke further about a feeling that could be likened to a temporary state of cognitive dissociation. From his report of what happened he was unable to process the information in the moment. He said *"it was almost numbing"*. Talking more about the numbed state and about the feelings of unreality of the in-the-moment experience for him and for his wife, Garrett talked about a mutually protective state he and Louise automatically entered when the diagnosis of BC was confirmed:

We were driving back home and we were almost talking to each other like ... this wasn't really happening. And we ended up stopping to have a ... get a glass of wine and just gather our thoughts about what does this mean, what do we have to do...

Chris, a medical practitioner, felt that his medical training and years in practice did not offer insulation from the intensity of shock and anxiety on hearing the news of his wife's BC. He commented that he *"certainly had a fair bit of anxiety ... about the diagnosis"*, saying, *"It was quite confronting initially"*. Despite his education and *"insight"* into the practicalities of the medical aspects of cancer, Chris said that his response to diagnosis was *"exactly the same as everybody else. And so I acknowledged that was what I was doing and that was actually quite helpful"*.

Chris was able to acknowledge his reaction was one of personal anxiety as well as professional concern. This awareness energised him to mobilise his resources, and while he had unsettling questions such as *"What did it mean"* and *"What was the future going to hold, for her, for us"*, he urgently prioritised his thinking. Chris was able to galvanise his concerns into action and *"took control of the process at this point and plugged her into this specialist I thought she should see"*. One of the critical aspects at the beginning of the journey for Chris was to know Terri was provided access to the best medical care available. Chris was also able to reflect on the condition of his relationship with his wife and concentrated his

attention on *“probably the very next thing ... the very next thing I thought was, well, how can I change my way that I relate to her to help her?”*

Rob and Jenny began their experience of BC taking somewhat different action. After initial investigation into her symptoms Rob said Jenny had intuitively felt that *“it was going to be bad news”*. Exploring his personal experience, Rob recalled an unexpected stressor:

the biggest impact on me ... was in terms of your ability to concentrate and to remember things. Because you have got at the back of your mind ... you're preoccupied with what has happened ... and what lies ahead.

Despite his fears, Rob's commented that his years of experience in the field of education meant he hoped the experience of guiding and advising others would help him navigate the situation. Rob said his response was to immediately take on the role of the *“moderating husband”* and in that role *“its my job to put the counter ... you know ... in most cases it's 50/50 - whatever it is, if it's a cyst, [maybe] it's not cancer ...”*. Rob's concentration appeared to be that he was focused on bringing a steadying influence to what he observed as Jenny's fear. Casting a protective shell around his own thinking, Rob worked to allay any tendency for them to engage in worst-case scenario thinking. His focus was for Jenny *“not to jump to conclusions here”*.

The desire to remain a moderating influence changed quickly for Rob when it came time to receive confirmation of the suspected diagnosis and he spoke of his recollection of going with his wife to the breast clinic. Talking about this first visit to the hospital generated strong emotional expression in Rob as we spoke. Asked if he wanted some pause time so as to stay with his feelings Rob indicated he was willing to continue. He said *“No, no... A little grief comes out when it comes out. Cos it's not a bad thing. I haven't really had much chance to tell the story from my perspective”*. Rob also commented that the visit to the breast clinic *“was a confronting journey”* and that at first *“we're going with the general stream of traffic in to [the hospital]”*. The shock of reality about why they were at the hospital jarred Rob's moderating mindset:

And then you turn left for the corridor that takes you to the breast clinic and suddenly ... and then you turn left and right again and you walk in and

there's a room full of women with a small smattering of men there as support. And you think, "This is serious".

Rob quickly realised "*there's a fair degree of anxiety in the room*" and he recalled the disturbance in his own thoughts in that moment. "*If you're allowed to swear [during the interview], you go ... oh shit ... you go ... you say oh no ... this is ... this is fair dinkum*".

Coping with BC required each of the three couples to come to terms with diagnosis on an intellectual level within a short timeframe, to make decisions that would have lifelong implications, and to emotionally adjust to now having BC as a permanent 'partner' in their everyday existence. Integrating BC into their thinking about life expectancy, relationships, career family, finances and faith faced three significant others with the task of "*getting my head around all this*".

6.4.2 Being the strong one: "*I really needed to be as strong as possible for her*".

The ways in which Chris, Garrett and Rob processed an unwelcome diagnosis were dissimilar in some respects and similar in others. What stands out is that each husband chose to focus on different aspects of the physical, emotional, social, and practical, tasks ahead. Terri's work as a laboratory technician meant Chris and she were able to understand the biomedical implications. From the position of at first thinking she had a malignant melanoma, Chris commented that he felt Terri was able to acknowledge and come to terms with BC. Her acceptance of the situation was buoyed by her Christian faith and she "*prayed a lot... she committed it to God*". He also explained that Terri was able to include significant others in her daily life as a way of allowing emotional support. She "*allowed her sister and other friends to be around*".

Talking about cancer was difficult for Garrett and Louise. They had communicated sparingly about her BC until they both arrived at a mental and emotional acceptance of the inevitable. Garrett explained that he quietly took on the role of a researcher, finding out whatever he could about something that he "*never had known ... about breast cancer ... other than try and get it early, people have mammograms and all that sort of stuff*". At the same time Garrett exercised caution

about sharing what it was he began to discover and learn and the meaning he was making of that information. *“I suppose as I looked up stuff I could see this is really, really serious”*. He went on to say *“I needed to just get my head around all this ... so, I’m on the internet, I’m finding out stuff ... while she was just dealing with the whole ... just what it meant to her ... for her... the whole emotional impact of it”*.

Garrett talked about his uncertainty about what to say or not say in initial post-diagnosis conversations with Louise. He was deeply concerned about the perceived crisis that was unfolding, but at the same time did not want to overburden Louise or destabilise her sense of coping by an imposition of his need to discuss what he was finding during his internet searches. Garrett’s ongoing hesitancy to be the one to initiate cancer-related conversations with his wife related to his perception of her fears of death. He was deeply concerned about what would happen with Louise’s realisation of the truth that the BC was, for her, terminal.

Garret’s sense of personal loss was evident during the interview as he described the relationship between he and Louise as strong, loving, and supportive *“from our marriage point of view we’d probably got ... in the months leading up to finding out she had cancer, we were sort of feeling like we really had made it and in the best place we’d ever been as a couple”*. In a comment about having been a successful businessperson and able to provide well for his family, Garrett also said *“Yeah, it was good. We didn’t want for anything”*. However, diagnosis and treatment significantly influenced, in a negative way, that sense of being in the *“best place we’d ever been”*.

For Garrett and Louise there was not going to be a positive outcome; there was no way to appraise a terrible situation in a positive light, and Garrett decided that he would be the one in the partnership who would provide the emotional strength for them both. Garrett’s willingness to become strong for his wife at a time of extreme vulnerability was highlighted when it came time to share the very difficult news with family members:

...there was a lot of emotions going around ... angry, you know ... but I do remember though, like when it came to telling my wife’s family and that, I was very much the spokesperson and I felt that I was ... I had to be as strong

as possible for her so ... and I sort of felt that very early, on that I really needed to be as strong as possible for her ... um ... that was a real challenge to me, to be as ... to be on top of things.

Similarly, Chris was aware that going through stressful events “*can make or break a relationship*”, and this gave him the impetus to choose to review the way he related with Terri and create change. He said this was “*a big change*”. To promote change in the relationship meant Chris was willing to re-consider the current structure of their lives and BC. At first thinking about Terri’s illness and how he could help her, Chris found himself wondering “*where’s that going to fit into what I do with myself*”. With awareness that concentrating on his relationship with Terri would mean, “*I would [need to] give up certain extra-curricula ... things that weren’t work-related necessarily*”, his ultimate decision was that “*I would put that [their relationship] as the highest priority in my day-to-day life*”. As a consequence, Chris reduced the amount of paid work he was willing to accept.

Rob and his wife held “*a basic set of values and beliefs that resonated together*”. He explained “*We’re both Christians and have Christian values as anchor points to our lives*”. At the outset Rob and Jenny felt they had assurance from God that the outcome would be positive for them. The strong Christian faith they shared had the effect of guiding the attitude Rob and his wife had to her situation. On the path that lay ahead they felt able to draw optimism and emotional resilience from their faith system.

In summary, the way each of the three husbands managed the task of needing to “*get my head around all this*” reflected that each one called on previously relied-on internal and external resources to help process the event. The resources they drew on included the capacity to understand what was needed physiologically and to assemble expert medical care, the capacity to be able to enact rapid change in the way of relating, and the capacity to glean information from a range of sources and collate a personal management ‘strategy’. Another resource for two of the couples was their strong Christian faith and connection with the God they believed in. All of these resources were utilised in an effort to maintain life in as normal a state as possible. Normal for each of the couples was a world that did not include BC and in

which there was familiar processes, balance, and being in control. SOs reported that since diagnosis life had unfolded in an unfamiliar and ‘alien’ world.

6.4.3 Disorganisation and unrest: “*She was very keen on things being as normal as possible*”.

When describing their overall experience of supporting their wife during treatment and beyond, all of the husbands reported making efforts to maintain as normal a life routine as possible despite the disruptive changes occurring. Chris portrayed himself as a person with a tendency to “*become a little bit anxious as a personality*”. Referring to his capacity to quickly assemble expert medical care, he found that “*doing the thing with the doctors actually was quite useful in terms of dealing with that.... because that reduced my stress levels*”.

With two teenage sons to consider, Garrett and Louise chose to inform their sons about aspects of the BC trajectory only on a ‘need to know’ basis. When thinking about changes made Garrett said Louise “*wasn’t one to just change things totally, at first*”. Garrett admitted that if Louise’s blood test results were optimistic the boys were told this fact. However, results that indicated a downward trajectory were not shared. This way of communicating with their sons was adhered to in an attempt to maintain a balance between living under the shadow of a terminal prognosis and keeping some sense of normality in the family unit. “*She always was very keen on things being as normal as possible*”, said Garrett. A complicating factor for Louise was the death of her father from prostate cancer three months after she received her initial diagnosis of BC. When her prognosis was announced as terminal, the idea of sharing the bad news with family at a time when processing the loss of her father was a powerful challenge for Louise:

[It was] was pretty hard for her to see her father going through the end of his life from cancer having only recently been diagnosed herself. So it was a bit of a blow to everyone. No-one really saw it coming.

From his comments, it seemed no adequate or relevant words could describe the depth of how Louise and Garrett were feeling when they knew they would be adding to the burden of loss and grief for everyone they loved. Louise and Garrett were in unison when they chose who they would tell, or not tell, about her terminal

BC diagnosis. As a couple they decided to be significantly restrained about which significant others would be informed as to the seriousness of her illness. Garrett was clear that Louise did not want to add the burden of further strain, despair, or sorrow to her family's grieving process. In particular Garrett felt that Louise's mother was scared of cancer and would therefore find it difficult to know her daughter was also going to die. He summed up his observation: *"I think [her] mum just couldn't deal with it ... just couldn't deal with it. And of course she was gonna do the same thing when she found out about [Louise]"*.

Garrett said Louise found ways to try and maintain the essential elements of a normal life. He commented that she had awareness of the fact that attending treatment appointments always meant he would necessarily be absent from work for some hours or perhaps longer. In this regard Louise encouraged him not to take any more time off work than was absolutely necessary. His comments emphasised that Louise: *"was always very practical on things like my career and all that, so she wouldn't want me to be away from work any longer than I really had to be."*

Despite the suggestion of fear about a prognosis, Garrett intimated that Louise consistently demonstrated a stoic approach to her BC treatment regime. This appeared to have been linked to the expressed request from Louise that they maintain outward signs that daily life be lived as normally as possible.

Rob highlighted that his full-time teaching position imposed the need to consider how to find a way to balance commitments to his professional life and personal life. In weighing up the varying demands of his work, a desire to be supportive for Jenny, and his commitment to overall family harmony for their four adult children, Rob made efforts to maintain a steady emotional presence for Jenny. He also sought to facilitate supportive communication and provision of what seemed emotionally helpful for Jenny. At the same time, he expressed clearly that in the initial stages he did not want to wrest control of her life away from his wife:

So how do you do that when your partner's going through this really significant thing? When do you need to take control? When do you need to be leaving space? So... its that ... call it a dance if you like... that whole process. Give and take. When is it supporting, when do I take the lead?

However, Rob also acknowledged that Jenny might not have felt supported by his choice to attempt to seamlessly integrate into the routine of daily life, the emotional, physical, financial and everyday household demands they, and the family faced:

I was still teaching - full-time teaching; [the] school was pretty good. I could take time off when I needed it - in short bursts and what have you ... Was there any point in taking 2, 3 or 4 weeks of sick leave. At what point do you take it... and suddenly when you do need it ... to support your partner ... you've used it up already. And, also trying to maintain my commitments at school, students' exams, and all that sort of stuff. I think Jenny found that a little bit hard. I think she ... maybe I had misplaced priorities... but I thought, no, I've got to keep life going as normal as possible here.

Rob expressed an overall perspective on supporting his wife through BC and how important it was for him to remain mindful that “*you could say it's a life-defining event, a life-changing event, but it doesn't have to be a life-destroying event*”. Where his perception differed from that of his wife was that her personal experience of BC may have been that it definitely was a life-destroying event.

One of the ways of keeping things normal throughout the treatment regime and beyond involved conscious efforts on the part of the women to maintain their appearance. Chris and Garrett both spoke about the fact that treatment did not leave their wives looking especially ill. Rob also spoke of his shocked surprise at the way his wife maintained an energetic physical presence almost immediately after she emerged from the mastectomy and reconstructive surgery. The perceptions of each of the husbands spoke strongly about the way each couple approached coping, adjustment, and external appearances during their wife's challenges with treatment for BC.

