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

Helen Wilson

The University of Notre Dame Australia

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

Thesis submitted for the degree
Doctor of Philosophy

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Helen Wilson
B.Bus (HRM); M.Couns.
School of Arts & Sciences
Discipline of Counselling
University of Notre Dame Australia
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Abstract

Using a phenomenological lens this qualitative study explored the experience of self-compassion in self and other relating in Western Australian women breast cancer survivors (BCS). A purposive sample of 17 participants were drawn from women aged between 35 and 70 years of age who had completed treatment for primary breast cancer and had been disease-free for a minimum period of 12 months. Participants were asked to take part in an in-depth semi-structured interview. Additionally, eight participants interviewed engaged in three, one-hour *Opening to Self-Compassion* sessions and three, four-hour sessions (12-hours in total) of a *Personal Reflection Program*.

Data was gathered using one-on-one semi-structured interviews with three participants who each were a significant other (e.g., spouse) in the life of a woman with breast cancer. Three counsellors working with BCS were also invited to take part in a semi-structured interview. Interpretive Phenomenological Analysis (IPA) was used to analyse data from all interviews. The *Opening to Self-Compassion Sessions* and *Personal Reflection Program* were analysed using a participant observer method. Major themes identified that BC survivor participants had difficulty prioritising their needs over needs of others, and only post-BC began to consider their own needs. Through a focus on physical survival BC had brought a realisation of personal resourcefulness previously unrealised. Self-compassion was not well understood and a number of participants reported concern about being judged as selfish. Interviews with Significant Others revealed challenges in witnessing their wife’s physical illness and emotional distress as well as attempts to retain a sense of normality in life. Counsellors interviewed reported experiencing a deep state of compassion when working with BCS.
This study makes a contribution to enhanced understanding of ways women living with long-term after-effects of breast cancer relate with themselves and their body. This study also provides valuable information on whether self-compassion can help ease emotional burdens of survivorship. The question is whether self-compassion can support healthy mobilisation of intrapersonal resources and support reduction in post-treatment anxiety and depression in survivors of breast cancer. The findings make a valuable contribution to the design and delivery of psychological interventions for BCS. In particular the relevance and implications of inclusion of self-compassion training in counselling interventions for BC survivors is highlighted.
Statement of Authorship

I affirm that this thesis is entirely my own work, and contains no material previously published or written by another person, except where due reference is made in the thesis, and it contains no work which I have previously presented for an award of the University or any other educational institution.

Helen Wilson
23 May, 2018
Acknowledgments

With much gratitude I acknowledge the women who so willingly shared personal stories of their experience of breast cancer and living beyond the pink ribbon. Without their generosity and support this research would not have been possible. During the years of this project what kept me going was the knowledge that through our connection I was a privileged ‘holder’, for a brief while, of part of their personal stories. Completion of the project is a means for me to give back and honour the richness and depth they have added to my life. I think of these women often with gratitude and affection and to this day carry a mental picture of each one as they told their story. My wish for their lives is that they flourish and continue to be nurtured by their own strength and resourcefulness.

I would also like to acknowledge the three men who were absolute in their commitment to supporting their wives through breast cancer. Their unique perspectives on the experience of living through BC with their wife contributed a broader vision to this project and challenged and extended my thinking. I am extremely grateful for their genuineness, openness and their help.

The three professional counsellors whose generosity of spirit, practice wisdom and wealth of knowledge and experience helped me understand more of the human side of my research are women whom I deeply appreciate and admire.

Each person on the supervisory team brought a unique expertise and perspective that blended seamlessly into the planning and implementation of this study. The process of bringing this thesis to conclusion involved surrender of what often seemed at the time like precious ideas I hoped I could simply secrete somewhere in the text and not lose. Letting go of the way I thought I wanted the thesis to be helped me find the way it could be.
To my supervisors: Dr Jacqui Dodds who offered incredible input about what self-compassion and being compassionate meant. Jacqui’s support and enthusiasm for the project kept me on task. Her patience when life got in the way of my progress was very much appreciated! As an experienced and respected psychotherapist and PhD Cum Laude Jacqui provided inspiration to me to continually improve the level of critical thinking and to approach scholarly writing about breast cancer with discipline, creativity, and mindful awareness. Jacqui has been an exemplary model and a resource about the experience of self-compassion, breast cancer, and the experience of writing a PhD thesis. I am forever grateful for her wisdom, skill, and support.

