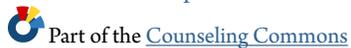

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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in
Western Australian women survivors of breast cancer

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Chapter Ten

Limitations and Future Research

10.1 Limitations

While this study has provided a glimpse into the experience of SC in women who have BC, a number of limitations were identified that, in a future study where differing populations of people with BC were to participate, greater variety in narratives may be harvested.

In this study one such limitation was related to levels of participation. Women with high motivation to support other women would possibly be more likely to have volunteered to participate in the study. Similarly, women who were open to sharing the narrative of their BC experience could be said to be more willing to take part in a study that was qualitatively driven. It could also be expected that women whose preference was to put the experience behind them and move on with life would not be prompted to participate.

A desire to avoid going back over their BC experience combined with a study that asks women to do just that creates the potential for a mutually exclusive response to an invitation to participate. As a result the experiences of self-compassion in women who a) prefer to be future-focused and not revisit their BC experience along with b) women with strong resistance to openly discuss issues such as personal growth, sexuality, body image and breast surgery, do not form part of the constructed narrative on the topic.

Age of participants was another limiting factor. For this study women from 35 – 70 were invited to participate. The overwhelming majority of women who responded were in the 45 years to 70 years age range. What this means is that the

experience of younger women who may not yet have had children, or those who have young children to care for, is not represented in the results. Neither is the experience of very old women survivors of BC able to be reported. It could be anticipated that further research with a younger population of women with BC may highlight narratives that reveal a leaning toward more personal awareness of the need for self-nurturance.

Research into the lived experience of very old women survivors of BC may point to a different process of adjustment to the disease. Exploration of women with BC who are under 50 years of age may also highlight increased levels of psychological distress. The same may be found to be true for women who are single parents. Only a small number ($n = <5$) of participants in this study were single parents. Those who were single parents took part in the interview process but did not join the focus groups or personal reflection program.

Importantly, Aboriginal women are reported to have less optimistic outcomes from BC than their non-indigenous counterparts (Reath & Carey, 2008). A significant limitation in the study was the absence of Aboriginal women from the participant groups. Aboriginal women did not participate, nor did a significant other in the life of an Aboriginal woman diagnosed and treated for BC. Several issues come to light immediately when considering the vulnerability of Aboriginal women to a decreased opportunity or likelihood of taking part in an exploration of the experience of self-compassion. In the first instance, the term 'self-compassion' may not have meaning; it may not be a linguistically or culturally relevant term. However, it is hypothesised that using a different terminology and talking about self-kindness and treating oneself well would be likely to have relevancy for Aboriginal women who survive BC.

Some of the challenges facing participation in this type of study relate to issues such as (i) the need for diverse approaches because Aboriginal women per se are not able to be viewed as an homogenous whole; (ii) the influence on health-care decision-making of diversity within Aboriginal identity and traditional beliefs; (iii) issues of power, racism and socio-economic inequality; (iv) lack of access to hospitals and medical care for Aboriginal women living in community; and (v)

Aboriginal women's cultural perceptions of counselling. Each of these factors would present a barrier to participation and would need to be addressed in a broader exploration of the experience of SC in Australian women who have BC.

An overall limitation was the lack of diversity in the demographic of participants. This limitation related to socio-economic status, cultural diversity, and marital status. The same disease can be experienced very differently in different culture and this points emphasises that varying explanations may exist across cultures for the cause of disease. Similarly, treatment preference in addition to sources for support and advice may vary according to belief systems and cultural mores. Participants in the exploration central to this thesis were an homogenous group keen to engage in a process of self-discovery and personal growth. However it is acknowledged that different ethnic groups may have negative experiences of mental health care (Henderson, Evans-Lacko & Thornicroft, 2013).

The importance of social support and stable partnerships was a hallmark of the group of women who took part in this study. All participants, except one were in long-term marriages with spouses still living. The one exception was a participant who was in a long-term marriage but during the early part of her treatment separated from her husband. None of the participants was non-English speaking, although the parents of one woman had originally come to Australia as refugees from eastern Europe when their daughter (participant) was a small child. Absence of representation from women of Asian or middle-eastern origin presented a limitation in understanding the nature of self-compassion in the context of cultural expectations and culturally-defined health behaviours. BC in women defined as low socio-economic status was not able to be explored in this study since participation was confined to women who worked largely as professionals in the fields of teaching, nursing, or administration.

All women who participated lived within a relatively small geographic area bounded by the metropolitan area of the city of Perth, Western Australia. Women living in rural and remote areas did not participate. One way to address this limitation would be to set up a matched cohort from rural and remote women alongside their city counterparts. The use of technology such as Skype to conduct initial interviews

would address the challenge of distance. Access to medical treatment for BC could be compromised for women from small rural communities because of distances required to travel for regular treatment. Alternatively, women may need to leave their community and make a temporary move to the city in order to complete a treatment regime. The notion of SC for these women may be completely different to women who are city-based.