6.4.4 Turbulence and treatment: “*If its tough stuff you may not hear it*”

A significant theme was related to the experience of treatment and the perception each husband had about how their wife navigated the treatment regime. Two women had, in their husband's opinions, been able to maintain an outward appearance of normality without, in the beginning, significant change to their daily

living. However, Garrett and Chris talked about their understanding of the fear and anxiety felt, but not outwardly expressed, by Louise and Terri.

Firstly, Garrett spoke of the need to keep in mind an ever-present fear of the unknown activated strongly by each subsequent visit to the oncologist. He talked about the value, for the person being treated, of having active engagement from a close family member who was willing and able to provide support by attending appointments with specialists. For Garrett what was significant was the need to keep in mind the cognitive disorganisation that can accompany the shock of hearing bad news:

I think its very important to have somebody there with you, cos if its tough stuff you may not hear it ... um... you may not actually... I think it's always good to have an extra pair of ears.

One of the most incongruent aspects of his wife's experience of BC for Garrett was the fact that over the course of her illness, Louise did not look as he had expected. Externally she did not appear to be a person who was dying. His words illustrate the puzzling truth:

But physically ... and this is the thing ... and even til only weeks before she died... you'd never really know there was anything wrong with her... she never looked ... we never got to where she would lose her hair ... We never even got to that level of chemo Well, she lost a lot of weight in the last handful [of weeks] ... but that's another story.

Talking about Terri, Chris commented that overall “*Physically ... she didn't look particularly unwell*”. His comments indicated that Terri was able to maintain her outward appearance with very little alteration. However, Chris did disclose his observation that in her own mind things may have been different. Her response to hair loss and other outward signs of BC meant her emotional pattern was to quickly moved to worst-case scenario thinking. Chris commented that Terri's tendency to ruminate was tempered by her strong desire not to “*drop her bundle*”:

She got some unpleasant side effects. She didn't like her hair all falling out ... um ... and she didn't like things like ... numbness in her toes and fingers. She tends to catastrophise ...I think that's the word ... a little bit

with these things ... [imitating a very distressed voice]- "I'll never get my fingers back, my fingernails will never come back, my hair will never grow back" ... those sorts of things. But other than being a bit anxious about those aspects of things she actually did rather well. And she did not drop her bundle at all.

Rob's wife underwent a simultaneous mastectomy and TRAM-flap reconstruction. In the days immediately following her surgery Rob was extremely surprised, and cautiously optimistic, when he observed her self-stated limited need for post-operative pain relief. Aware of issues such as fatigue and fear, Rob said he was "gobsmacked" by Jenny's capacity to recover physically and to display energetic resilience by engagement in physical exercise so soon after the devastating news of BC and subsequent major surgery:

...then I went in the following morning, and I've gotta be honest ... for me ... I would've been lyin' back on that bed pumping that morphine in, doin' whatever. That's the way I imagine I'd be going ... but I could hear 'Jenny' talking. And I walk around the corner. She's out of bed, she's sitting up in a chair.

Rob's response was to again attempt to bring a moderating influence to his wife's comeback from surgery. He spoke briefly about his own trauma from his past, but did not enter into specifics, when his teenaged sibling had surgery. Thus Rob expressed confusion and discomfort as to how Jenny could really be in such a positive mental and physical state:

And, within a day or two, she's going down the gym, and she's doing walks. And I am like gobsmacked. I am sort of thinking "alright, ok, but ... just take it easy, take it easy".

The experience of treatment for Louise and Garrett involved variability in results. After initial treatment "*she responded really well ... and actually went into, I suppose what you'd call remission, where tumour counts went right down*". At that time Garrett disclosed that he and Louise had a type of subtle, unspoken, but reciprocal, agreement about not asking questions of each other or of the medical

team. *“But I think it was a bit ... certainly on my wife’s part she was a bit scared of asking too much stuff ... you know, like the idea of getting a prognosis ...”*.

As the disease progressed Garrett was aware Louise was not one to want someone sitting holding her hand or offering commiserations, instead she again encouraged him to continue to work. *“And that even happened later on when we had some bad scans, you know, she’d still be choofin’ me off to work, you know, saying “you don’t have to hang around”*. Amazed at her capacity to manage pain levels and to tolerate extremely unpleasant medical interventions Garrett commented about his ‘role’ as onlooker to Louise’s endurance:

I mean, I was amazed at how many needles she had to have. I mean every time we went in ... we had to have another canula put in ... but she was determined not to have a port put in. ... so I had to sit there and watch it happening ... when she had to have needles to kill off any oestrogen ... but this huge needle, just looked like a prong stuck in her stomach.

Despite Louise’s insistence after a radiation treatment that *“You can head off now ... I’m OK”* Garrett found himself prioritising his attendance at her treatment sessions. For him it was important to be present to the ‘process’ so Louise would not have to face the rigours of treatment alone. Garrett’s way of bringing a sense of normality to unpleasant chemotherapy sessions was *“We just made it a bit of a thing”* - *“I’d go and get a couple of coffees”*.

Given that fear, anxiety, distress and disruption have been chronicled as persistent experiences for women and couples coping with BC, the ways in which the couples cared for themselves and each other as they moved through treatment and then adapted to living with BC is important to understand.

6.4.5 Caring for ourselves: *“It’s a shared journey”*.

In terms of care for themselves, practical considerations such as work demands, family needs for support, and strategies for managing change, had to be taken into account. For Rob, Chris and Garrett these were interwoven with previously accepted norms in the couples’ relating as well as their expectations of

themselves, and how they could now manage to reshape their lives to fit around the BC experience.

Alleviation of their significant physical and emotional distress, or limiting potential for exacerbation of that distress, was managed by positive efforts at self-care. In coming to a realisation that reorganisation of diet was one way to proactively resist the effects of cancer, two of the couples made contact with a cancer-focused retreat centre. The retreat centre offered the opportunity to experiment with adjusting their diet. The revised focus on vegetarian food, extending their knowledge about reduction or elimination of certain elements of their diet, and an overall more intense investment in self-care meant these two couples engaged in lifestyle changes that anticipated positive effects on their well-being in the early stages post-treatment.

On receiving the diagnosis, Chris reported he and Terri began to make immediate lifestyle and relationship changes. Chris emphasised that prior to her diagnosis Terri had held a long-term interest in preventative health issues. In terms of his own stress levels, Chris outlined an unexpected positive side effect of being willing to substantively revise his life priorities:

Making [Terri] the priority was incredibly helpful in dealing with that because I felt that ... I felt some sort of a peace about that ... that that was the right thing to do ... and I could do that ... so yeah ... I felt empowered.

On reflection Garrett admitted that he and his wife had tended to overlook, during the first year post-diagnosis, self-care strategies such as the possibility of making adjustments to their diet:

And I know it seems silly that we'd been going sort of 13, 14 or 15 months, but it was just the way we were I think. She was doing the treatment and looked after herself by leaving work and that sort of thing, but that's when we got really dinkum as far as diet and ... what else can we do?

Eventually, Garrett and Louise payed much more attention to the impact of diet. As part of their efforts to help her feel as well as possible, physically and emotionally, they did choose to attend “a five-day retreat ... and we changed our

eating habits". Although a year or more had already passed by since diagnosis, once Garrett and Louise made that decision to explore additional ways of maintaining everyday wellness, Garrett reported he was able to make consistently healthy choices for their diet. Attending the retreat had a direct effect on their sense of taking control.

Rob commented that he felt a working alliance between couples was desirable for successful outcomes to BC. He emphasised his view that *"In marriage you do become inter-dependent. There may be some co-dependency that people ... that some people want to be dismissive of. But you have to create opportunity and vulnerability in your life"*. In relation to living with BC Rob felt that *"the more it's a shared journey ... it is never one person's journey. It's the family's journey. It's the journey of the significant others"*. The role of nurturer for the family was one that he had been willing and able to take on. This role became more significant as Jenny's mental health declined in the year after completing treatment.

6.4.6 Her self-image: *"The place just lights up when you walk in"*.

When speaking about his wife's self-image Garrett commented that *"I wouldn't say she had low esteem, that's not quite right. Cos she was actually fantastic ... and very well loved"*. His perception of his wife's self esteem seemed positively influenced by the nature of their relationship in addition to responses towards Louise that he observed from others within the family and in social settings. Garrett's comments highlighted a wistful sadness about Louise's self-perception:

I would often try and tell her ... Obviously I was biased, I was her husband, but I'd ... she just wouldn't have it when I said, you know, you walk into the room, and I'd say "the place just lights up when you walk in", and she just wouldn't have it. She would always come up with some negative comment to any compliment.

In this next statement the indication was that Garrett was genuinely bemused by his wife's inability to regard herself as positively as he and others did including her ongoing issues with her body image:

I used to tell her, you don't know it, you don't realise it ... just how beautiful you are, and how well loved you are, and how you light up a room. Because ... she had red hair and it was just natural, and she had freckles and

she was never what she would want ... you know ... she was never petite or anything ... so she was very down on herself a lot over how she looked. ... so she had a lot of body image issues, well and truly.

The topic of self-image was one Garrett spent some time discussing. He talked about the image Louise had of herself and how she came to relax the desire to be different. A poignant statement from Garrett illustrated this change: “*before she had cancer she was worried about her freckles*”. In reference to the problem posed for him by Louise’s persistent negative self-perception, he talked in particular about one emotionally ‘painful’ consequence:

... when we look at photos and home movies and photos and that ... there were so many where she was always the one behind the camera ... she didn’t like it being on her ... and actually a couple of times I put it on her and she’d snap at me about it ... she became far more ready to have her photo taken ... later...

As well as talking about Louise, Garrett also mentioned the change in his own self-perception since Louise’s death. His self-image had been adjusted significantly from his realisation of the depth of Louise’s struggle with her sense of self. As an example of how he had changed to a more positive self-image, Garrett talked briefly about his decision to enrol in tertiary study. He talked about how he had at first felt a “*fraud*” who had “*got by maybe on someone else’s coat tails*”. This was similar to the low self-evaluation that Louise had battled with up until her death. Receiving praise for his work meant feeling “*embarrassed*” at first, although Garrett said he had recently begun to think “*maybe I actually do have something ... maybe its all true and I just didn’t know it*”.

Rob described Jenny’s self-image in the following way:

Always been a pretty energetic person. Very creative. Usually good fun. Can be spontaneous. And... enjoys a bit of flexibility in life and unexpected things. Probably tended to be a bit driven... Some of that, I think, had to do with ... her age when we first met... She was 15 and I was 19 when we first met.

Rob made further comment about positive aspects he was attracted to in Jenny around both her personality and their shared values and beliefs:

The things that attracted me to [Jenny] was the fact that she is an outgoing person, she was musical, we had a basic set of values and beliefs that resonated together. We're both Christians and had Christian values as anchor points to our lives.

Referring to his wife as a person who was a high achiever, Rob also said that his observation was that Jenny was “*a little driven ... she felt quite driven to excel*”. He stated that Jenny had a “*bit of a breakdown*” and felt “*emotionally overwhelmed*” when her father was killed. Jenny’s father’s death coincided with her birthday and this, Rob said, was “*a pretty significant trauma for her*”. Rob then made some observations about Jenny’s strategies for coping with stress:

[She] can be reactive to things ... if you're the husband, or the male, you just have to cop it sometimes ... it's a bit like an unexploded bomb. I have to put all the safety gear on. And it doesn't matter how hard and how careful I approach it, it has to explode. It's just part of the deal. If I defuse it without it exploding then I haven't done my job properly.

Chris also commented about his wife’s self-image but said that having BC had confronted Terri with issues of feeling that “*she was not a worthwhile human being*”. He recalled Terri saying to him that she felt as though she was a “*waste of space*”. Chris highlighted that Terri never felt as though what she was doing or had done was “*worth very much*”. He summed up her self-image in the following way:

I think she had some real issues of self worth. I heard a lot of negative statements about herself... about ... especially when she didn't do things according to the standards that she set, which were high. She would say she was useless and worthless, and those sorts of words... well not particularly those words, but they're the sort of ... the meaning of the words.

6.4.7 Intimacy, sex and sexuality: “*We'll find other ways of connecting*”.

Changes to their relationships in terms of intimacy and sexuality was a topic of concern for each of the husbands. They spoke of the need to negotiate and accommodate

changes to their physical relationship. In particular, Garrett mentioned the negative side effect of the medication:

there was a side effect to that in that it certainly had a big impact on her libido and I know she worried about that, and I sort of said, that's ok ... we just had to live with that. And that was OK.

He continued to say that during her treatment for BC he and his wife had to re-shape the form of their intimacy, which meant, “*Well, it was just a cuddle*”. This comment was followed by some moments of reflection and tearful expression of emotion after which Garrett quietly said, “*I'd be happy with that now*”. The dilemma for Garrett was that Louise's death brought such an untimely end to the joy of that shared physical contact. However, he was clear that once Louise had been diagnosed their sexual functioning was something that was a focus for neither he nor Louise. Once her diagnosis became terminal Garrett was clear that they had a more critical issue to face in how to move towards the end of Louise's life.

