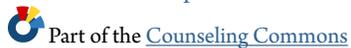

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Beyond the Pink Ribbon: An exploration of the experience of self-compassion in
Western Australian women survivors of breast cancer

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Chapter One

Motivation for the study

The exploration of self-compassion (SC) and development of this thesis has been motivated from two main sources: one professional, one personal. Each of these motivators, in equal measure, stimulated my interest and provided personal energy to embark on the task of presenting the narratives of women's experiences of self-compassion as survivors of breast cancer (BC). The journey through this thesis has been as much a deeply personal, emotional one as it has been an academic one of discovery through research.

1.1 Professional motivation

At the outset the aspiration to take on higher degree research was motivated by a desire, as a professional counsellor and counselling educator, to better understand and learn more about the ways people navigate through their emotional experience of a life-threatening or chronic illness. Many planned conversations, as well as meet-over-coffee chats with a range of academics, counselling colleagues, and women survivors of BC, created a vessel for refinement of the embryonic ideas swirling through my mind. Listening to others talk about their experience of embarking on a significant piece of research, as well as listening to the narratives of cancer survivors, allowed me to concretise thoughts and ideas. From these conversations, questions formed around what it was that helped survivors of BC cope with post-treatment life. This then became the central focus for my work.

The concept of having a pro-active, self-aware individual take up the role of effective monitor and manager of their own health could be regarded as integral to favourable outcomes from a medically-oriented care perspective. However, a persistent question revolved around evidence from research literature, as well as anecdotally, that indicated not all breast cancer survivors feel competent, energetic enough, or ready, to assume responsibility and ownership for ‘driving’ positive post-treatment change.

At the outset of this project self-compassion was a relatively new term applied to Western psychological conceptualisation of self and other relating. Neff (2003) was a pioneer in formal research into self-compassion as a protective factor in relation to psychopathology. Findings in a significant number of quantitatively-based studies on self-compassion have relied on Neff’s (2003) Self-Compassion Scale in either the full or abridged version of the measure. To assess self-compassionate relating through numerical scores may not tell the full story. Therefore it seemed valuable to gather women survivors’ stories of self-relating, and their perception of what it would mean to be self-compassionate. The usefulness of collecting narratives specifically about self-kindness arose out of questions about the potential for increased awareness of the benefits of inclusion of effective self-compassion strategies in therapeutic work. Findings from a study of self-compassion in a University student sample led to a proposed model of the links between self-compassion and wellbeing and self-coldness and personal distress (Brenner et al., 2018). Of particular interest in that study was the authors finding that “women reported less self-compassion and greater self-coldness than men” (p. 353). Importantly, health behaviour and adherence to medical regimens has been shown to be associated with the capacity for self-compassion (Terry & Leary, 2011). Increased self-compassion has been cited as having an important role in mental health in the aftermath of stressful life events (Scoglio et al., 2015), as well as facilitating healthy responses to living with chronic illness (Brion, Leary & Drabkin, 2014; Dunne, Sheffield & Chilcot, 2016). Therefore, the notions of self-compassionate self-relating as well as fear of self-compassion became particularly relevant for women vulnerable to mental health challenges as a result of, or pre-existing, diagnosis and treatment for breast cancer. Although much of the research into SC had found positive benefits it was considered important to explore the lived realities of self-relating post-BC.

At the beginning of this project, literature searches indicated that focused attention had not yet been paid to the influence of self-compassion as an emotional regulation strategy for Western Australian women living in the aftermath of breast cancer. For women to be able to more positively influence their self-relationship through an intervention such as self-compassion hinted strongly at a potential to manage stress and negative psychological sequelae. In turn, being able to manage stress responses could have important implications for positive effects on immune system functioning for survivors of breast cancer.

The experience and understanding of survivorship, the process of ageing for a woman's body, in addition to effects on close relationships, became the starting points of my enquiry. Optimistic though the current survival rate is for women diagnosed with BC, survivors will continue, across the long term, to experience psychological and physical sequelae. To me this highlighted the potential for emotional and developmental needs to silently slip from social and individual consciousness when women progressed from being a patient to the long-term task of being a survivor.