10.2 Suggestions for further research

All facets of experience of cancer hold potential for exploration of the concept of self-compassion for moving through the experience of existential suffering, and for locating reasons to move into a new life and create meaning in life. In addition to the implications for coping with the emotional, cognitive and physiological consequences of all forms of cancer SC offers a broad range of areas of further research.

Specific to exploration of the experience of surviving BC, this study investigated the experience of self-compassion in female only breast cancer survivors. Breast cancer is most commonly portrayed as a disease of women, however, it is acknowledged that while relatively uncommon, this disease also affects males. Though the risk for males to be diagnosed and treated for BC in Australia has, in 2010, been calculated at 1 in 688 male persons (140 individuals in total) (Cancer Council Australia, 2014), it would be important to consider the experience of self-compassion in those men diagnosed. In cases where BC in males is diagnosed at a later stage, the mortality rate is correspondingly higher (Klein, 2010). The diversity in survival gap may mean men's experiences of BC would be different from that of women survivors (Forti, 2011). To explore the concept of the experience of self-compassion in men with BC could advance the understanding of male breast cancer, and direct efforts into BC-related issues that tend to become genderised.

A qualitatively-driven study to explore whether the construct of self-compassion holds value and significance for bio-psycho-social adjustment for males diagnosed with BC would have importance for development of interventions to support self-care and positive self-talk for Australian males at risk of depression.

Research into ways in which men who have made significant intentional change in their lives have been able to find their own way to self-compassion would provide significant data to develop greater understanding of enhancement of psycho-social interventions that inform cancer survivorship care for men.

Prostate cancer (PC) is a cancer that strikes at the very heart of what it means to be male. Further research into SC post-treatment cancer care conducted with individuals and groups of men treated for prostate cancer. Constructive group therapy with a focus on the exploration and development of self-compassion could be researched for the potential to bring additive influence on psychosocial gains for men diagnosed and treated for PC. For men with prostate cancer, research that can provide recommendations for self-compassion to improve long-term adjustment after prostate cancer.

Breast cancer affects not only the person diagnosed. Loved ones of people diagnosed with cancer are vulnerable to psychological distress. The spouse, family and relatives of the person diagnosed with cancer become secondary patients (Mullan, 1985). In the immediate outpouring of sympathy, empathy and support for the person undergoing treatment the needs of the family and significant others of the person identified as the 'cancer victim' can be easily overlooked or neglected (Mullan, 1985). Further research, for instance, into the usefulness of couples-focused self-compassion could provide guidance for developing resources to support improved communication and emotional health in couples. The same principle could be applied to counselling for family disharmony; psycho-education about self-compassion could be used to support balanced relating within a family system.

Applying an Attachment Theory (Bowlby, 1982) lens to the topic of self-compassion also holds relevance for research into the effects of childhood attachment style and adaptation to living as an adult survivor of cancer. Such an investigation may then provide direction for broader understanding of the relationship between a capacity for empathy and compassion in the professional counsellor and a client's emotional experience during the therapeutic process. Research into self-compassion, adult attachment and the demands of professional counselling - such as feeling the

emotions of others and responsivity to the needs of others – could shed valuable light on new ways to address professional functioning, self-care, and compassion fatigue.

Research into whether self-compassion has relevancy for BC survivors who identify as Aboriginal, as well as the relevancy of the concept of SC for subgroups of the Australian population that may have negative perceptions of dominant Western health discourse. This may be achieved through exploration of the implications of including narrative communication using, for example, storytelling or personal narratives, in preference to more informational forms of communication to develop awareness and understanding of SC. For example, group psycho-educative programs that highlight SC as part of post-treatment regimes for Aboriginal women with BC would advance insight into the relationship between self-compassion, cultural difference and the experience of BC. The potential influence of self-compassion on end-user's cultural perceptions of health care offers a research direction that could guide investigation of dilemmas in treatment adherence in a range of chronic illnesses, not just breast cancer or cancer.

Further articulation and interpretation of the importance of SC as a central tenet in counselling people with cancer of all types may help extend our understanding of how an individual's self-relationship may then influence their relationship to their health and overall wellbeing. The question of who cares for the carers of people with cancer and other forms of chronic illness highlights the need for further research into whether cultivation of self-compassion provides both direct and indirect benefits to both carer and the person cared for.

10.3 Chapter summary

This chapter has reviewed limitations inherent in the study. Areas for future research have also been highlighted.

As a recently developed domain of research, the concept of self-compassion and self-compassion training has been identified as a valuable addition and adaptive approach to managing stress and coping with adverse life challenges. The practice of self-compassion appears to offer help to significant numbers of people with a range of issues including persistent negative self-beliefs, recovery from trauma, and coping

with chronic illness treatment adherence and chronic pain. Further research is needed to evaluate the usefulness of SC as a support for people with forms of cancer other than BC, for example, men with prostate cancer. SC and its application in the training of health care workers, therapists and frontline mental health carers has been identified as an area for further research. Continued research and evaluation of self-compassion, self-compassion training and self-compassion practice as both an individual and group intervention offers a clear for ward direction to extend the range of effective, emotionally beneficial interventions.