My Changed Body:

Breast cancer, body image, distress and self-compassion

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Statement of Candidate

I certify that the work on my thesis titled "My changed body: Breast cancer, body image, distress and self-compassion" has not been submitted for any other degree nor has it been submitted as part of the requirements for a degree to any other university or institution other than Macquarie University.

I certify that this thesis is my own work and it has been written by myself. Any help and assistance that I have received has been properly acknowledged within my thesis.

Ethics approval was granted at the following times during the course of the PhD: Study I, on 8th April 2010 (Ethics Reference HE27NOV2009-D00198); Study II, on 15th June 2012 (Ethics Reference 5201200298); and Study III and IV, on 5th February 2015 (Ethics Reference 5201401083).

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Astrid Przezdziecki

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Date

List of original publications

This thesis is based on the following original publications, which are referred to in the text by Roman numbers. Original publications are reproduced with permission from their copyright holders.

I **Przezdziecki, A.,** Sherman, K., Baillie, A., Taylor, A., Foley, E., Stalgis-Bilinski, K., (2013). My changed body: Breast cancer, body image, distress and self-compassion. Psycho-Oncology, 22(8):1872-9. Doi:10.1002/pon

II **Przezdziecki, A**., & Sherman, K., (2016). Modifying affective and cognitive responses regarding body image difficulties in breast cancer survivors, using a self-compassion-based writing intervention. Mindfulness; 7:1142-1155 Doi:10.1007/s12671-016-0557-1

III **Przezdziecki, A**., Alcorso, J., Sherman, K., (2016). My changed body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer. Patient Education & Counselling, 99(5):870-4. Doi://dx.doi.org/10.1016/j.pec.2018.12.011

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Statement of Contribution by Author

I: In paper I, Astrid Przezdziecki alongside co-author Kerry Sherman was intimately involved with generating the research concept resulting in this publication. Astrid Przezdziecki was primarily responsible for designing the study and collecting the data. Astrid Przezdziecki was the primary contributor to preparing the manuscript by generating the first draft, editing the draft to incorporate comments and feedback from co-authors, and responding to journal comments and suggestions for revision.

II In paper II, Astrid Przezdziecki alongside co-author Kerry Sherman was intimately involved with generating the research concept resulting in this publication. Astrid Przezdziecki was primarily responsible for designing the study and collecting the data. Astrid Przezdziecki was the primary contributor to preparing the manuscript by generating the first draft, editing the draft to incorporate comments and feedback from the co-author, and responding to journal comments and suggestions for revision.

III In paper III, Astrid Przezdziecki alongside co-author Kerry Sherman was intimately involved in generating the research concept resulting in this publication. Astrid Przezdziecki alongside co-authors Kerry Sherman and Jessica Alcorso was intimately involved in designing the study and collecting data. Astrid Przezdziecki co-contributed to preparing the publication manuscript, generating the first draft, and reviewing the draft to incorporate feedback and comments.

IV In paper IV, Astrid Przezdziecki alongside co-author Kerry Sherman was intimately involved with generating the research concept resulting in this study. Astrid Przezdziecki was primarily responsible for designing the study and collecting the data. Astrid Przezdziecki was the primary contributor to preparing the manuscript by generating the first draft and incorporating feedback from the co-author.

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Abstract

Negative alteration to a woman's body image is a common consequence of breast cancer diagnosis, associated medical intervention and treatment side-effects. Despite the inevitable occurrence of adverse side-effects and the distress it causes for some women, body image difficulties for a subset of breast cancer survivors are not always adequately addressed. Self-compassion is a novel psychological approach that has been used in non-oncology contexts to assist with distress and body image disturbance. However, such an approach has not been applied to difficulties experienced by breast cancer survivors, and hence constitutes a gap in the psycho-oncology research literature.

The overall aim of this thesis was to explore the utilization of a self-compassion-based intervention to address body image disturbance in this population, using a series of four studies. An initial cross-sectional exploratory study (Study I) investigated the relevance of self-compassionate approaches to body image and its possible relationship to psychological distress. It was found that self-compassion was a significant factor in the relationship between body image disturbance and subsequent psychological distress in breast cancer survivors, with evidence of self-compassion acting as a mediator of this relationship. A proof-of-concept pilot study (Study II) was then undertaken to investigate the acceptability and feasibility of a self-compassion focused writing activity to assist with body image difficulties in breast cancer survivors, the "My Changed Body" intervention. It was demonstrated that self-compassionate writing produced immediate reduction in negative affect and enhancement in self-compassionate outlook, compared with individuals in the expressive writing only control group. Given the promising outcomes from this research, a third study (Study III) was undertaken to investigate the potential