I began to wonder what might happen to authentic joyfulness and a sense of flourishing in life in the process of self-restoration after a woman had completed her medical journey through BC? I wondered if patterns of negative self-evaluation hindered the capacity of some survivors to be able to offer themselves the same emotional support they would willingly give to others. A query also arose in my thinking, about the effect on immune system functioning for the person with a chronic illness, from less than positive, or even toxic, self-relating. From these considerations a question emerged about whether there might be a missing ingredient to positive psychological recovery. What seemed clear was that any intervention or strategy would need to be helpful for women to give emotional kindness and generosity to themselves during their survivorship. At the same time any psycho-social intervention needed to be able to avoid becoming an imposition of additional emotional, psychological and social demands. The key to unlocking this doorway seemed to lie within an exploration of the relationship a woman had developed with herself and with her body prior to BC and how she related with herself post-BC.

In thinking about ways that could support and promote healthy psychological outcomes throughout survivorship, it felt critical to first arrive at a clearer understanding of the non-medical, non-disease aspects of the lives of women who had completed treatment and were living with the label of ‘survivor’. At the same time I found myself fascinated by the pink ribbon culture that had seemingly enveloped breast cancer. My thoughts were drawn to consider ways in which the relationship with self, and relationships with significant others, may influence restoration of those relationships post-treatment. In addition, could lack of self-compassion lead to negative distortion in processing fear of cancer and of personal evaluation of risk of recurrence. A 21st century heightened awareness of the prevalence of BC, in conjunction with trends toward commercialisation of BC survivorship could mean a person with low self-compassion may feel some pressure to align themselves with a perspective on BC recovery that might not be psychologically healthy.

My aim was to conceptualise a trajectory that could lead from a position where a woman might encounter persistent negative self-blame, to a state of being self-compassionate and, then ultimately to a capacity for effective self-care and self-soothing. I thought about the limitations life histories can impose on the direction of psychological adjustment to challenge or crisis. These ideas were still in the formative stage when I came across a television program featuring Kristin Neff. Watching the program piqued my passion for non-pharmacological ways that would support emotional regulation and reconnection with inner life skills, joy, and a stable sense of psychological wellbeing. Within a matter of weeks I had located Neff’s construct of self-compassion (SC) (Neff, 2003) and the ‘adventure’ had begun.

In my exploration to uncover a broader concept of human relating, Neff’s work on the topic of SC (Neff, 2003), with its central idea of relating with ourselves with a greater focus on a wiser and more affectionate self-relationship, provided an invaluable link. Neff’s (2003) concept was that encouragement of the key elements of SC involved compassionate relating with oneself, self-kindness, acknowledgement and aware acceptance of the imperfection of human existence, along with conscious quarantining of habitual self-judgment. The construct of SC offered an invaluable concept to support emotional agility in a broad range of people. Prompted primarily

by those early writings of Neff (2003) in the first decade of the 21st century, a significant amount of literature has since been generated on the topic of SC and its usefulness as a means of emotional regulation.

Self-compassion was a concept that seemed extremely straightforward in its explanation, but that could bring challenge in its application and practice. I wondered if its simplicity masked the value for people whose personal resourcefulness may have been blanketed by criticism from those around them, and who then may have struggled under the weight of ruthless self-criticism. It felt as though Neff's conceptualisation of SC delivered a resolution to my wondering about a missing ingredient in the existing strategies that support human wellbeing and promote sustainable mental wellbeing. SC appeared to offer an ideal trail that I hoped would lead inexorably to a reconnection with and maintenance of self-warmth, self-understanding and compassionate communication with self and with significant others. My strong belief was that SC had the great potential to help cancer survivors emotionally thrive - rather than simply survive.

As a concept, SC excited my professional mind and nourished my personal enthusiasm. My interest in SC led me automatically to the question: what is the experience of self-compassion in women with BC who are survivors of breast cancer? My question was further intensified by the apparent potential to explore ways to robustly live as a cancer survivor without self-judgment. My questioning then led me to consideration of the personal resources of women, and ways in which those resources might hinder or help individual resilience in the face of adversity.

