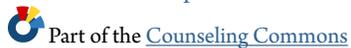

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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in
Western Australian women survivors of breast cancer

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Chapter Eleven

Conclusion

In the 21st century the power of biomedicine has made serious illness may seem something of an aberration. Humans, today, generally expect they will live a long and healthy life. A paradox is that at the same time, there exists hopeful anticipation that medical research will continue to present findings that offer higher rates of survival from illnesses and medical conditions once considered certain death sentences.

11.1 The current situation

With one in eight Australian women likely to experience BC in her lifetime the statistics on the impact of BC on the Australian population are well known. Steady advances in medical science and early detection have transformed the landscape of diagnosis and treatment for BC. Early detection of BC, an expansive body of medical research, and ongoing development in medical technology and medical procedures, now combine to offer women diagnosed improved optimism about longer-term survival rates (Doyle, 2008; Miller et al., 2016), with critical five-year survival rates increased to confidently optimistic levels (Seok et al., 2010). Those advances in treatment have led to unignorably positive survival rates. The result is that women with BC currently comprise the largest group of cancer survivors in the United States of America (Ellsworth, Valente, Shriver, Bittman, & Ellsworth, 2012; Mallinckrodt, Armer, & Heppner, 2012). The statistical data for BC survival in Australia is consistent with that of other Western countries with BC also comprising the largest group of cancer survivors (Australian Institute of Health and Welfare, 2017). Hopeful as the current statistics on physical survival of BC appear,

existential concerns are an ever-present companion for survivors of a disease where risk of recurrence can forecast a poor prognosis (Koch et al., 2014; Lichtenthal et al., 2017; Worden, 1989). This means that the result of unaddressed fear of recurrence indicates the fearful state is likely to remain stable over time (Lebel et al., 2014). A biomedical response has, traditionally, not catered for emotional and existential needs in the long-term BC survivor. The biomedical response can offer a standardised patient-centred care package that would include monitoring for cancer recurrence and overall wellbeing. Ideally improved understanding and ability to meet existential needs of BC survivors means considering a woman's personal BC diagnosis, her stage of survivorship, and her reaction to diagnosis and treatment. It therefore becomes increasingly important to include a focus on self-compassion as a means of attending to potentially unhelpful notions of service to others, fear of selfishness, and lack of self-kindness.

11.2 The future: Emotional wellbeing and the aging survivor

Public health policy is not traditionally a domain that can ensure attention is devoted to the emotional wellbeing of long-term BCS. However, as governments and societies in general orient themselves to the increasing prevalence and financial, emotional and social cost of a chronic health condition such as BCS, increasing awareness of the fit between BC, mental health, aging, and quality of life is likely to continually highlight a need to review how best to care for survivors' emotional needs. Psychosocial interventions tailored to enhance the internal process of self-compassion can assist a 'moving on' in a 'hasten steadily' way that fosters greater emotional wellbeing and life satisfaction (Seligowski, Miron, & Orcutt, 2015). Interventions that contribute effectively to psychological health and wellbeing could be expected to result in reduction of the overall cost of health care for communities. Ideally those interventions would provide optimal, or improved, quality of life and satisfaction with care outcomes for BC survivors (Butow et al., 2015).

Transition to long-term BC survivorship heralds in a new range of psychosocial challenges as a survivor resumes their social and employment roles and activities, encounters less contact with breast care professionals, or as will be the case for some BCS, continues to rely on treatment such as hormonal therapy to reduce the risk of recurrence (Koch et al., 2014). Emotional distress can be activated

by the experience of late after-effects of BC, such as vulnerability to impaired health and functioning (de Moor et al., 2013). Attempts to ‘tame’ negative emotional reaction to the disease by countering BC with externally-imposed positive attitudes may have limited effect. Emotional sustenance for survivorship over the long term requires significant re-consideration. The appeal of putting a cosmetic face of optimistic cheer on the challenges of BC survivorship avoids the reality of an agonising encounter with existential concerns. Similarly, reliance on socially accepted, or dictionary-type explanations, of psychological processes, or rationally-focused solutions to BC-related emotional challenges may not guide creation of interventions helpful for positively responding to the needs of BC survivors. And yet, whatever has been found to be effective and efficient methods of easing emotional distress has been regarded, in the literature, as a positive process of extending understanding and development of greater knowledge about improvement in long-term health outcomes for survivors. Gathering the perspectives of women who have survived BC beyond the five-year survival mark provides information that can confidently support the design and implementation of psychosocial interventions.