acceptability of an online version of the My Changed Body self-compassion based writing intervention amongst breast cancer consumers and breast cancer-related health professionals. This development study indicated moderate to high acceptability for an online self-compassion based writing intervention. The final study (Study IV) investigated, in a randomised controlled trial, the effectiveness of the online self-compassion writing intervention on negative affect and self-compassion. A total of 206 breast cancer survivors were randomized to receive either the self-compassion online intervention or an active control condition (i.e., unstructured expressive writing). It was found that women assigned to the structured self-compassion writing intervention exhibited significant less negative affect, particularly for younger women. Moreover, older women receiving the My Changed Body intervention had a significant enhancement of self-compassion.

In sum, the findings from this thesis have important implications for researchers, health professionals and breast cancer survivors. This research has been the first to investigate and apply self-compassion as a possible intervention for adverse body image changes in breast cancer, hence addressing a current knowledge gap. The research findings have been translated to create and evaluate a user-friendly, accessible online intervention that is simple for health professionals to administer. Finally, and most importantly, female breast cancer survivors have been provided with a novel, evidence-based, effective approach that can, depending on their age, decrease negative affect related to adverse bodily changes and improve their levels of self-compassion.

Structure of this thesis

This thesis is presented for examination as a thesis by publication and comprises of two parts. Part One consists of an introduction of relevant concepts, establishment of a context, a review of relevant literature, and a statement of aims. Part One contains three chapters: Chapter 1, a review of breast cancer and body image, Chapter 2, a review and discussion of the relevance of self-compassion, and Chapter 3, a review and discussion of writing interventions with a focus on body image difficulties and breast cancer. References for the three introductory chapters are combined with references from the concluding discussion chapter, and are located together at the end of thesis.

Part Two consists of four sequential empirical investigations of self-compassion for body image distress amongst breast cancer survivors. Each of these studies constitutes its own chapter (Chapters 4-7). Three of these manuscripts have already been published, and another is being prepared for journal submission as part of a larger research investigation. For published manuscripts, a copy of the paper in journal format has been inserted into the body of the thesis. This has been done with the kind permission of the relevant publishers. For all accepted papers, the submitted version of the manuscript is included. Each of the four manuscripts incorporates its own literature review/introduction, reports its own methods, results and discussion in detail and contains the relevant references.

The thesis concludes with an overview and general discussion (Chapter 8), which reviews the findings of the empirical studies in the larger context of previous research, thus summarising the content of both Part One and Part Two. The discussion also addresses the question of the extent to which self-compassion approaches are relevant to body image distress in breast cancer survivors, and the impact of the

translated My Changed Body intervention on target population use. In this section the findings from each study are discussed in relation to each other, the previous research, and theoretical/translational aspects. The discussion also addresses the strengths and limitations of the thesis and directions for future research.

Following the discussion, there are nine appendices that contain the participant information, consent forms and study questionnaires (Appendix A to D), ethical approval of the studies (Appendix E), awards and grants awarded to the researcher who undertook the thesis research (Appendix F), conference presentations (Appendix G), invited presentations given by the candidate (Appendix H), and (Appendix I) a summary of the theoretical framework of this research.

Definition of key terms

Appearance contingent self-esteem / self-worth: a tendency to base one's thoughts and feelings about self-worth upon meeting certain standards of appearance. High levels of appearance contingent self-esteem can have negative consequences for the individual, including greater adverse effects from body comparison (Patrick, Neighbours, & Knee, 2004).

Appearance evaluation: the emotional and cognitive level of satisfaction with one's appearance, and whether there is a discrepancy between self-perceived bodily characteristics and desired characteristics (Cash, 2011).

Appearance investment: the cognitive-behavioural importance placed upon appearance and physical attributes by the individual (Cash, 2011). With dysfunctional high levels of appearance investment, appearance is seen as central to an individual's self-worth, which is distinct from adaptive valuing of one's appearance (Cash, Melnyk, & Hrabosky, 2004). Appearance investment is considered to be comprised of two main facets: self-evaluative salience (SES) and motivational salience (MS), (Cash & Labarge, 1996).