To understand women's experiences and to hear the voice of women about what it was like to be a survivor, it seemed essential to uncover more detail about the essence of self-communication and the nature of the relationship with their body and their feelings. Therefore, initial self-questioning focused on whether a sense of personal goodness and value, for the person whose life trajectory was now inextricably linked with a chronic illness, could be enhanced through a compassionate self-relationship. The second question I faced was whether relating with self in a compassionate way would have a positive influence on relating with significant others. Additionally, there was the growing question about what specific

personal resources might provide a sense of recovery of an inner state of overall ‘goodness’ as opposed to feelings of ‘failure’ in body, mind and feelings. In response to these ideas, the sometimes often obscured power of women’s voices became a strong guiding principle.

At the outset, the concept of SC as presented, looked as though it could aid the creation of a post-BC personal narrative characterised by greater self-congruence. The task was for me to discover more about the larger context and realities of the lives of women survivors of BC. This undertaking heralded acknowledgement of the desire and need to gain reliable knowledge about women’s actual experiences of relating with themselves before and after BC.

From understanding more about the self-relationship for survivors of BC the hypothesis was that more could be discovered about the most prevalent influences that shape their relationships with significant others post-BC. As a result of a distillation of these ideas about the nature and essential ingredients of relating with the internal and external relational environments, the relationship with self became a central focus around which other aspects of relating revolved.

From my reading and personal engagement with SC, integration of the central elements of the practice of SC offered beneficial, yet gentle, means of engaging a woman’s self-healing potential. The resources that foster self-healing and soothe intense emotional states activated by fear, anxiety, helplessness or powerlessness can get trapped in unproductive negative thinking. Presented in the literature as a resource for ongoing self-awareness and mindful maintenance of mutually nourishing relationships, SC sparked my thinking about living life in the shadow of BC. For many survivors this is a life that would be expected to extend for the normal life span - well beyond the threshold of the much-desired post-treatment five year survival point.

Research has highlighted depression and anxiety as the most prevalent post-treatment issues for women with BC. My thinking was that when suddenly catapulted into the vortex of BC, a woman, and her family, are instantly faced with issues of mortality, recovery, survival, sexuality, dependency, financial strain, and

the demands of caring for family. The process of grieving for a past way of life that suddenly becomes non-existent, and the ever-present concern about survival, and how to cope in an uncertain future, now created a clear tapestry of emotional and psychological challenges women faced post-BC. My focus was not on identifying physical wear and tear as a result of a negative self-relationship. Mine was not a cause-and-effect interest. My interest was to consider and question whether SC might restore lost communication with self, body and others, and support emotional agility through a more flexible and healthy self-relationship. What the concept of SC could offer was a model of self-guidance to help create a vision of a future renewed self who could embrace emotional wellbeing.

The path of self-compassion offered the potential to significantly alter, in a positive sense, unproductive results from habits of shame, guilt, and lack of self-worth that may have persisted lifelong. Research had indicated that some survivors of BC find themselves unable to step back and gain psychological ‘distance and perspective’ on what happened as a result of their diagnosis. Previously effective in creating and managing life, they may now find themselves overwhelmed by stress. They may feel helpless and blame themselves, or feel helpless and want to blame others.

Research into SC provided evidence of an effective way to foster ongoing personal growth and development through the simple task of self-kindness rather than the path of achievement being forged through habitual harsh self-criticism. From the literature on SC, indications were that the construct offered a significant basis for deeper personal reflection that could lead to healthy self-restoration at times of distress or confusion. Despite evidence that increasing self-compassion was a powerful facilitator of positive affect, individuals high in self-criticism had been found to resist or fear receiving compassion from others as well as fear of being compassionate to oneself (Gilbert, McEwan, Matos & Rivis, 2011). This meant deeper reflection on the influence of self-criticism on one’s capacity for being open to social and emotional bonds with others. An incisive review of my own habit of resistance to being cared for by others occurred during the time of listening to, digesting, and interpreting the life stories entrusted to me by the women who participated in this study. Consideration of the human capacity to be self-

compassionate, fear of compassion for self, and resistance to feeling compassion from others was a constant companion throughout this PhD quest.