Rob also talked about significant changes to the sexual relationship with his wife. His perspective on communication about changes to sexuality and sexual functioning post-BC was that “*I think it's an important issue. And I think it's a thing that people don't always talk about*”. Post-treatment Rob and his wife did discuss intimacy and their sexual relationship. Rob's perception was that he and Jenny were willing to accept change and regularly assess their needs and adjust the way they expressed intimacy. He mentioned the need to be able to support Jenny even though there was “*the loss of certain aspects of that relationship and ... doing the readjusting ...*” Rob commented that for him, readjusting meant being acutely aware of how Jenny was feeling at any point in time so that he felt that couples needed to be able to remind themselves that “*... I can't be making these sorts of demands ... you know ... where is my partner at in terms of her headspace and how she's feeling?*” In response to the personal distress Jenny felt about the change in their sexual relationship, Rob offered a solution. Knowing his wife loved the game of Scrabble, he said to her “*look, what we'll do is we'll play Scrabble and we'll just be really good friends. We'll find other ways of connecting and keeping things going. Even that we can manage*”.

However, Rob felt less optimistic about Jenny's adjustment to the changes in their physical relationship:

I think she's in another place where she doubts her desirability and she also feels flat and unhappy that she's not able to be more sexual and not more overtly involved ... the colour's gone out of it ... and it's not necessarily the most enjoyable experience ... even for all the work we put into it.

Chris spoke about the relationship with his wife in more abstract terms:

I think all relationships are unique anyway, but ours... we haven't had children, and that ... that was something we dealt with in the 80s. As we tried to have children and were unable to ...

Chris was also clear about the value in his relationship with Terri of having been able to enjoy interests in common:

We didn't have children but ... therefore we've spent a lot of time together. We developed interests in common. Bushwalking especially was something that we found, 'cause we did have to find interests in common and that's one of our better ones because we can spend a lot of time out bushwalking and really love it.

Changes to sexual expression in their physical relationship was not the only thing Chris and Terri, Rob and Jenny, and Garrett and Louise were coping with. The world of BC brought with it, at worst, the fear of death, at best, questions about life post-treatment. Chris stated that he was aware in the bigger picture “*we don't know how long we've got together*” and because of that he felt “*we've got to make every moment count*”. Making every moment count meant re-organising thoughts about how life was expected to progress, having difficult conversations about the reality of the situation, and how to interpret what is happening for their wife and themselves.

This theme highlighted that the husbands in this study worked with their wives to be able to revise intimacy and sexual expression. The outcome was that this part of their relationships became ‘relative’ to the bigger issue of the giving and receiving of love, care and support. Intimacy was expressed not so much in physical

ways but in the sharing of as much love, presence, and acceptance of the situation as they were able to give to each other under the circumstances.

6.4.8 Emotional support: *Support for me, support for us as a couple.*

A supportive relationship can provide a buffer against development of negative mood post-treatment. Although each couple had their own distinctive experience of BC, the experience of BC was pervasive in the lives of each of the couples. Uncertain at the start about the new reality that was to unfold in their daily existence, Rob, Chris and Garrett had little or no preparation to emotionally absorb and then integrate the meaning of BC for them; that was to happen as they were swept along by a fast-paced response to diagnosis.

Chris, Garrett and Rob each spoke about the emotional support they wanted to, and felt as though they were able to offer their wife. With an overall understanding that life would never be the same again, the task of managing and supporting the emotional needs of their wives was handled in different ways by each of the husbands.

Rob reported that having been a couple since Jenny was in her mid-teens, he felt he knew Jenny very well. He described Jenny as presenting the image of being “*outgoing*” and “*usually a pretty competent and confident person*”. Rob commented, however, that in reality, for emotional and practical support, Jenny “*relied on a fair degree of support from me over the years*”. Rob commented that because he and Jenny had become parents when Jenny was in her teens, he had to become capable to help with day-to-day care for their four children. He talked about his ability to cook meals, manage the children’s arguments, and “*do all of that sort of stuff*”. Rob talked also about his capacity to offer a stabilising emotional influence for Jenny since the death of her father.

Rob talked about anxiety and stress Jenny experienced due to a workplace event in the year prior to her diagnosis. He stated that Jenny “*has said a few times that her cancer was caused by the stress of this event*” and spoke of the emotional fallout for them as a couple from that workplace event. He observed that Jenny began to lose sleep and become highly anxious. In talking about Jenny’s emotional needs

Rob commented that Jenny “*doesn’t like anything hidden*”, and “*she requires a high level of transparency, engagement and connectedness*”. Rob also talked about feeling some confusion about how best to support his wife when he said:

And ... the other interesting thing is how do you support someone who’s used to a reasonable degree of independence ... I’m now faced with a confident and competent person who is now working through a significant life event which understandably is going to impact her ability to meet some of the challenges of life. I can’t just go in and take over.

Rob commented that a husband needs to have “*the psychic ability to recognise when he needs to be the listener only, to perhaps feed back what she’s heard*”. For him, there were two distinct support roles he needed to be aware of, and he needed to be able to distinguish between. Rob stated that he had to be mindful of when Jenny was needing to emotionally “*discharge*”, as opposed to “*when she’s asking for Mr Fixit*”. This meant that he felt he had to be available for her to explode at as well as be the person who could fix whatever practical matter required attention.

In describing Jenny’s emotional needs Rob talked about the fact that in the early days post-treatment he felt that “*we’re coping, we’re coping really well*”. However, in observing what he named as Jenny’s “*manic up*” after completing treatment – a time she herself had referred to as being on a huge ‘high’ - Rob admitted that he had wondered about whether BC conferred some type of specialness on some women. He wondered if there was, as he put it, a “*celebrity status associated with the illness*”. Rob said that when Jenny returned to her usual daily routine, he became aware of the difficulty she went through as she transitioned from patient to survivor. In the interview Rob also disclosed that for Jenny a perceived social invisibility of trauma she personally had experienced with BC seemed to cause her considerable personal suffering. He used the following words to sum up what he observed as the lack of outward signs of having BC. In particular, he highlighted common and highly visible signs of BC such as wearing scarves and turbans. He reflected that for Jenny this meant:

She’s gone from someone who’s obviously a cancer sufferer and getting treated, to somebody who is now looking [physically] pretty normal, and didn’t have anything that sort of told everyone that she had cancer. So

suddenly she's getting back into the normal routine of life ... but not feeling normal.

Rob commented on his attempts to help Jenny arrive at some degree of control or mastery over her increasingly depressed mood and frequent times of crying. He said that he tried to help Jenny understand that crying was 'normal' and that *"what you're doing is healthy"*. Rob felt he attempted to alert his wife to his perception that her mental wellbeing was declining. Nevertheless, a depressive state began to overwhelm Jenny. Their focus on survival became less concentrated on the BC diagnosis and more connected to maintaining Jenny's mental health. Rob recalled times when Jenny was *"fairly reactive"* and *"highly strung"*. He spoke about his growing concern about Jenny having a *"major meltdown"* at some time; about his allowing her to *"sort of vent and let all the emotions out, and again trying to say [to her] well, again, 'this is something you've gotta ... you've gotta let the grief out'"*. In an effort to validate her sense of isolation and aloneness in returning to everyday life, Rob talked with Jenny and recalled that he had acknowledged *"it is your life, there's no going back, and it's no-one else's and you have to live with it ... that's the place we've got to come to ... that this is reality"*. Rob commented about feeling compassionate about Jenny's suffering. He referenced a time when on a brief holiday he would often look to see if the emotional pain of what had happened was still reflected in Jenny's eyes. Rob's observations were that Jenny's suffering did not decrease but steadily escalated.

What lay ahead for Rob and Jenny was, he said, *"pretty confronting"* as Jenny became psychologically unwell. The result of her mental un-wellness was that she spent some time in hospital. Rob reported that despite Jenny trying to see things in a positive light she was *"struggling to function"*. Throughout subsequent suicide attempts and electro-convulsive therapy Rob said that as much as he could he *"tried to keep the routine and the normality of life going"*. He felt that in keeping the daily routine of going to work and attending to family was his role. Rob reported that he was keen *"to continue to support, to be there for the other person"*.

In talking about their capacity as a couple to support each other in difficult times, Garrett said he was proud of the relationship he and Louise had developed. He

describing Louise as “*a very strong woman*”. However, he also spoke about the deep sense of loss for Louise once she was diagnosed; the loss of a life lived without cancer. As a couple, the grieving process was something they shared with each other but not with others. Garrett’s observation of one significant aspect of their support for each other was that they could have spent more time talking with each other about how she was feeling. He said:

She grieved ... when we had our times together just sitting and talking ... it probably wasn't enough ... but she just grieved for her old life ... she just wanted her old life back when she didn't have this thing hanging over her. Yeah ... I can remember her saying that.

After talking briefly about that grief, felt so strongly by Louise, Garrett then changed his tone of speaking and made the following comment: “*but yeah, I suppose the difference was she had more visitors.*”

Without focusing on whether he too had grieved for their old life, or whether he had explored, in his innermost self, the poignancy of Louise’s statements about being forgotten, Garrett moved to talking about a positive aspect of their relationship. He said their marriage had grown to a point where:

[in] the months leading up to finding out she had cancer we were sort of feeling like we really had made it and in the best place we'd ever been as a couple. We could go away, just the two of us, and really enjoy just going away.

In terms of support from others Garrett highlighted a “*weird*” feeling for them as a couple in the weeks soon after Louise was diagnosed. He remarked that they felt “*it was like someone had died. We had people, flowers ... and people there all the time*”. At that time neither Garrett nor Louise had come to full acceptance and realisation of the eventual outcome of her prognosis.

Positive support from family members prior to Louise’s diagnosis was a solid part of life with Louise’s family. Louise had “*a pretty special relationship*” with some members of her family, especially her two sisters, and this was expressed in emotional support for Louise and for Garrett once her diagnosis was made known.

As an example of the support they received Garrett recalled that one cousin was able to provide Louise with Reiki sessions in an effort to help her stay on top of the effects from BC treatment. When the full extent of her prognosis was known Garrett and Louise along with several of her family members embarked on an extended holiday to the USA with the decision to have this last family holiday being made by Louise.

Overall, each of the couples had been able to receive support from family during the time when the wives were in treatment. For two of the couples the woman with BC struggled with a change in support that they experienced once treatment was completed.

6.4.9 Grief and talk of death and dying: *Making every moment count.*

The question about how and when to open conversations about death and dying was highlighted by Garrett in sharing his eldest son's response. After his mother's death, Garrett asked his sons about their experience of learning their mother had a terminal diagnosis of BC:

I actually asked them recently ... the eldest son ... he sort of reacted ... he said, "well, I knew it was bad", he said, "but you and mum seemed so ok ... like it was gonna be ok and that, and so I just thought it's gonna be alright.

Garrett spoke further about feeling disappointment that he and his wife had not made time to talk privately with their two sons before making the announcement to the wider family that Louise would not survive the disease. In the first instance Rob and Louise alerted their sons to her diagnosis. Rob recalled that "*they came home in the afternoon, and we told them then ... and of course at that stage we didn't know how serious it was.* However, once the situation for Louise's outlook had deteriorated:

I would certainly tell them differently though. All the family was again waiting at [wife's] Mum and Dad's place, and the boys were at home. And I just sort of rang the eldest son and said "you and [your brother] ... wanna drive over now?". The both of them said we felt like everyone was looking at us, and we didn't know whether we should be crying, or not crying.

Rob expressed sadness that he had not thought of the emotional reaction the two boys would have to the news that their mother was going to die. It seemed as though Rob and Louise tried to convince themselves the news was a case of information exchange rather than a devastating blow. Rob completed this part of our conversation by saying *“If I had my time over again, I would have a quiet time with them”*.

Garrett explained that he often found himself drawn to concern about the future *“on days when I was on my own, driving to work, or driving home from work I would be thinking about what it was going to be like, what was gonna happen”*.

Another aspect of support mentioned by Garrett was related to comments his wife had made about people’s ability to remember, and to be able to support those suffering loss and grief. Garrett summed up his recollection of Louise’s comments in the following words:

Having cancer herself and seeing how people, even close family, still went back to living their life and life going on, she would say “That’s exactly what’s gonna happen when I go. She had this idea that “see, people don’t stop”. People just get on with life when you go ... they forget about you.

Trying to think and act in his wife’s best interests meant that Garrett avoided being the one to open a conversation that might lead to the topic of death and dying. *“Oh, we didn’t talk enough about it. Its something ... it’s the one thing I regret”*. He pointed out that his desire to avoid talking about cancer and death so as not to create additional emotional distress actually resulted in temporary disconnection between he and his wife: *“so, it was a handful of times where she really blew up at me ... which she’d always say sorry for after, but ... it was that no-one would talk about it”*.

Garrett talked about the emotional challenge as he balanced the tension between being open and honest, with times of attempting to shield his wife from further distress. He also talked about his wife’s perspective on communication about her cancer with their sons. Speaking of his wife’s wish to protect their sons from suffering by not telling them what was actually happening until very late in the process, Garrett said her idea was *“it was very much a case of ... they didn’t need to*

know stuff". In hindsight, his reflection on the way he and Louise communicated with each other and with their sons about her terminal BC, brought a comment from Garrett about the tension between giving space and time for emotional expression, as opposed to being emotionally strong and thinking that was protective for others. The question arose from his conversation about who was being protected by the resistance to sharing factual information. Garrett talked about his conviction that he needed to be strong for Louise, and his confusion, on reflection, about a choice he now considered as not helpful for anyone - in the bigger picture:

I know now ... I'm an expert on it ... that's not helpful ... for anyone ... the chance to be able to express yourselves emotionally ... and I still had ... felt ... this need to be as strong as I could be ... so I didn't.

Garrett talked about the change in an attitude he had that to be the husband mean he needed to be 'strong'. He commented this was an attitude that had changed only since his wife's death:

It's not always easy, but I'm more inclined now to go ... instead of worrying about what so and so are thinking ... which they probably aren't ... I'm more likely to say ... aaah ... you don't have to ... you don't have to ... take it easy.