Associate Professor Caroline Bulsara has been tireless in her support; always available any time I needed help. Her caring and compassionate spirit was always evident as was the depth and breadth of her knowledge about PhD research, as well as her valuable wisdom about promoting empowerment for women with BC. I am indebted to her for encouraging me to be clearer in my writing and to consider interpretations other than the ones I surmised. The early morning café chats, her presence and her personal encouragement has been an essential ingredient in my success. Caroline’s friendship and enthusiasm for my project provided a safety net in the times when feelings of isolation and struggle without liberation threatened to consume my sense of purpose. Thank you.

Professor Martin Philpott provided solid mentoring in the early days and helped keep my thinking stabilised when I would drift off course. His mentorship has been invaluable to me.

I dedicate this thesis to my partner and my children. To a wonderful life partner, Mark Pearson, who had an unwavering belief in my capacity to complete a life-long dream, thank you for sharing my life, for nourishing meals that would somehow appear without any fuss or fanfare, for your guilt-free house cleaning, and for always relating to me with a compassionate heart and mind. Your trust in me and your love helped me finally believe in and love myself.
To two beautiful, amazing children, Greer and Elliot, who have shared my life - thank you. Your enthusiastic love of life and your capacity to love me as I grew and developed as a mother always motivated me to strive to be the person I was meant to be, and to be the best me I could possibly be. Watching you both elegantly and resourcefully navigate the amazing successes and challenges of your lives has made my life a rich and deeply moving experience. Each day I am grateful for and celebrate your presence. May you always feel loved by me and may you be nourished outrageously by life.
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Abbreviations Used

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>BC</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>BCS</td>
<td>Breast cancer survivor/breast cancer survivors</td>
</tr>
<tr>
<td>ET</td>
<td>Expressive Therapies</td>
</tr>
<tr>
<td>EWB</td>
<td>Emotional wellbeing</td>
</tr>
<tr>
<td>FoCR</td>
<td>Fear of Cancer Recurrence</td>
</tr>
<tr>
<td>ILS</td>
<td>Inner life skills</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>OtSC</td>
<td>Opening to Self-Compassion</td>
</tr>
<tr>
<td>PRP</td>
<td>Personal Reflection Program</td>
</tr>
<tr>
<td>PTG</td>
<td>Post-traumatic growth</td>
</tr>
<tr>
<td>PWB</td>
<td>Psychological wellbeing</td>
</tr>
<tr>
<td>SC</td>
<td>Self-compassion</td>
</tr>
<tr>
<td>SO</td>
<td>Significant other</td>
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</tbody>
</table>

Note: The term ‘breast cancer survivor’ (BCS) has been used throughout this thesis to refer to women in the study. It is acknowledged that only one of the women, of the 17 interviewed, had passed the five-year post-treatment mark whereas others ranged from 1 – 4 years post-treatment. This means that the women interviewed were each in the early stage of responding or reacting to treatment for BC. Use of the term BCS has been applied because it is a commonly used term in the literature. In their study into improving BCS psychological outcomes and quality of life, LeRoy et al (2018) took the stance that cancer survivorship begins at the time of first diagnosis of cancer. Their perspective is in line with that expressed in the USA by the National Coalition for Cancer Survivorship (https://www.canceradvocacy.org/news/defining-cancer-survivorship/). The term BCS was also one agreed upon by the women and Significant Others in this study. In interview the women said they did not want to be defined as either a victim, or a person still battling cancer. They regarded themselves as cured, a survivor – a person who no longer had breast cancer. Women participants objected to the phrase ‘living with cancer’ as they did not want to be stigmatised by a
label. Overall, there was no consensus reached about a term that would best describe the women and so the term BCS was one to which all participants agreed.

Universal agreement about the term ‘survivor’ has, so far, not been reached. Research has identified that once the 5-year survival threshold has been crossed a majority of women treated for BC resume the social and work-related functions of their pre-diagnosis life. Resumption of life in a ‘new normal’ does not however mean that self-compassion lacks relevancy for survivors of BC.