1.2 Personal motivation and reflection

The distinction between the strongly evaluative nature of the concept of self-esteem as opposed to the kinder stance of SC provided a key that unlocked significant personal revision of my long-held perfectionist traits (Neff, 2003). For me, SC became an invaluable influence on my passage through this thesis. SC became an overarching mechanism for conceptualising conscientiousness, revising my intrapersonal dialogue, reviewing interpersonal relating, and investigating any blind spots I might hold around potentially ‘gendered’ perspectives about women, relationships, and BC. The women in this study were the ones who generously and gently help me explore these personal questions in greater detail.

The process of talking about, thinking about, researching, and writing about women and BC has, for me, been a richly textured journey. So much has happened during evolution of this study. Some of the more notable markers have been the weddings of my children, work-induced separation for almost two years from my partner, two interstate moves of home and work, packing up and moving house a total of five times, the unexpected loss of two much-loved relatives to cancer, reconnection with a half-sister adopted out at birth, the birth of four grandchildren, and, for good measure, a very real question for my sisters and I about the BRCA1 gene identified in a living female family member who had survived breast cancer.

One of the most outstanding personal features of these past years has been the very great privilege of being a listener to, and holder of, personal narratives of a group of women BC survivors. This thesis has enabled me to get to know eight amazing women who have each taught me so much about compassion. In addition I was fortunate to have the honour of being able to interview an additional group of nine women survivors. These nine women made a very significant contribution to my comprehension of what diagnosis and treatment meant for them.

The time spent with each and every woman who took part in this study was invaluable in getting as close as possible to an understanding of the challenges of BC

survivorship. The women were patient, gracious teachers and ‘guiding lights’, especially the eight who took part in the Opening to Self-Compassion (OtSC) sessions and the Expressive Therapies Personal Reflection Program (PRP). Each of these personalities, and the interviews and groups they attended, drew me closer to deep reflection about how we experience self-compassion, what being self-compassionate means, how self-compassion can add to the richness of life, in addition to understanding fear of being self-compassionate.

The *Opening to Self-Compassion* (OtSC) sessions had the purpose of providing time for the women to come together, address topics that they may not openly discuss with family, and begin to form safe relationships with each other. My focus was that those relationships would then be ones in which they could feel trusting and safe enough to give voice to their experience. This would mean that during the *Personal Reflection Program* (PRP) sessions, this smaller group of women would likely be willing to explore at depth their experience of BC, and share their unique narratives of needs, desires, and motivations for life post-BC. Three one-hour OtSC sessions were also a time for women to orient themselves to the topic of SC and consider their reaction or response to the idea of being compassionate to oneself. The format for both the OtSC and the PRP was created with flexibility in mind. The women’s responses to questions posed in the OtSC sessions were used to form a basis for the direction of group discussion during the PRP sessions.

From my encounters with the women and my evolving relationship with research, the hope is that my own experience has been a useful guide for me in how to *be* for people, not only those who have survived cancer, but for people who encounter a personal struggle to feel kindness and forgiveness for themselves.

For several decades I had been fascinated by phenomena of persistent pre-ordained negative cognitive, and emotional, conceptualisations that companion us in life. In my life these negative conceptualisations dictated how I was able to respond to myself and others in times of stress, loss, or emotional strain. Despite extensive personal therapy to repair events and relationship experiences from my past, I am able to confess that despite healing well from my past, the lived experience of how to be compassionate to myself continued, sadly, to remain somewhat elusive.

In hindsight I can see that SC was definitely a mystery to me. My conviction was that compassion was an outward act entirely focused on giving to others. I wanted to believe that simply thinking well of myself and being of service to others filled my basket of self-compassion. However, attempts to think well of myself carried the constant risk of reprisal and unforgiving negative self-evaluation from an internalised negative and highly critical self. Whatever life goal I set myself was considered by my inner judge to have fallen short of some imagined benchmark. The accompanying sense of abject failure left a deep void in my relentless desire to reach a sense of peace. I wanted to enjoy feeling peaceful about who I was, but this needed to happen in a realm of genuine self-acceptance. The roadblock in my psyche remained one of inability to feel genuine self-acceptance. Some years of personal therapy improved my self-esteem, facilitated healthier self-acceptance, brought a balance to my life, and a more positive way of relating with the outer world. But welcome as these changes were, being persistently kind and gentle in my relationship with myself remained elusive. In my thoughts and feelings self-kindness seemed to endure as an intellectual concept that was vague in its everyday application.