11.3 The women in this study

BC offers survivors a unique opportunity to become emotionally intimate with themselves as well as the chance to locate meaning and purpose in that experience. Despite having to wrestle with the personal calamity that is BC, the women who participated in this study spoke of their life as being infinitely changed through their experience of the disease. For many, the change brought a re-alignment with their values and strengths, as well as awareness and re-evaluation of what now mattered most for them; for example, time to be in relationships that made life worth living, as well as the ability to unquestioningly accept their emotions - both positive and negative. Yet for others, at the time of participation, the future still contained the dark spectre of depression, with no sense of their being able to locate a safe psychological place inside themselves, or in the outside world.

All participants spoke of the harrowing journey they had made a) through treatment, b) through accompanying a partner through BC, or c) through the process of offering counselling support. They spoke of the constant effort required to ensure continuation of the ‘healing’ process – a process concerned not just with

physiological recovery, but one that included existential and emotional need such as a desire to seek spiritual healing (Schreiber & Edward, 2015). Despite the rigours of the treatment process, some women survivors talked about BC being “*the wake up call I needed*”, pointing out that the disease had given “*permission to do what I need to do to get myself into a better place*”. Although none of the survivors who participated would have welcomed a recurrence of breast cancer as a way to gain personal insights, self-connectedness, new friendships, or a feeling of life being “*blessed*”, the return to a previous way of life that was not personally coherent, kind, or respectful to them was non-negotiable. And yet, in spite of the stories shared, and with new-found respect and validation for themselves (Schreiber & Edward, 2015), old habits of not thinking well of themselves quietly persisted, albeit in an unclear, shadowy form. This quiet, but pernicious, dynamic continued to place at risk of erosion, gains made through an heroic struggle to be among the growing numbers of those who had survived.

To ‘be’ self-compassionate was something new, uncertain, and ‘untested’ in the lived experience of the BC survivors in this study. Interpretations of the term were relative but incomplete. Many participants regarded self-compassion as a skill to learn and to be ‘done’, rather than attitudinal and behavioural development and integration of a way of being. Self-kindness and a more accepting and less judgmental relationship with themselves remained dependent on reducing feelings of shame, guilt and blame related to fear of being judged as selfish or self-centred. However, what was clear was their passion for being alive had helped shift these women’s emotional proximity closer to being able to acknowledge and prioritise their self-worth.

11.4 Survival and self-compassion

Long-term BC survivorship, a survivor’s psychosocial needs, and maintenance of emotional wellbeing as a BC survivor ages is a research frontier that offers a significant amount of territory to be explored, or revisited. Not more than half a century ago BC was a disease that could result in surgical disfigurement, and a less than positive outlook for women diagnosed (Chang et al., 2016; Olson, 2002). Issues of adaptation to survivorship and living with the after-effects of BC have long been the concern of researchers in the fields of psychology and the social sciences

(Clark, 2017). In the search to better understand the transition from BC patient to living with the after effects of BC as a chronic illness, research has looked extensively at what it is that determines quality of life, and positive or poor adaptation. The intention in this study was to explore the experience of self-compassion in women survivors of BC. The construct of self-compassion was considered in this project as a potential contributor for assisting psychological repair after emotional disruption from BC.

SC can function as a powerful and effective accessory to the scope of relief provided by conventional psychosocial interventions that have already been tested and recognised as useful for BCS. As women, and their significant others, age the survivor will encounter specific age-related psychosocial needs. Health care needs of survivors may be compromised or compounded by psychosocial concerns such as loss and bereavement, the effect of shrinking financial resources, as well as reduced physical energy levels. Physiological issues such as second cancers or recurrence of BC will also precipitate significant additional emotional distress. Therapeutic support through counselling is most effective when offered from an understanding of a client's own personal values and beliefs (Cooper & McLeod, 2011; McLeod, 2013). The findings in this study indicate that fundamental to harmonious wellbeing for survivors in older age will be self-compassionate self-recognition, and a capacity for self-assurance that who they are has not been replaced by identification only as a person who has survived breast cancer. Directing warmth and self-understanding inwards to oneself appears to offer an important and efficacious change mechanism that can reduce psychological distress, integrate an orientation to care for themselves, and foster greater harmonious emotional balance for survivors of BC (Shahar et al., 2015).