Garrett also had some questions about what inhibited friends and family from communicating more frequently with him after Louise's death:

Is it ... I dunno ... are they so scared of trying to be able to say the right thing. And eventually it gets a lot easier just to stay away, and then it becomes too long that you've stayed away, and then it becomes too hard to show that it's been wrong staying away so long?

Because Rob and Jenny felt optimistic from the outset that her BC was not going to be terminal, fears about death and dying seemed to be expressed more often in emotionally-charged expressions of anxiety. Rob spoke about the change in his wife from a position of strength and optimism to her entry into a deep and unexpected depression. He referred to a conversation with Jenny in which he attempted to help her understand the emotional process she was going through:

She's still on the high, but things are starting to change. ... I'm telling her 'what's happened to you is a significant and traumatic event, and you have to allow yourself room to move through this and to grieve and then to accept and reconcile with what's happened'. I said this ... 'You can't get away with anything for nothing'. I said [to her] 'there's an emotional cost to this and you have to work through it. You've gotta grieve, otherwise you're living in a different place'.

Chris mentioned that without children he had “*tended to be a little more selfish perhaps*”. He recounted that “*my mind was often occupied with things to do with myself and my endeavours and although ... I tried not to ... I would have tended to have taken her a little bit for granted I think*”. Living with the uncertain future that BC forces on a couple had forged a change in Chris. He no longer felt there was time to be complacent or ignore things important to Terri:

I actually do think about her more often and what is helpful for her. Ah... there's this thing about blokes coming home to The List (laughter) and the guys wanting to sit down and watch the footie ... but I see 'The List' now... not that there's a physical list ... but the things that she wants ... as a positive.

Chris clarified this thinking further by saying that anything important to Terri had become:

A thing I want to do to enhance her life because she really enjoys that ... she really appreciates those things ... and that's half the value of doing them. Whereas I wouldn't have seen that before. I'd think 'oh, we'll get that done [eventually] and ... you know ... I didn't want to go and do that other job [that Terri needed done].

Chris commented that the consequences for him from the disruption BC brought to everyday life, had, he said, caused him to question previous assumptions about the value of activities in life to which he had devoted time and energy. Finding new meaning in his life involved integrating Terri and her illness into his thinking so that she was a more ‘visible’ part of his considerations. The degree of change has resulted in Chris having a sense of constructing a more ‘holistic’ lifestyle:

But now I [think] that's for her ... [and so] that matters ... and I think I want to help her more now. That's actually been quite a good thing for me because I'm less stressed about not achieving some of the other goals that I had that I don't think mattered anyway. Yeah ... so I'm quite happy about that.

The three participant husbands (SOs) were able to talk about how BC had affected and changed their lives, and the loss, of certainty and expectations about life they had enjoyed prior to BC. These SOs were also able to discuss the understanding and knowledge they gained as a result of the experience of BC. That knowledge and understanding was relevant not only to their relationship with their wife, but also to their relationship with themselves.

6.4.10 The meaning of self-compassion: *Living an authentic life.*

A theme that emerged as significant for each of the SO's was that of creating a post-BC life that was authentic for each of them. This desire for authentic living seemed to stand in contrast to the life two SO's had created prior to their wife's BC. For Garrett and Louise, Chris and Terri, and Rob and Jenny, BC involved the necessary accomplishment of important and unpleasant tasks that were stressful. The consequences of any tendency toward procrastination were untenable. Chris was able to find the way to relinquish projects, reduce his workload, and weigh up his commitment to interests other than those that he felt were beneficial to Terri and himself *"for me its letting go of projects, plans, activities and thinking more in terms of the people and the values that will improve quality of relationships in your life"*.

Kindness and self-understanding of what he and his wife needed was demonstrated by Garrett when the *"redundancy door was left open for me and I took it"*. Without another job to go to Garrett and Louise were able to accept that the time they had left together was important. *"We were just walkin' on the beach one day and we said "we'll be ok" and so it was great ... we had time to ourselves"*.

The concept of self-nurturance brought forward this comment from Chris *"Self-compassion, that's interesting ... I'm not sure. I try to relate it to myself ... I*

don't know ... looking after myself ... Yeah ... [pausing for a moment or two] ... I think that is true".

Similarly, Garrett felt that development of a kinder self-relationship meant a release from an old pattern of always thinking about judgment from others or the needs of others. He talked about being able to accept that he deserved to feel free in himself:

I think, for me personally, it's almost like being able to give myself a break, being able to forgive myself and accept that ... actually tell myself, you know, you've been through a lot ... you deserve ... whatever you wanna do, you deserve to do it. Rather than always worrying about what other people might be thinking.

Rob's many years in the teaching profession had helped him develop a sense of boundary between what he was responsible for and what he could not control. He remarked that 'professional wisdom' had taught him that he could not control others, and if they acted out in extreme ways, that was not his fault. "*What I'm responsible for is how I manage that situation*". Rob also commented that he understood when "*your rational part of your brain says ... you need to take some time out for yourself ... you've got to recognise and listen to that*". On balance, he considered that there were both benefits and risks to being self-compassionate. He made a clear statement about what he saw as a need for "*realistic assessment*" of one's needs and motivations rather than using the idea of self-compassion as a convenient mask for not doing what needs to be done:

Compassion ... [pause] ... self compassion is interesting because there is a genuine, realistic assessment of where I need to be kind to myself, where I need to say, whether we use the analogy of the adult or the child, and looking after the inner child ... But where you're rational part of your brain says actually you need to take some time out for yourself ... you need to find a place to have a good cry ... that there is a degree of compassion which is connected to your ongoing survival and you've got to recognise and listen to that.

Rob offered his notion of when self-compassion might not be useful or helpful to a person:

There is the opposite compassion which is the emotional indulgence, you know, where you give yourself over ... it's a tantrum type thing ... it's the child that goes to the extreme ... so, self-indulgent compassion is a form of narcissism. It can become destructive because you're overwhelmed by your own grief.

Rob went on to talk about the problem of “*not allowing yourself to feel ... where you become too stoic*”. He said, “*that's not good either because that will be acted out*”. Overall, Rob summed up his statements with a comment about a lack of compassion for self. To him it meant “*you will not have compassion for other people*”.

Chris spoke about the Christian concept that implies “*there is a value in yourself and that you need to be loved*”. He added that “*in the context of a relationship with God that's all about God loving you*”. Commenting that some people may be “*inclined to think that it's all about ones' self*”, Chris could see another side of the argument that “*if you say you're going to be utterly selfless then that's a denial of the reality as well*”. He commented that sometimes the concept of self-compassion could be regarded as relating to being “*self-indulgent versus complete selflessness*”. Talking about self-compassion Chris also highlighted his belief about the need to give to oneself in order to be able to give to others. Furthermore, when discussing the idea of living an authentic life, living true to oneself, Chris liked the concept of authenticity as being an integral part of self-compassion.

Garrett talked about the meaning of self-compassion. For him, being self-compassionate involved living an authentic life. The essence of his perspective was summed up in the following statement “*Self-compassion is ... I keep thinking almost ... true to myself in a way. That's probably what I keep coming back to ...*”. However, Garrett admitted that prior to the experience of his wife's BC, “*I would've seen that I had a job to do and it was my role to provide for the family, be a good husband, ah, you know, have a good career ... have some fun too*”.

The deeply personal journey of BC had generated some unexpected reflection and questioning of what it meant to walk alongside their life partner and to *“definitely (strong emphasis placed on the word definitely) ... feel all the emotions”*, but know *“you are going to have to support that other person”* (again said with emphasis). This ‘double-sensory state’ of feeling their own emotions, feeling for the other, and yet acknowledging that in practical terms that *“you’re not the one suffering”* activated a need and desire to remind themselves of the basics in life. For the three husbands this meant to focus on the fact that some aspects of life will need to be surrendered, and other aspects will be held close. One of Rob’s philosophies for living was that *“you’ve got to try and keep as many options open as possible so that they can then choose, as things unfold, what it is you’re going to keep and what it is you’ll let go”*.

Self-compassion was summed up by Rob who said that *“self-compassion ... important ... and we always swing between extremes, but I think recognising that trying to bring yourself to the balance point. We should come to a point of balance”*.

6.4.11 Back to basics: *“Its letting go of projects, plans, activities and thinking more in terms of the people”*.

Coping with illness such as BC catapults couples into an existential uncertainty in which life as it had been known is up for review. The crisis faced by Rob, Chris and Garrett had brought them to review their self-understanding, their relationships, their personal strength, and appreciation for life. The three men spoke of how they managed the demands of an extremely challenging event that caused anguish, fear, discomfort, and anxiety for their wives and for themselves. While the event was the same for each, their experience was different. At the time of interview, Chris, Rob, and Garrett reported positive effects for their lives in both psychologically and in relation to the practical aspects of life, the basics.

Speaking about how BC has eventually brought positive growth into his life, Chris commented *“well, for me its letting go of projects, plans, activities and thinking more in terms of the people and the values that will improve quality of relationships in your life”*. Overall Chris felt that the experience of BC had been positive because it helped him to re-focus and adjust the priorities in his life. From

over-involvement in work-related projects, the future for Chris and Terri was one where the basic foundations of human relationships mattered much more than they ever had done.

Part of Rob's personal experience of BC was a state of inertia in his sexual relationship with Jenny. *"For us as a couple, it ... it does seem as though things are in mothballs to some extent ... for the relationship... in this moment of stasis ... while we're working with these things [referring to BC]"*. Rob spoke about the strength of the commitment between himself and Jenny. He recalled that their attraction to each other when they were young was because they *"actually liked each other as people. There were similarities in our gifts and the way we would operate"*. He went on to say that the current *"stasis"* had brought him to *"go back to what are the fundamentals of the relationship"*.

Garrett highlighted that as a consequence of the loss of his wife to cancer he now had developed a more existentialist view to life. *"I don't think too much about the future. I'm not all that keen on living too long either, which is very unlike me before"*. He shared that in the months after Louise's death *"I used to think about death a lot. I still do. I've just about got my funeral planned out in my head. One day I should put it all down in writing or none of it will ever happen."*

Garrett said he never seriously entertained the option of suicide as a way of relieving his own suffering. He was clear that *"if I was really honest ... I was never ever gonna do anything like that to myself"*. Nevertheless, what was important to Garrett was that realising the additional pain withholding expression of feeling could cause, he no longer wanted to anaesthetise his feelings. BC had helped Garrett to reorganise his thinking about what was important in life. He compared the practical and careful person he felt he was prior to his wife's BC, with what he had come to regard as worthy of valuing about life. Life in the future now looked different to Garrett. This was highlighted when he commented on his reminiscences *"...because reality is death. Like losing my wife. That changed my identity, in the family, everything changed"*.

6.4.12 The future: “It doesn’t stay dark forever”.

The husband participants in this study were optimistic about the future. Rob and Chris had eventually arrived at a place of quiet acceptance of the presence of BC in their life that was an event over which they had no control. Rob in particular was confident his strong faith provided a solid base from which to continue to draw spiritual and emotional strength for himself to support his wife as she adapted to living with BC:

I just think it’s a very real journey and I think that reality of that relationship with God is about sharing pain with Him and about drawing strength. And it’s not about me being a winner.

Chris talked about a tendency he and Terri had to see the future as always a long way off. The future had always been a horizon to which they could look ahead. He highlighted that for them now, it was as if BC had meant they had ‘arrived’ at that horizon “*and suddenly the future is with us now, and, you ... there’s lots of philosophical approaches to that, but ... we’ve become aware of this through the stuff we were doing through [our time at] ‘B’ [names a cancer retreat centre]”*. Engagement with the cancer-care retreats had helped Chris and Terri become aware of, and employ “*that concept of mindfulness, and ... being in the present, in the moment ... that sort of thing”*.

Garrett also stated that he now had a different perspective on what mattered in his life. He felt more aware of, and positive about, how he and his sons had “*all gone through something that we can always use as a ... a bit of a reference point”*. After his wife’s death Garrett decided to enrol at university. This was something he had sometimes wondered about but had never followed through. Chris was very close to completing a Bachelor’s degree in counselling, and found that he enjoyed the fact that friends and colleagues felt safe to be able to open to him about their personal challenges. Garrett felt his formal study of professional helping had brought a sense of purpose for his life. Although he disclosed that he experienced some sense of guilt because of his enjoyment of a newly developing role as a professional counsellor, Garrett felt that he could accept that life can hold new purpose and meaning after a profound loss. He commented that he “*found it quite relieving ... to hear, and be able to help someone else ... so its a little bit of selfishness about it I*

suppose". It seemed as though Garrett's newly-found professional direction helped reduce any sense of being isolated in his grief. The most noticeable dimension of life for Garrett had become the search to find how he could live life in a personally "authentic" way with a focus on what really mattered, rather than on a socially acceptable construction of success. His stated perspective was "So I think that's probably the biggest [for me]. It's just that ... how we live... the less concern with the material sort of living that ... [be] more interested in the bigger stuff".

In the case of Jenny and Rob, although they were engaged in an ongoing struggle to help Jenny overcome depression, Rob remained confident they would emerge from the shadow of her despair. The teachings, and value they placed in their Christian faith, were something he and Jenny felt they could rely on without exception. For Rob it was not a matter of slavish devotion to practice, but what he felt was a deep personal knowing that his God was present and available. The strength of their faith had provided Jenny and Rob a source of assurance that "He's there ... He's been with us right from the word go ... in our relationship and in this journey ... we just have to keep trusting Him and keep walking the walk". Rob's faith did not blind him to the reality of the situation. It did not mean he ignored what needed to happen when Jenny was admitted to hospital for psychiatric care. He did not use faith to refuse the electro-convulsive therapy they felt had to happen. To highlight his ability to preserve balance between pure faith and acknowledgement of practical realities Rob said:

We will get to a place where we will look back ... and I won't say 'Oh thank God for everything that's happened'. But maybe we will see things, and maybe we will be a help to somebody else, to other people and to say yeah I know how you feel cos we've walked that walk, but it doesn't stay dark forever. A new dawn comes ... you know ... and it does, it does.