Discovering a small but unmistakable breast lump at age 22 was not good news to me. Just six short weeks from my wedding day, a prompt visit to my GP to discuss the lump resulted in an urgent late afternoon hospital check-in with surgery booked for early the next morning. Even though my GP had not mentioned the word cancer, my thoughts immediately went there. Within 24 hours I had gone from concern about the colour of bridesmaids bouquets to wrestling with my fear of death, and deeper questioning moments about what the future might hold. Employed at that time by an insurance company I had access to myriad medical reports and so had an awareness of the ominous potential of finding a breast lump. The spectre of death, or serious illness that might still result in death, felt a sudden, heavy burden.

The words I did not want to hear, the ones that wove my worst fears into a terrifying tapestry were delivered by a well-meaning nurse as I was prepped for surgery. In a rather knowing voice she told me that once the doctor was 'in there' he might have to take the whole breast or both breasts, depending on what he found. Stunned, gagged silence and violent retching all the way to the operating theatre was

my only response. There was no peace of mind despite the powerful anaesthetic that eased my physical self into a state of unaware sleep.

Only now as I look back can I recognise that the choice not to disclose this experience to anyone except my soon-to-be husband probably came from an extraordinary lack of warmth, understanding and compassion towards myself. There was no conversation with my GP. Surgery to remove the lump was scheduled for Friday and I exited hospital early Monday morning before the doctor did ward rounds so I could arrive at work on time. I wanted to ignore my experience and simply get on with life. Fortunately for me the eventual outcome was positive and no further medical intervention was needed.

The principles of life that I had absorbed - primarily from teachers in my school days that began with Year 1 when I was just four years old - lacked a foundational theology of hope, optimism, beauty, freedom, and grace. In place of these principles, I had translated what I was told in to constant negative self-evaluation for fear of not measuring up to what I realise now was an impossible goal.

Somewhere around adolescence I developed what I would call a 'phobic response' to the disease called cancer. I never fully understood why that was so, but looking back believe it emerged from the death of a much loved grandmother whom I expected would live forever. When confronted with the "C" word the feeling that gripped my body was cold, silent, terror. I could barely stand to say or hear the word. Any mention of cancer made me feel vulnerable to inevitable attack from a swiftly silent, deadly foe. It was a feeling I struggled to hide. But I felt shame at this failure to cope, a failure of what I thought was my usually resilient nature.

My emotional immobility at the mere mention of cancer was exaggerated. I knew this at an intellectual level. Despite this, I grew adept at hiding any hint of fear on the outside, while internally I remained unable to control the dread of cancer catching up with me. My fear was compounded further a few short years later when a close work colleague died of stomach cancer. At twenty years of age she had, only a few months earlier married the love of her life. Her death seemed desperately unfair and I wrestled with the 'why her' question. As a result cancer became, for me, an

indiscriminate, insidious, and capricious nemesis, lurking relentlessly in the shadows of life, waiting to claim its next victim.

It seems obvious now that cancer did catch up with me. But not in the way I had anticipated. In 2011 and 2012 the experience of facilitating group counselling with women who had survived breast cancer proved to be the place where I was both confronted by the thing I feared most and nourished by the thing I feared most. Inspired by women in those groups their wisdom taught me to be with them in a way that helped me regard their encounter with BC as what I would call a form of ‘pregnancy’ – a privileged time of taking the role of a type of patient midwife able to witness the re-birth of each woman’s own self. The Self that emerged after BC often, but definitely not in all cases, presented a revitalised sense of life.

As a therapist I have been privileged to witness the life benefits for those clients who have developed compassion for themselves. The tension for some clients as they separate the fear of selfishness from what it means to treat themselves with kindness has been profound. For some the fear of being selfish had kept them in servitude to out-dated attitudes that denied a flourishing in life.

The process of inquiry I have set about with this research is one that seeks to combine careful methodical process and analysis with knowledge from the heart. I hope the final document reflects the heart and soul of how women have found compassion for themselves as they navigated their way through the challenges of living beyond the pink ribbon.