Integration into the structure of the personality of the key ingredients of SC brings the capacity to self-soothe and reassure oneself (Falconer, King, & Brewin, 2015). SC and giving warmth to oneself in difficult times can engender hope and optimism for new attitudes, behaviours and meanings to emerge in the integration of the BC experience. To be self-compassionate is not about adding another task to a list of what needs to be attended to each day. Self-compassionate communication is not about pushing on so as to maintain an upbeat demeanour, or overlay difficult

feelings with positive thinking. What the construct of self-compassionate relating presents is a way for survivors of life-threatening and chronic illness to move hopefully towards a new, personally acceptable future in which the person experiences release from 'life' denying negative self-criticism. The new horizon they move toward offers a refreshed personal future.

Extension of life, or cure of cancer, is not the dominant relevancy of SC for counselling for BCS. Nor is SC a panacea for all psychosocial 'ills' connected with BC. However, the construct of SC can support a shift in paradigms of care for BCS. SC requires looking deeper and learning more about oneself, not as a form of self-castigation for mistakes made, or to find a reason from external environments to explain what may have gone wrong in life. SC is a way to cherish and nurture the self.

11.5 Conclusion: Revisiting the aims of this study

The intention of this study was to illuminate the idiosyncratic as well as the common factors in the experience of SC in women who live with the legacy of BC. Primarily, the aim was to contribute to the body of existing research data that seeks to understand what women most need from health care systems, in addition to what personally enriching process might enhance their long journey through cancer survival.

One aim of the study was that the findings might serve as a basis for exploring, creating, and testing SC-focused interventions that 'resource' emotional and spiritual wellbeing. To do so could serve as a means of increasing the depth of understanding of how a woman who lives long term with the after-effects of BC experiences emotional support from providers of post-treatment care.

This study also sought to extend available knowledge about the emotional and existential aspects of living, long-term with BC. Part of the consideration was whether engagement in arts-based mindful activities to generate self-compassionate relating could be a useful and constructive way to open the for BC survivors. Powerful though they may be in the hands of a skilled technician, neither the

microscope, nor the surgeon's scalpel can heal emotional suffering, restore lost hopes and dreams, or remove fears of a BC survivor who faces an uncertain future.

Findings in this study could potentially assist helping professionals extend the basis on which they understand the ways women BC survivors relate, post-treatment, with their body and with significant others. Another useful outcome would be to discover whether a brief intervention for training survivors in self-compassion could enrich the range of intra- and inter-personal responses to self-identity post-cancer treatment.

Women diagnosed with BC have had no pre-diagnosis preparation for having a life-threatening illness or for processing the rapid changes that take place once a diagnosis is made. They may not, at the time of diagnosis feel ill, or have experienced being ill in the time prior to diagnosis. Systems that become firmly fixed in a woman's existence once diagnosis is made impose treatment realities and protocols, labels, expectations, assumptions, and socially constructed meanings to having cancer and what it means to become part of those who survive – or who do not. Neither may a woman, at time of diagnosis, necessarily have encountered the concept of self-compassion or have developed comfort with a self-relationship characterised by kindness to self and a capacity to 'sit with' uncomfortable feelings.

Optimism surrounding BC survivorship could conceal the possibility that while a woman may more than likely be saved physically, she nevertheless will remain something of a 'mistress' in another unintended relationship. That relationship becomes 'another lover', one that requires vigilance, or that is not always kind and compassionate to her emotions, needs and desires. That 'other lover' exists in an inalienable connection to medications that prevent or minimise opportunity of recurrence, life-preserving medical tests, a relationship with her body that demands vigilance and attention, and paradoxically, for those who are willing, a relationship with a deep and personal source of life. For survivors of BC self-compassion presents a resource to be able to truthfully maintain "the delicate balance between being too kind and too harsh with oneself, between being too easy in welcoming imperfections and too merciless in resisting them (Bransen, 2015, p. 317).

This study explored and reviewed SC as an integral part of an ontological process for women in which they simultaneously encounter a journey of physical and emotional hardship, and healing, that activates a process of self-transformation. The findings have important implications for the training of counsellors within an Australian context. In addition the findings hold significance for counsellors in practice. The indications from this study suggest the practice of self-compassion would be a beneficial self-development skill for the wellbeing of an individual and ultimately for the wellbeing of communities.