Chris and Garrett also spoke about the 'new dawn' in different ways. Garrett had found his new dawn in his training for the role of counsellor. Chris had found a new dawn by re-prioritising his life so that for however long they had together he could make every moment with Terri count. Rob's trust in his faith system was the 'glue' that was holding everything together while he and Jenny negotiated the mental health system.

6.4.13 What might help: “*The medical side is needed but the psycho-oncology is really needed too*”

The SOs had a mixed response to the question about what they thought might help the person whose partner is diagnosed with BC. Having a strong belief in a faith system was highlighted by two of the husbands, as was the need for attention to be paid to the ongoing mental health of BC survivors.

Rob felt that it was important to develop a capacity to know and understand the God you believe in. Balance and being able to find balance in life was another theme in Rob’s talk about what might be helpful in the face of a life-threatening illness. He felt an important personal capacity for humans was the ability to respond emotionally to others. His view was that without being able to feel compassionate toward others:

You will lose your ability to respond emotionally because ... this is my theory anyway ... because you will have built walls that are so strong ... to protect... to stop yourself feeling the pain, you won’t be able to enjoy the colour of life you’ve created.

For Rob, what would help was an anchor in life such that religion had provided for him. In addition, he felt it was important to know and understand the function of emotions as a prelude to offering compassion to others. Without being able to feel the painful times in life, Rob felt that enjoyment of life would also be inhibited.

Garrett’s experience had left him with the perception that there was more that could be done to provide emotional and psychological support for families in which one person has a diagnosis of cancer. In particular, he felt that more emphasis could be placed on helping couples understand the true nature of negative reactivity that might be exhibited by their children when under extreme stress because of uncertainty or fear about a parent’s cancer diagnosis:

I think the big component that needs to come in is that psychology side ... helping people with families how do you deal with children. We had a fair bit of stress with our younger boy during ... when Louise had cancer. And we didn’t know how to handle it. We thought he was being an arse ... and how

could you be doing this while mum's got cancer. And a bit of knowledge would've gone a long way. So, I honestly believe ... the medical side is needed but the psycho-oncology is really needed too.

Chris spoke about BC and survivorship as being like a “*sword of Damacles*” that the person diagnosed, and their family, will never know “*when it's gonna drop again*”. He felt that the fear of cancer recurrence was always going to be present in their life, no matter how well a person thinks they have processed that fear. Therefore, Chris believed that sensitivity needed to be observed by “*being careful about your speech and your language so that you are being affirmatory rather than negative*”. Another focus that Chris regarded as vital for wellbeing was to “*practice the activities that are replenishing to your energies*”. Chris also commented that a process of ‘holding’ painful emotions gives the opportunity to not only acknowledge those painful feelings, but to “*get perspective on them*”. The key ingredients for living in BC survivorship, for Chris, would involve acknowledgement of the fear that comes with survival, as well as acknowledgment of the fact that humans experience painful emotions and can come to terms with them. In addition, he spoke clearly about involvement in those things in life that are nourishing to the heart, soul and mind, and having the willing capacity to be compassionate to the BC survivor through mindful communication that was affirming and life-giving.

6.4.14 Section summary

In this section, thirteen themes identified from interviews with three significant others in the lives of three women who were diagnosed and treated for BC were discussed. The themes highlighted that, for the couples represented in this study, what was important was a need to keep things normal, make every moment count, as well as maintain a sense of balance about life. Discussion about self-compassion emphasised, for two of the group, how important they felt it was not to succumb to self-indulgent thinking and behaving. Balance in life was considered as a critical life skill. That balance however, was not one that denied the need, as humans, to express emotion or the need to receive care and love.

In terms of what would help survivors of BC the men talked about their perceptions of compassion, loving-kindness toward others (especially a cancer

survivor), in addition to engagement in the activities of life in all its shades and colour. What seemed apparent from the discussions with these significant others was the distinct differences in ways they had responded to distress in their wives during the adaptation to BC process. There was a general awareness in each of the significant others of the points of vulnerability in their wife. What was clear was the escalation in level of distress in each of the significant others when their partner was physically or emotionally unwell. Well-established patterns of relating as a couple could have, however, blinded them to discovering alternative ways of responding to distress. This appeared to be the case for two of the significant others. Seeking mental health care did not seem to feature as a critical or useful step in their thinking. In the interviews there was an expressed ambivalence about the usefulness of being self-compassionate as a way to facilitate relational change, whether that change was intra- or interpersonal in nature. Concern about selfishness presented as the stumbling block to consideration of the potential of self-compassion as an antidote to self-criticism. The speculation is that training in self-compassion, as a couple, may have raised their competency for resolution of intrapsychic conflict and consequently aid in strengthening a positive connection within their relationship.

6.5 Findings from counsellors' reflections

Eleven major themes and six minor themes were identified from analysis of transcripts from interviews with three female counsellors who, as part of their professional work, had provided counselling support for women with BC. Pseudonyms have been used for all three participant counsellors. Names chosen were Mardi, Bridget and Alison. The counsellors expressed positive motivation to support women's optimistic adaptation to life post-treatment for BC. They each commented about how counselling support that could help access, and process, distressing emotions was something they regarded as productive and positive for women's mental health in BC survivorship. The counsellors offered emotional support, in addition to practical help such as organising fund-raising events and peer support groups, as a means of disabling potential negative after-effects of the women's experiences. According to the counsellors the principal negative after-effects that they recognised as most debilitating for women were guilt, self-blame, self-criticism, and shame.

Table 6 presents basic demographics for the counsellors who took part in the study. Each of the counsellors worked within different contexts that presented differing constraints and freedoms. Despite differences in the each counsellor's fundamental orientation towards the nature of counselling work, analysis of the three interviews presented observations that frequently reflected commonalities in the perceptions of challenges for women survivors of BC.

Mardi had completed a Master of Counselling degree and worked with a cancer care and support organisation for eighteen months prior to the interview. Describing her role as "*multi-variant in that it covers any scope that sort of ... that walks in the door*", Mardi had organised and facilitated BC support groups and provided individual counselling support to women with BC, whether newly diagnosed or living with BC for many years. Another part of her role was to arrange social events to raise research funds and heighten BC awareness within the broader community.

Bridget was a trained counsellor who had four years experience in a hospital setting. Her role involved offering counselling support to people with a chronic or terminal illness. In addition, her role with the pastoral care service at the hospital included working with women who were currently being treated for BC, or who had completed treatment for BC and were now an outpatient. Bridget's work covered both individual and family counselling combined with pastoral care duties.

Alison had over eleven years experience as a private practitioner since having completed a Master of Counselling degree. During her career Alison had spent twelve months as part of a cancer support team at a large public hospital. For seven of her years in professional practice Alison had worked as a contract counsellor with a cancer care organisation.

#	Name (pseudonym)	Years in practice	Practice location
1	Mardi	18 months with support group	BC care/support organisation Individual counselling
2	Bridget	4 years counselling experience	Private hospital setting Individual and family counselling
3	Alison	Over 11 years in practice	Private practice 7 years referral clients from a cancer care organisation

Table 6: Counsellor participants

The discussion with Mardi highlighted that during her time in the field of counselling she had awareness of the value of ‘doing’ as well as of ‘being with’ women. Mardi described her role as *“a lot of work with women that are dying ... and particularly then work with family members around that time”*.

Alison expressed a strong commitment to focus on providing counselling not just the women themselves, but for their family and extended family members. In contrast to both Mardi and Alison, Bridget indicated her focus was to help women through the initial trauma from hearing their diagnosis. She talked about *“journeying with”* patients and also mentioned feeling relieved to find a breast surgeon at the hospital who was *“very open to ... emotional and spiritual support”*. For Bridget, embracing a psycho-spiritual perspective had, she said, helped her understand emotional suffering as something that occurred both as a present moment experience as well as part of the ongoing larger picture of life.

Rather than regard the differing perceptions of their work with women with BC as a contradiction, or a purely personal preference, there was also the consideration that their practice perspective having been influenced by the needs, expectations and objectives of the organisations they were part of. For example, Mardi was part of a BC care organisation that had an holistic focus on provision of practical and emotional support for women with BC, as well as being part of the fund-raising initiatives for research. On the other hand, Bridget’s counselling was offered as an essential part of a counselling and pastoral care service provided within the context of a private hospital. Individuals and families encountering a harrowing journey through cancer diagnosis and treatment were referred to Alison by a cancer

care group. In her role as a private practitioner the referral process meant Alison could engage with as few or as many of the family members she felt necessary in order to support the emotional well-being of the person diagnosed.

Alison placed importance on restoration of healthy relationships for the woman. As a counsellor, in private practice, her perspective was:

that relationships that people have not only with themselves, their self relationship, but with those that are their beloveds, that they may wish to communicate and speak in a way that is more intimate and more real and the changes might be made ... and they wish to speak of things they've never spoken of before...

The eleven themes identified in the transcripts of interviews with the counsellors - listed in Table 7 - underlined their professional assessments and observations of women survivors of BC. Those assessments and observations formed the basis of counselling practice that supported enhancement of quality of life for women post-BC. The transition into survivorship was regarded as a major point of transformation and growth by the counsellors. This perspective is consistent with literature and help them manage the psychological side effects of medical treatment as they process. The major themes highlighted in the interviews pointed to the direction for counselling to help a woman with BC engage in a friendly, emotionally supportive and more flexible relationship with herself. Ultimately this process would mean a survivor would be able to better know and understand herself.

MAJOR THEMES FROM COUNSELLORS
1. Bearing witness: <i>"They're still part of the world"</i>
2. Not just putting bandaids all over the place
3. Personal challenge for counsellors: <i>"I don't want them to die"</i>
4. Being real: <i>"It's about how they actually see themselves as women - they're supposed to be all things to all people"</i>
5. Youth, sexuality, death and dying: <i>"For them - It's just one thing on top of another"</i>
6. The chaos inside: <i>"What if it doesn't work"</i>

7. I'm different, but what does that mean? <i>"A new sense of normal"</i>
8. Self-blame: <i>"I'm normally the cause of their happiness"</i>
9. Time to heal and grow: <i>"It's a long process"</i>
10. Self-compassion: <i>"Finding self as important as the other. It's like a blossoming"</i>
11. Survival and reconstructing life with a toolbox: <i>"I have evolved"</i>

Table 7: Major themes from counsellor interviews

Presentation of the major themes begins with the counsellor responses to the way in which they personally experienced their work with women with BC. The themes linked with each other and, similar to the findings from participation by women BCS, there was a 'space' of overlap in which themes overlapped with several points of interaction with each other.

The counsellors each held the same perspective on the therapeutic relationship. Their professional perspective was that it offered an open and safe context for supportive listening and therapeutic intervention as women told their life story. From the interviews it was clear that the counsellors allowed the women to relate their narrative in as much or as little detail as they were able. Furthermore, the counsellor reflections indicated they were of one mind in talking about the value of collaborative conversation and professional intimacy within counselling sessions. They acknowledged that the counselling relationship allowed time for women to be listened to, and time for women to reflect on what they heard themselves say. The sessions, from the counsellors' points of view, brought a 'legitimacy' to the unique way in which each client wanted to express her feelings about her BC experience. The counsellors reported they felt privileged in taking the role of a witnessing companion on the voyage of self-discovery.

6.5.1 Bearing witness: *"They're still part of the world"*.

A key function of survivorship is the reorganisation of a woman's sense of self. BC brings a crisis in the meanings to those aspects of life that had previously provided a sense of substance and structure to life. The three participant counsellors made statements that indicated they felt privileged to bear witness to the active and

deliberate attempts women with BC made to renew their sense of self-confidence, self-worth and self-identity and to bring new meaning to life.

At the start of our interview during a particularly busy day, Mardi expressed a willingness to make a contribution to this study, commenting that for her the field of BC was “... *great work; privileged work...*”. For Mardi, supporting women with BC gave her both a personal and a professional sense of living meaningfully. Although she felt her work with women with BC was “*very full on*”, she qualified that statement with the comment that “*I love this group of clients ... [there is] so much you can do ... there’s so many different areas that it [BC] involves ... often its to do with issues they’ve had for many, many years ...*”. Her professional satisfaction and joy in counselling women with BC was reiterated when Mardi commented about her work “*its such rich work because it just involves everything really ... and ... I really love that sort of work ... it’s great*”. The intrinsic rewards for Mardi in her counselling women with BC became evident as she spoke about her involvement in her work. Mardi commented that “*its such a privilege to work with these girls and to get involved with their families ... and you can see that you make a difference ...*”.

Alison also pointed out that she was “*loving the work I do*”. For her, witnessing the telling of a life story, and being part of the person’s meaning re-making, was “*an honour*”. Alison regarded cancer as “*the catalyst ... quite frequently, for sometimes facing death and the journey towards death. It’s the catalyst for talking about matters that perhaps have been left to attend to one day, or preferred not ever to attend to*”. She felt that her nursing background was a positive factor in being able to assess and isolate aspects of life that are a client’s most immediate concerns. Alison also referred to “*beginning at the beginning*” with a client in order to establish trust and connection. Handing over, in a sense, the initial appointment to the immediate need to assess physical and emotional wellbeing, Alison alluded to being able to hold the space and witness the story the client wanted to give when they first meet. “*And, just the same with anyone that comes to see me, you know ... how are you sleeping? ... and just addressing the physical things first*”.

The process of witnessing a client begin talking about their BC was what Alison referred to as being “*the grenade in the water*”. The way Alison defined that

statement was *“You know... It wasn't there before, and you could just go along ... avoiding all the things you might talk about ...”*. Further explaining her comment, Alison's interpretation was that the grenade in the water meant that the focus on a client's BC brought a powerful imperative to the therapeutic relationship, because *“obviously when you're talking about death it changes the conversation”*.

What Alison reported as central in bearing witness was that she felt it important *“to understand the context of [a client's] world and what's important to [that client] ...”*. She would simply ask a client to *“... tell me a bit of this story”*. Alison had also witnessed the additional emotional and physical tension aroused in some clients by attending what may be their first ever series of counselling sessions. She commented *“you know, people are sitting there, like, oh, (mimics person sitting tensely on the edge of their chair)... and maybe by the end ... they may have ... aaah, it didn't kill me (Alison indicated a client's release of physical tension by settling back and relaxing), this woman didn't eat me; this is not so bad after all”*.

Bridget made the statement that *“counselling people with cancer – its not hard work”*. She also talked about the value of the counselling relationship and the need for counsellors to have the capacity to offer women a safe and protected psychological space because:

for me, it's very ... soft ... (in a very soft voice) .. it's like there's a delicacy with it ... you have to get them to the stage of ... acceptance and, you know, the grief and the sorrow has to ... almost be at one. They just have to let it out ... however they can...”.

By way of example, Bridget mentioned one client in particular whose life story she felt had never been fully heard and known. *“And I remember thinking about this with an elderly lady who came in for breast cancer, but totally related her story to miscarriages. She was 66 and her ... trigger ... was right back to her loss of three pregnancies...”*. The experience with this particular client was a reminder to Bridget that *“as a counsellor who's going to meet these women, that everybody is uniquely different in relation to how they perceive what breasts are about in their world ... who they are in the world”*.

Bearing witness to the uniquely lived experience of BC was regarded as a “*privilege*”, an opportunity to observe as women “*re-invent themselves*”, as they faced the professional challenge of being “*ready to let them fall, but also ready to lift them up*”. The participant counsellors each saw the support they provided as an important part of helping women with BC live more in the present, and to be alive and vital in a feeling, sensing way.

6.5.2 Passionate work: “*Not just putting bandaids all over the place*”.

The idea that as counsellors each were bearing witness to stories of distress, emotional torment, or trauma, exposed a second major theme. That second theme was one of being useful, effective and making a difference for the women counselled. The responses from the participant counsellors indicated that they held a clear focus about the nature of their work. For them it was a case of not applying, to a woman, a therapeutic ‘disguise’ so that the women might appear more organised, more able to cope. BC was acknowledged by each of the counsellors as generating an inwardly chaotic emotional state.

In relation to this theme Mardi talked about how “*it’s nice to feel you make a difference and not just put bandaids all over the place*”. The ‘bandaid’ effect Mardi spoke of related to the value she felt emerged, for both client and counsellor, from the counselling process. For Mardi it was meaningful work “*being involved in people’s lives, making a significant difference ... helping people get through difficult times...*”.

Mardi talked about working through the fear that couples felt when confronted with BC and the common result of stress-related breakdown in communication within the partnership. She recollected that she had felt heartened when a BC client commented that their family had previously tried counselling to reduce negative communication, with no positive outcome. Their experience of the counselling process with Mardi brought the comment that their work with her had been “*really fantastic*” and they felt “*on track now*” and as a family “*we’re all happy now*”.

Alison stressed the importance of working compassionately with a survivor of BC. Her comments acknowledged the reality that a lot of BC survivors “*they’ve never been to counselling before*” and now a diagnosis that has the power to end their life has brought them to her therapy room. She referred to cancer as a catalyst for discussion about mortality. Alison said that the counselling sessions were a time when the survivor - and their family – could “*talk about matters that perhaps have been left to attend to one day, or preferred never to attend to*”. For Alison, counselling support for a BC survivor was time and space to listen to themselves, to find what it is they want to talk about, and have their experience honoured and respected in a trusting and compassionate relationship. “*They need to be able to trust me*” she said. This comment brought to attention the dramatic effect a BC diagnosis can have for a person who has never considered exploring their personal niche in their lived environments. Alison felt that if a survivor has had a previous negative experience with counselling, has limited understanding of what counselling is, or how it can help, or if they attend counselling as a conciliation to suggestions by medical or family support, then a trusting relationship with her would be important before they would feel safe enough to express the inexpressible. Alison felt that to work compassionately was to “*understand the context of [your] world and what’s important to [you]*”.

Bridget talked her observations of the importance of being aware and sensitive because “*there are fears and anxieties that they hadn’t even considered*”. Helping the BC survivor build awareness of their emotions was for Bridget “*the biggest thing*” in her work. She commented that cancer is a family experience for some people. Genetic counselling about the likelihood of BC was something Bridget observed as likely to generate anxious concern. In her statements about her work with survivors Bridget made a point of working with sensitivity to the fact that some people take the attitude ‘*Oh, I’m going to leave it [testing] until its necessary*’, and others had a mindset of ‘*I’m going to get every test under the sun and prevent it*’.

Each of the counsellors spoke about their work as offering challenge. Apart from the challenge of working in a ‘sea of stressful emotions’, they acknowledged the unique opportunity to step back from offering a cognitive map devised by another person and applying that framework in bandaid fashion over emotional wounds that

require a more agile, flexible approach to emotional support. That agility and flexibility was mentioned by the counsellors, not in those exact words, but commented on in their discourse as having the capacity to work with whatever comes through the door in ways that are helpful to the client's varied concerns.

6.5.3 Personal challenge for counsellors: “I don't want them to die”.

Despite statements about the love they have for their work, Alison, Bridget and Mardi each referred also to the challenges inherent in daily involvement in a domain of distress, fear, loss and grief. The three counsellors referred to challenges in different areas of their work. For Mardi the challenging aspect of working with women with BC was the heightened awareness of her own personal values. Bridget referred to challenge in letting go of theory, of developing self-kindness and self-care in the process of caring for others. An overall concern for the future wellbeing of younger women diagnosed and treated for BC was a common theme amongst all three counsellors.

For Alison the challenge was primarily twofold and centred on the uncertainty of the person referred for counselling as well as the conversational exchange that can happen and individual needs that arise when family members come together to discuss a distressing event. A secondary challenge for Alison related to the fact that as a counsellor she is not always aware of a future prognosis or eventual health outcome for her clients. Her comment highlighted this challenge:

but for me I think the most challenging thing is always ... I don't want them to die. (Very long pause) That's the most challenging thing, and you know that some people will [die], and that sometimes you won't know. You won't know... I don't have their six monthly report of you know, how they're going ... that is the most challenging thing ... I don't want them to die. I just don't.

Alison felt that the not knowing whether the client with BC lives or dies was a significant landmark a counsellor in cancer care needed to come to terms with and accept.

Managing the individual expectations of family members of the person with BC can present in-session challenge for a counsellor. Alison pointed out that family

members have their own agenda about what needs to be addressed in a counselling session. The challenge in this scenario is, as Alison highlighted:

The client says what they're wishing to speak of ... and should they be bringing other members of their family, which they may do in the progress of our time together, the family members may come in and expect to be part of it, and so often they will bring up things. And then they might go off, but something's been brought up ...

To clarify her comment that a client “*might go off*” Alison said this referred to the challenge of working with a family where one or more of them expresses strong emotions about the situation. As an example Alison recalled a family of nine (all adults) who came to her for counselling after diagnosis. Her response was to help each person work with “*stuff that comes up*” in the sessions.

Alison's comments about what challenges a counsellor in the field of BC faces meshed neatly with the challenges spoken of by Bridget. The language of BC and the way of communicating with a woman with BC was a challenge Bridget spoke about. Her words accentuated the notion that sometimes there are no words, nothing that can be said that will make things better and the challenge of sitting with a woman's emotionally painful feelings and simply holding the space open for them to express in whatever way they can:

So the challenge is ... the language often ... that you use so ... what is it like? ... what [do] you know? The challenge is just staying with that ... and it might be tears for weeks and weeks and weeks... before they can even say. It seems like a long time. It's quite challenging for me to be... to sit there and think there's any words that's going to come that's going to be of help.

As an illustration of this point Bridget spoke about a client who was “*so beautiful to look at ... stunningly attractive*” but who, on reflection, Bridget said had “*no self-worth at all*” and was about to undergo a double mastectomy. Bridget was moved by the lengthy struggle this client had with “*grieving this sense of who she was*”.

Bridget commented further on her experience of professional challenge: “*I have to say to them ‘It’s challenging to begin with. It’s very difficult for me to even have an understanding of what this is going to be like for you so. Can you help me?’*”

The organisational setting in which Bridget counselled also presented a challenge for both counsellor and client. A busy hospital, in Bridget’s experience, limited the potential for a woman to have enough time and a space ideal for exploring feelings in a way that could help with overt expression of emotion, working toward greater self-understanding, and discovering self-compassion:

You know it’s always in a place where there’s a lot of intrusions ... on the ward, and a lot of times you see them really just being very vulnerable and then ... sitting up ... somebody’s coming in ... so they move out of it.

6.5.4 Physical changes and being real: “*Its about how they actually see themselves as women – They’re supposed to be all things to all people*”.

The place of self-compassionate relating in BC survivorship was accentuated when the counsellors spoke about their observations of how women managed physical change and their relationship with their body after treatment for BC. In regard to this, Mardi had observed that:

It’s really about how they actually see themselves as women, as ... individuals, as mothers, as wives, as partners, or whatever it might be ... and that takes a while for them to really understand the significance of ...um... whatever the treatment might have on them.

Mardi explained that some women “*really react really strongly to any of the physical changes that they go through – they really find it so confronting*”.

In a discussion about the impact of treatment on a woman’s relationship with the body post-BC Alison commented on her observation that many women found themselves significantly confronted by changes to their body from surgery and also the strenuous physicality of treatment regimes. Alison spoke about her way of inviting women to reflect on and talk about the reality of their body image prior to BC. She said this was not to deny the huge impact that surgery, radiation, chemotherapy, breast reconstruction, or scarring had on the women, however, she

saw the relationship with their body as a larger issue to be brought forward for discussion. Alison's comments were that each woman may have a different idea about what is important to them about their body, as well as what they feel is important about being a woman.

Speaking specifically about clients' sense of personal attractiveness, Alison felt that for most women "*Oh, everything goes*" and in this statement she was talking about changes such as those that take place in or to a woman's breasts, hair loss, and change in body functioning. However, Alison mentioned one exception, a woman who as a result of BC had engaged in counselling with Alison, and who was clearly able to exert her sense of personal agency in her own way:

Except for the darling one who said I'm just going to get them nipped and tucked and they're going to be perfectly level and she said "I've even said to the surgeon ... 'Oh, what are those things... that you make the level... a ... spirit level...'" she said "Never had even nipples before. I'm gonna have them now". She was so funny. She wasn't grumpy. She wanted to survive and she wished to be light-hearted in a very constructive way.

Bridget spoke of the post-treatment body with which a woman has to build a new relationship. She described some women's reactions to treatment for BC by recalling their comments such as "*it's like you're just a piece of meat*". Bridget talked about the effect on women's psychology from "*invasive*" but life-saving procedures that involve a woman's breasts. She made the point that burns and blisters as a result of radiation therapy turn a previously special area of the body into something that is painful and "*scorched*". Bridget also raised the issue that post-treatment women begin to change their style of clothing and prefer to choose "*very baggy clothes, very loose fitting*" to avoid irritation to the breast area. Women also seemed to need time, Bridget said, while they were "*in the process*" of treatment to experiment with clothing that will provide what is most nurturing for their body after treatment.

Bridget spoke further about the focus on physical wellbeing and the relief felt by a woman when each stage of treatment is successfully navigated. She also pointed out the initial experience of excitement as their body heals. However, she hinted at the temporary setback to that relationship when after-effects of treatment can

interfere with a woman's feeling of femininity. For Bridget one thing that stood out was the fear women experienced when first seeing themselves "*without that part of your anatomy*". This comment linked to comments from Mardi and Alison about BC taking women to the point where they include in their focus what it is that is 'real' for them.

Revisiting her comments about the non-negotiable task of relating to their post-BC body, Bridget stated that:

It's very traumatic to go and look at yourself that first time with these stitches and...even to feel it ... So the initial trauma from hearing cancer, having an operation, and having to visually look at it.... It's a big challenge there for them. And not knowing how they're going to look - especially with a double mastectomy ...

In relation to "being real", Mardi's work with BC survivors had given her the impression that personal values and revising a sense of what is important in life featured strongly in recovery. Personal values and personal empowerment were also emphasised when Alison referred to one woman in particular who struggled to stay with her own decision not to have breast reconstruction, despite her husband's expressed desire for his wife's body to be re-constructed in a way familiar to him. Commenting that not every woman felt as that particular client had, Alison emphasised the highly individualised nature of a woman's relationship with her body. Alison reiterated her interest in understanding the nature of the woman's pre-BC relationship with their body.

Both Alison and Bridget emphasised the effort they had observed in a woman's journey in her attempts to move beyond BC. Their conclusion was that on completion of treatment women sought to regain a state of personal integrity, a state of "*being real*", and of beginning to allow a kinder, more authentic self-relationship. Finding what was now 'real' was part of theme four; the theme about women with BC having to relate with themselves as different physically, emotionally, sexually, socially and spiritually.

The challenge to a woman's sense of femininity, the rebuilding of a relationship with a changed body, and being real connected to a further theme that was a focus for all three counsellors. The theme that emerged in their conversations was BC and younger women, particularly in relation to sexuality, death, and dying.

6.5.5 Youth, sexuality, death and dying: “*For them - It's just one thing on top of another*”.

In contrast to an emerging view in the field of BC care about the need to monitor, evaluate and meet the needs of the older BC survivor, older clients Bridget had counselled seemed to cope by doing what they may have always done, and just got on with life without expecting that their needs in survivorship would be something they could ask for help with.

Mardi, Alison and Bridget each made comment about the added dimension of distress for younger women going through treatment for BC. As counsellors they felt acutely aware of the un-lived life for a survivor who had children to raise post-treatment, or for whom treatment meant denial of giving birth to a child of her own. Bridget summed up her comments with the observation that “*the women in their 60's are very much more matter of fact ... stoic ... get on with it*”.

Bridget recalled two young women with BC each of whom had an image that she would be stoic about BC until she herself was diagnosed. She spoke about the change of mind that happened for both when they were diagnosed with BC. Prior to diagnosis both young women felt that BC was just a matter of fixing the disease with medical treatment and then getting on with life. One of the women commented that because BC is “not part of your life” she would have felt less empathy and compassion for women in survivorship.

For Mardi, diagnosis for younger women was as if life had become “*one thing on top of another*” for them. She commented that BC meant the “*whole notion of themselves changes entirely*”. Mardi's comments related to her understanding of the aggressive nature of premature menopause as well as her knowledge of the effects of “*long-term treatment of the drug that they're on*”. Her perspective was that the changes to both physiology and psychology were undeniably life-changing:

I find the young girls ...lots of them really struggle with losing their hair. That's almost a bigger thing for them, and they really, really find that very, very confronting, and yeah and ...um... and then the decisions about what they might want for themselves as far as reconstruction goes.

Alison also talked about feeling especially touched by the efforts younger women had to make to engage fully with BC as a long-term companion both in their life and in the life of their husband and children. She reflected that young women feel the shock, not just of the health implications of BC, but a reverberating shock that *“this is not how its meant to be”*. In that comment Alison was referring to the abrupt ending to assumptions about health and the future. She added that young BC survivors with school-aged children worry about how everyone in the household will cope with the demands BC places on a family.

The topics of sexuality and sensuality for a woman post-BC, and self-compassionate relating with oneself as a sexual being, drew substantial comment from Bridget, Mardi and Alison. All counsellors referred to changes to sexual functioning and a woman's sense of being a sexual being for the younger BC survivor as *“life-changing”*. In terms of sexuality and sensuality, Bridget made the point that the age of diagnosis and treatment made for significant difference in the after-effect on a woman's sexuality and sensuality. Her comment referred to the absence of one or both breasts and the difference this would make for a younger woman who is sexually active, or who desires to be available to an intimate relationship. This issue was highlighted by Bridget and Alison as significant when counselling the younger survivor.

When personal attractiveness was intimately linked to an acceptable physical form Alison stated that loss of a breast and the resultant scarring heavily influenced a woman's notion of herself as a sexual being. She commented that many clients who have had a mastectomy feel embarrassed about seeing themselves naked. Further comment from Alison emphasised that *“there is something about femininity and womanliness, and I suppose the breast is part of being a woman, its her shape ... its such an obvious thing ...”*. On this same topic Bridget made reference to the high

visibility of both single or double mastectomy, stating “*it's a huge life-changing event because its so visual ... they can't hide it ...*”.

The change in sexual functioning was something Mardi felt particularly relevant for younger women with BC:

Plus along with that [menopause and drug treatment] is the sexual difficulties they may have particularly related to loss of libido and perhaps vaginal dryness and those things. For some young women it's absolutely life changing and really distressing ... Because for the young women it really is very, very difficult ... they might have had both breasts taken off, perhaps reconstruction, but perhaps sometimes that's delayed ... as well as losing their hair because most young women would have chemotherapy, plus then thrown into menopause all on top of one another ... and often dealing with little children as well ... and so they're dead tired and fatigued, and it's just one thing on top of another.

Sexuality and being able to make a decision about having a sex life were aspects of life Alison thought were usually put to one side while the more immediate question of physical survival and the demands of the BC treatment regime were addressed. For Alison the question of death and dying commanded greater attention in the time immediately after diagnosis. However, Alison also commented that she felt each woman had her own unique time for directing her focus towards reconsidering her sexuality.

On the topic of mortality, Bridget referred to a liminal space that becomes a feature of life after diagnosis. Although BC impolitely confronts a woman with her own mortality and activates the struggle for survival, Bridget reflected on another facet of BC for women who survive - fear of what the future might hold:

Maybe its not so much the fear of dying, it's the fear of being different, or looking different, or “Can I still make love to my husband, or will he still find me attractive?” So there's a lot of fear going on, so if you can bring it out and say its ok, but lets see what you're really afraid of, we might, eventually, get to the fact that “I'm not intimate with my husband” ... and that's a big thing to say.

Because of her understanding that BC is “so... curable”, Bridget commented that “*the cancer, per se, doesn’t come into it so much as it would with the diagnosis of [a different] cancer where existential issues come up*”. Despite that comment, the existential issue of fear of death, opening the conversation about death and dying and contemplation of their own mortality was regarded by all three counsellors as a strongly salient, and distinctively fear-inducing ingredient in the personal crisis initiated by BC diagnosis and treatment. Despite the fear, Mardi pointed out that her observations of women with BC was:

Initially they'll be dealing with what they've got to do, how they can do that, and they keep themselves really busy. But ultimately it is the feelings and emotions that they're really grappling with that often takes them a long time to start to deal with ... things of the heart.

Mardi spoke openly about a professional challenge for her in working with younger women diagnosed with recurrent BC. Her comments linked to those she made relevant to the third theme of challenge for the counsellor in working with a vulnerable population such as BC survivors:

Women who have secondary breast cancer ... and perhaps ... when they're initially diagnosed and the ... the reality of their situation, but yet not lose hope, and not lose a sense of who they are in amongst it all when their treatment is so constant. Often they're having chemo weekly and that might go on for years ... and you know with all the issues of family life around them ...and the small children, often babies, and stuff like that ... it can really be quite stressful for them and really difficult for relationships ...

Mardi continued to talk about the process of re-prioritising life that some women with BC embark upon:

I think it all opens up. You go through a life-threatening illness and sometimes it will take their lives. I think that it helps them to re-evaluate where they are in their life and what they might want for themselves and their family that's perhaps lost along the line.

Discussion about sexuality, death and dying and younger women with BC led to the major theme of some of the challenges women face when their sexuality is

impaired either in the short term or the longer term. The life-changing effect of BC for younger women at a time in their lives when they may be raising their children, and simultaneously may be coping with a recurrent cancer was commented on with empathy and compassion by each of the three counsellors.

6.5.6 The chaos inside: “What if it doesn’t work”.

Bridget talked of her observation of there being “*chaos inside*” for many survivors. She said her work with women had led her to conclude that many women felt a lack of certainty about who they were. Bridget felt that the many roles women fulfil tended to dilute their capacity to stand forward in one particular way. Her comments were that women’s thoughts turn to: “*I am... trying to be mum, trying to be wife... trying to be... whatever they’re trying to be ... (reflecting on her own words) ... professional*”. Fear born of the loss of control was also a focus for Bridget:

But fear is there ... “what if it doesn’t work?”, “what if I’m one statistic that doesn’t survive?” ... and I think its about addressing the fear and saying its ok ... to be afraid... but “how can I live with that fear?”. And its still there, “but how can I live differently?”

Her work with women with BC had led Mardi to form an impression that the treatment process absorbs women in an initial “*loss of control*” and a subsequent “*regaining control*”. Fatigue, premature menopause, and the impact of medication were acknowledged by Mardi as significant factors in generating feelings of loss of control and the surrender of a sense of personal autonomy. Mardi stated that loss of personal autonomy was something present from the outset of a woman’s journey with BC. She took time to comment on her witnessing of women who she said do not feel there is enough time to come to terms with what has to happen for their chances of survival to be maximised. Mardi also talked about the women feeling like they are “*on a treadmill*” and needing to make important decisions for the future. She talked about her observation that for some women it is only after treatment has happened that they have time to integrate and then cope with what has happened to them. Drawing on her experience of counselling women diagnosed with BC, Mardi commented that once women go through treatment then the psychological challenge is about their self-identity, “*how they’re feeling about themselves and what they*

might like moving forward". This time of trying to integrate BC into their life was a very "*confronting time*" said Mardi.

Alison highlighted the torment some women encounter when they find themselves wondering and worrying about "*How did I get it?*", "*Why did I get it?*", or "*What did I do wrong?*". This 'wondering' that Alison talked about was not spoken about by the women survivors in the findings for this study. In contrast, a significant number of the women participants said they made a firm decision not to ask themselves those questions. Alison also commented on reports from clients who, in their counselling sessions, felt distressed because their BC had not been "*picked up as early as it should have been*". Alison used the term "*rage*" to describe the emotion expressed by those of her clients who felt their BC had been missed or misdiagnosed.

On the whole Bridget and Mardi confirmed that the transition from diagnosis, to treatment, to survival (or not) was a chaotic time when a woman was presented with needing to make her way through the medical system in a way she had never needed to do until diagnosis. The comments from Mardi provide a link to another important theme – a theme of being different, but wondering what that would mean, and knowing that being different means there is a need to embrace a new sense of normal.

6.5.7 I'm different, but what does that mean: "*A new sense of normal*".

Diagnosis and treatment for BC, according to Bridget, means women "*certainly join the world of cancer ... which is a different world*". Encountering themselves in a different world and of relationships no longer being the way they were prior to BC, meant adjusting to what Mardi called "*a new sense of normal*". This encounter and adaptation to a new sense of normal was described at length by the counsellors. Referring to women's adjustment to a changed self, Alison's perspective was that "*They work out the people who are good for them and who are their friends, their real friends. Who could be real and comfortable and listen to them*".

Many of the women Bridget had met post-BC were able to frame the experience of entering that different world within themselves as opportunity. Bridget commented:

The whole world opens up, where they have to start to really look at what has meaning and purpose. What is life really about? A lot of them turn it into an opportunity to say, "You know, well, here I am now, and how can I live life as well as I can".

Conversely, in referring to other women who encountered significant change in worldview, lifestyle or way of relating, as a result of BC, Bridget said they struggled with trying to accommodate, or integrate, their post-BC different self into a life they had created pre-BC. Bridget pointed out that some women choose to reject the life alteration that BC offers. Her interpretation of their choice was that some survivors of BC find it easier to resume an existence in which they are the person *"that somebody [else] wants them to be"* and live in a way that others need them to live. Bridget stated, however, that the discomfort of others, who no longer recognise the woman who has survived BC, underpins the decision to try to fit back into the pre-BC life. But, their identity, values, and energies are changed *"without a doubt"* said Bridget.

In her comments about fear, difference, a new sense of normal, Bridget defined what she saw as a 'hunger' in women survivors of BC for a deeper level of connection with themselves and others in relating:

Because often the people ... who go to the place of unwrapping and grieving ... go to a different relationship with themselves because they want 'real' ... they're always saying there's no time ... especially the person who changed totally ... she's [saying to herself] "Just get on with life" ... but it's really about "How do I live differently ... And ... It's not preparation for dying, it's "How does it teach me to live differently?"

The search for a way to live differently seemed to involve conscious reflection about how a BC survivor relates with herself. To live in a way that means normal life activities can be experienced in a such a way that rumination, self-blame

and self-criticism do not overpower the capacity for self-kindness was a theme highlighted by each counsellor.

6.5.8 Self-blame: “I’m normally the cause of their happiness”.

Being the one who causes of sadness in those they love was a theme that underscored the complexity of self-criticism. One aspect of self-criticism that added complexity was the feeling of unwittingly imposing an additional emotional and financial burden to a family. For Bridget self-criticism wasn’t always about being overtly hard on self and driving self into being, for example, a workaholic, or self-destructive. During her interview, Bridget was able to bring our attention to subtle variations in the ways in which her clients had criticised themselves:

This particular woman was so much the protector of her children. She was always providing for them. And she felt it was a responsibility of hers that she’d got this cancer and they were in sorrow. And often that comes up that they have a sense of responsibility ... it’s more the responsibility of the sadness that it brings to people. ‘I’ve got cancer and I’m the cause of their sadness, whereas I’m normally their mother who’s the cause of their happiness’. This is what they say ‘I don’t want to burden them with my... um... cancer’.

The potential lifelong influence of early life modelling on self-relating was also mentioned by Mardi when she spoke about a tendency for self-criticism and for a woman with BC to feel like she had created a burden for her family and friends:

I guess ... a lot of it is to do with family of origin ... and how they were brought up That’s why it’s so important to go back and to really look at all of that. A young woman who’s grown up in a very critical environment often ... really, really struggles with that critical self a lot more.

The complex origins for a woman of feeling like she is a burden or of engaging in self-criticism was also mentioned as having its genesis in some adverse life event that had been held as secret, perhaps for a long time. In regard to this Alison referred to life events not spoken of, and of BC becoming a impetus for some women to finally talk about something they might regard as “some kind of sin”:

Sometimes, before their marriage, some things within their marriage ... like ... an abortion, affairs, or things that had not been.... they wanted to talk about them. Its like saying ... its almost like some kind of sin that they've got ... giving them the 'whoops'. It [the issue] comes up, and its "I want to talk about this now". There's some kind of burden, this guilt, which I always say is ... one of the most negative non-constructive emotions that any of us can have ... to relieve themselves of this ...

Alison then described her perspective of self-criticism as psychologically toxic, as well as being exhausting and corrosive for the person burdened by self-criticism. Her view was that *"It comes from a place of resentment, and 'martyring', and self sacrifice, and that is ... that is pure poison ... I think ... inside"*.

6.5.9 Time to heal and grow: *"It's a long process"*.

The need was identified for clients to allow time for the process of healing and making personal change. For example, Bridget likened the process to a particular stage in a person's mourning process, emphasising that building self-acceptance and allowing herself time to grieve was important for a woman. Bridget also made the point that recovery from treatment was not a quick fix, and to her this meant women survivors becoming cognisant of giving themselves permission to grieve:

It's too early to re-set any ideas of if there's going to be a future or not, and how am I going to be. And because it's a long extended time... [emphasising] and it can be a long extended time ... you just open the door and ... it's very much an open door. It's not something where you say to the person "OK, seven sessions, you're going to come in and have at least . ." It doesn't happen that way. Not with cancer, breast cancer. It's very different.

Bridget extended her commentary about clients' needs to give themselves permission and acceptance to do less and be *"not the sort of person who's at the helm all the time. And it might have taken them that length of time for them to get there. It's not a quick fix"*. Bridget's interpretation of the experience was that there has often been a lifelong process of living with, regarding, and relating with oneself in a particular way. Reversal, for some women, of the way they have lived up until diagnosis, is something that Bridget considered could not be turned around within a

short space of time. For her, an emotional healing process was something that was, for most women with BC, going to take time and also needed time.

Time to heal and grow was felt by each of the counsellors as a missing element in the recovery process. They felt that the physical body did not take so long to recover from treatment, but the emotional and spiritual being of a woman needed much more time. Their comments about emotional healing needing time and space pointed towards the next major theme of self-compassion.

6.5.10 Self-compassion: “*Finding self as important as the other - It’s like a blossoming*”.

The themes from interviews with three counsellors recorded their impression that life for a woman post-BC is, from the perspective of the counsellors, not so much about physical change, but more related to how the woman actually sees herself - as a woman. Bridget and Alison talked of the realisations some women come to that they had expected themselves to be “*all things to all people*”.

During the interviews self-compassion emerged as a topic that the counsellors felt was not well understood or integrated into the lifestyle of many women prior to diagnosis and treatment. Therefore it was a skill to be developed and added to a toolbox that a woman could take with them into survivorship.

Talking about their perception of self-compassion, Mardi, Alison and Bridget all recalled instances in which a woman had blamed herself for the diagnosis. They talked about how some women acquiesce to pressure – internal and external - to return to normal and so do not allow time to find out who they are and what they need now. Each of them also stressed their perception that women with BC needed to engage in more self-care. When she spoke about the harsh effect of self-criticism on a woman’s wellbeing, Alison added:

... talking about breast cancer. It's a lot of learning about ... self care ... and I always think ... delete, delay, delegate in your diary ... the three d's ... in your diary ... and look at that ...and practice that ... do that like it's a meditation... notice that ... its part of that self care ...

Self-blame and self-criticism were emphasised by Mardi as something she commonly observed in the women she had counselled:

Well, most women will come in and say ... well, I know why I got this, or there's certain things going on. They're really tough on themselves a lot of the time. "I've been too stressed, I haven't looked after myself well enough, I haven't ... you know my diet's been terrible", whatever the reasons might be. And there'll be a multitude of different reasons, that they really attribute some sense of blame to themselves... While they're struggling with all that they really forget to just start to really be nice, and care, and be kind to themselves.

Alison also pointed out the extent to which self-blame played a negative part in her clients' psychological well-being. Speaking of one client in particular, Alison repeated the client's comment about "[I] must have been a naughty child that's why I've got breast cancer".

Alison continued with her recollections of ways in which women blame themselves and are not self-compassionate:

And there's this blame thing that if only I'd lived a different life, hadn't drunk so much, hadn't had sex with so many people, not been such a bitch to my mother, or whatever it might be... or didn't work so hard, I wouldn't have had breast cancer...

Bridget too mentioned one particular client who was ready to blame herself for the diagnosis asking "... is it because I drank when I was a teenager?" A point of interest for Bridget was her perception that, prior to BC, women often had little awareness of the value or need for self-kindness, stating that "I'd say 80% of them don't have it [self-compassion] beforehand. They don't ... 'cause they're not aware of it so much". However, Bridget had noticed that post-BC a significant number of the women she worked with did begin to focus on self-discovery in a self-reassuring, kinder, and more self-valuing way:

But going through the process, and having a different change in values and beliefs they do begin to do a lot of it ... a lot of work on themselves, they do allow themselves, and give permission, and start to see themselves

differently ... and ... not so much differently even ... its more finding themselves as important as the other.

Mardi's professional reflection meant she was also aware of a sense of contentment she herself experienced when a woman's self-relationship began to change. She commented that "... it's really lovely to see, too, when they start to honour themselves a little bit more." However, Mardi made comments that also emphasised learning to value self was not always a straightforward path:

Some people when I first start to do some work in this area of self-compassion, they worry that they're going to become selfish, or self-centred or whatever. And so gradually they start to see that it's about nurturing and looking after themselves, and they then have the capacity to look after others - their family and people that they love - in a completely different way.

Mardi talked about her way of introducing the concept of self-compassion within counselling sessions. She said she invited women to breathe, place their hands on their body and "*feel the warmth that they can generate for themselves*". Mardi had observed how responsive her clients were to her invitation, saying they realised they could "*slow themselves down ... centre themselves ... and feel a sense of caring for self*". Her comment was that there was a lot of self-blame going on at times and so introducing self-compassion in a gentle, non-threatening way meant "*you can just move that a bit and start to be kind to yourself*".

Alison mentioned that she talks about self-compassion "*with all people, wherever its necessary*". She then reiterated a point that was recurrent in her interview. The point she wanted to make was of the importance of women coming to a place inside themselves where they can begin to move towards feeling empowered in their lives:

Its like ... "this is my choice, I'm choosing to do this, this is something I can do" ... whether they're coming along to counselling, or whether they're choosing to do something ... doing some Reiki, some meditation, choosing to eat carrots all day or whatever, they're actively involved in their own ... and the more collaborative ... and I know they're all words like 'empowerment' ... but its like "I'm doing something ... I'm doing something for me, I'm

picking out the ones that are right for me, and don't tell me, but I'm having a go at these different ... and working out which ones work for me".

Bridget felt that women tended to leave themselves out of the care 'equation'. She said that self-compassion meant *"giving ourselves permission to just be in the world"*. Her observation from her work with BC was that *"self-soothing is our only way, really. And if we wait for other people to do it, it might never happen"*. Bridget said she encouraged her clients to first give to themselves what they would give to others. She pointed out, however, that her perception was:

80% of them don't have it [self-compassion] beforehand. They don't ... cos they're not aware of it so much. But ... having a change in values and beliefs they do begin to do a lot of work on themselves, they do allow themselves and start to see themselves differently ... not so much differently even, it's more finding themselves as important as the other. It's like a blossoming ... it's like all the nourishment ... and so the nourishment comes from themselves, from within, not from without.

Bridget spoke with an optimistic voice about what she called a "blossoming" process. This process was something Bridget felt she had witnessed when women were able to include self-kindness in their internal self-orientation. Likewise, adopting a psychodynamic perspective, Mardi felt strongly that the first step in the process of life reconstruction begins with finding self-compassion. She felt this was necessary before being able to explore self-identity and the ways in which a woman had constructed or accepted life pre-BC. *"And it starts with compassion, with being kind themselves ... and then you may be able to look at all the other things later on down the track"*.

The counsellors each commented that not all women were able to journey with ease from the self they had known, and cross a threshold into a new way of relating with themselves self-compassionately. Bridget talked, for example, of one client whose prognosis was terminal, and yet who needed to maintain persistent external denial in the face of an uncompromising reality. What Mardi, Bridget and Alison had noted as a beginning point to being more honest and open with a counsellor about fear or distress was when a woman survivor 'crossed' a

psychological threshold into a new realm of relating with themselves in a kinder, more self-honouring and more self-valuing way.

The counsellors talked about there being a capacity in women to initiate and drive substantial personal change. This they said was particularly so for women post-BC. All three counsellors talked about women's ability to bring awareness to the bigger questions of life, and to create values and beliefs congruent with a changed body, a different relationship with their body, and with clear knowledge of what motivated their desire to survive. Bridget called it "*reconstructing life*", however, she added that this time they could be supported with the help of a toolbox of emotional skills with which they could construct - or reconstruct - their life.

6.5.11 Survival and reconstructing life with a toolbox: "*I have evolved*".

Mardi's experience as a counsellor had convinced her that part of the process of helping a woman reconstruct life involved exploring with the client what it is that each woman valued and wanted to retain in her life post-BC. Mardi said she felt that this process aided a healthy embrace of what it was like to be empowered:

So I think for most people the whole searching ... and even ... that discussion about what are your values and what would you stand for, can really be very empowering for many of the women.

Alison spoke at length about the potential for positive life change that women with BC had identified in their counselling sessions. At the same time as acknowledging that "*I know they didn't want to have cancer, but all of them in all their different ways and all of their different ages say ... 'I am so different', and 'I don't want to go back to being that person'.*" To elaborate on her evaluation of the situation, Alison recalled a number of related statements she had heard from women with BC. Some of the comments included "*I am much more this person that is me. I've made changes*". Other women had commented that "*relationships are different ... they're more real*". Yet others had said to Alison "*I'm a better friend. As in ... I don't mean better, better, better ... I mean I am ... I have evolved*".

Bridget explained that she regarded BC as an opportunity, a catalyst for change that women might never have found. However, after commenting about BC being a challenging but growthful opportunity Bridget hastened to add *“not that anyone would choose to have cancer [in order to grow]”*. Her assessment of what happened for some women was that there was a type of ‘honeymoon phase’ in which there was a sense of excitement. The excitement was the feeling accompanying the discovery that the person has a sense they have what Bridget called a *“toolbox”* with which they can reconstruct life. The toolbox Bridget referred to was women being able to leave the world of cancer treatment with new-found awareness of self, new skills for ways to understand and regulate their emotions, and a sense of meaning and purpose to their experience.

Excitement was also generated, said Bridget, when post-BC women come to accept *“all we’ve got is now”*. This meant the women had developed an attitude that they can live in the world with a sense of immediacy and only thinking about the present, rather than, as Bridget reported, thinking ahead all the time and thinking of others’ needs. Bridget felt that women survivors lived with hope as an ever-present companion, and at the same time had to exist within a reality that embraced fear of recurrence. She was of the opinion that her role was to help women grow, while at the same time Bridget felt certain that her role was not to give advice or strategies for living. Extending her comments, Bridget stated that *“we [counsellors] give them a chance to practice, to play with [ideas]. And you know, intuitively that person will grow. But as the counsellor, you can’t do it, you can’t get them there, you have to give them the space to do it [grow] for themselves”*.

Comments were made by all three counsellors about reconstructing life, but doing so with what Bridget called a ‘toolbox’ that would include women having the skills to be able to make emotionally supportive responses to themselves as a way of self-soothing and self-calming.

6.5.12 Section summary

This section presented themes identified from interviews with three female counsellors who had provided professional emotional and psychological support for women with BC. The initial five themes related to impressions developed by the

counsellors from observations and experience in their work. The first theme “Bearing witness” related to the counsellors’ impression of themselves as being privileged witnesses to each woman’s efforts to survive and to make healing change in their life. The next theme “Not just putting bandaids all over the place” referred to the desire by each of the counsellors to support women in meaningful ways. A third theme involved comments about the personal challenge in working in a professional domain where there was a need to maintain optimism. A fourth theme opened the topic of how women “see themselves” as they experience life post-BC. The ways in which diagnosis and treatment for BC effected a younger woman, how it effected a woman’s sexuality, and the question of survival were all part of the fifth theme “It’s just one thing on top of another: youth, sexuality, death and dying”.

Themes six to eleven highlighted “The chaos inside”, along with the concern women have that “I’m different, but what does that mean? Sadness about the change from a position where “I’m normally the cause of their happiness”, led into the need for “Time to heal and grow”. “Finding self as important as the other”, and “Survival and reconstructing life with a toolbox” focused more specifically on the women’s experience of themselves and ways in which their self-relationship could be re-formed. These final six themes shifted the focus from the counsellor to their reflections on their work with BC survivors.

Overall, the themes spoke to the fact that life for a woman post-BC is, from the perspective of the counsellors, not so much about physical change but more related to how the woman actually sees herself - as a woman. Comment was made about the realisation that women can function from a mindset that they are supposed to be “*all things to all people*”. Additionally, other comments emerged, including a woman’s perspective of her illness being a “*burden*” to others, and of having to adjust to a “*new sense of normal*”. The outcome of the BC experience for some women was the development of a capacity to draw “*nourishment from within*” herself. The essence of what the counsellors spoke about was the process through which some women would re-evaluate their life and arrive at the point where they were more kind to themselves as a result of having BC.

In their efforts to understand the personal, psychosocial dimensions of a woman's BC experience, each counsellor became a benign receiver of difficult life narratives. Therefore, through the repeated act of listening to BC narratives, it is feasible the counsellors could be vulnerable to a negative skewing of their worldview. If that happened the result might be a negative influence on their sense of meaning and purpose. The evidence that emerged during the interviews was that listening to the suffering of others seemed to create in these counsellors greater compassion and capacity for tolerance of human distress. In terms of their practice with women survivors of BC, what stood out in their comments, was a highly professional commitment to their work, compassion for the enduring challenges BC presents, as well as a desire to search for a practice framework, rather than a theoretical frame of reference, that would embrace a sense of the importance and benefits of developing self-love in women post-BC. Their reflections on the way in which women related with themselves and how women related with the concept of self-compassion highlighted the need for models of emotional support to provide pathways for their clients to locate a renewed, yet sustainable, way of creating a nurturing personal niche in their inner and outer world.