Baumeister's Escape Theory: Baumeister theorised that people may use non-helpful behaviours to escape or avoid aversive self-awareness, especially if they fall short of expected standards. Ego threats may often be experienced as crises that elicit emotional distress and negative affect which remove optimal long range outcomes from the person's immediate consideration, and hence self-defeating or avoidant behaviours could therefore ensue (Baumeister, 1997). Amongst other difficulties, Escape Theory has been applied to body image and eating disorders (Gordon, Holm-Denoma, Troop-Gordon, & Sand, 2012).

Body appreciation: is appreciating the features, functionality, and health of the body. Body appreciation is not solely appreciating one's appearance or the extent that one's body aligns with cultural appearance ideals, (Tylka & Wood-Barcalow, 2015).

Body comparison: A general tendency to use others as a source of self-evaluation regarding one's own body and appearance, (Patrick, Neighbours, & Knee, 2004).

Body image: a multifaceted construct that includes an individual's cognitions, emotions and behaviours associated with their body and its functioning (Fingeret, Teo, & Epner, 2014).

Body image disturbance: concern about one's body and/or difficulties adjusting to body image changes. Disturbance of body image may occur during subjective processes in which negative thoughts, feelings and behaviours regarding one's body may be present, resulting in dissatisfaction with oneself, (Fingeret, et al., 2014; Hopwood, Fletcher, Lee, & Ghazal, 2001; Stokes & Frederick-Rescasino, 2003)

Breast cancer: Breast cancer is a malignant tumour that starts in the cells of the breast. A malignant tumour is a group of cancer cells that can invade surrounding tissues or metastasize to distant areas of the body. The disease occurs almost entirely in women, but can also be diagnosed in men. Two of the most common types of breast cancer are ductal carcinoma and lobular carcinoma.

Cash's Body Image Theory: views body image as consisting of two components: appearance evaluation and appearance investment. Appearance investment is further seen as consisting of two subcomponents: motivational salience (MS) and self-evaluative salience (SES), (Cash, 2011).

Chemotherapy: involves the use of drugs that kill rapidly dividing cells, such as cancer cells. Chemotherapy is a systemic treatment as it works on the whole body and

affects both cancer and normal cells. Common areas where normal cells may be damaged are the mouth, stomach, bowel, skin, hair and bone marrow. Damage to normal cells typically cause the side-effects associated with chemotherapy. Chemotherapy may be used in combination with surgery, radiation and hormonal treatments, and can also be given prior to surgery as a neoadjuvant treatment (National Breast Cancer Centre, 2007; Senkus, et al., 2013).

Ductal carcinoma: starts in the cells which line the breast's ducts, beneath the nipple and areola. The ducts supply milk to the nipple. Between 85% and 90% of all breast cancers are ductal. If the cancer is DCIS (ductal carcinoma in situ), it is well contained and not invasive. Usually ductal carcinoma is removed with a lumpectomy (wide local excision), and if the tumour margins are clear of cancer follow-up treatment may include radiation. If ductal cancer has spread into nearby breast tissue (invasive cancer) then a mastectomy may be needed, and chemotherapy may also be recommended (National Breast Cancer Centre, 2007; Senkus, et al., 2013).

Expressive writing: is a personal, uncensored form of writing that focuses on one's emotional experiences and does not have a set form or adherence to writing conventions such as proper spelling, punctuation or sentence structure. It is a therapeutic form of writing developed primarily by James Pennebaker in the 1980s which uses a typical prompt and specifies the duration of writing by the individual (Klein & Boals, 2001; Pennebaker, 1993; Pennebaker & Beall, 1986; Pennebaker & Chung, 2011).

***Higgins Self-Discrepancy Theory (SDT)*:** states that there are consequences that arise when individuals compare one self-state to another self-state, and find that a discrepancy exists between the two (Higgins, 1987). Three domains were described in regard to the self: 'actual self" or the current perception of one's self, 'ideal self' or

the self that one aspires to be, and an 'ought' self' which has characteristics the individual feels obligated to possess. Cash and colleagues conducted further work to apply self-discrepancy theories to issues of body image (Jacobi & Cash, 1994).

Hormone treatment: the growth of some breast cancers is affected by female hormones. In women who have been diagnosed with breast cancer, most hormonal therapies work by decreasing the amount of oestrogen and/or progesterone in the body or by stopping the cancer cells from obtaining these hormones. Hormonal therapies are considered if pathology results have indicated the presence of hormone receptors on the cancer cells. Hormonal therapies are systemic treatments and may be used in conjunction with surgery, radiation and chemotherapy (National Breast Cancer Centre, 2007).

Lobular carcinoma: begins in the lobes, or glands which produce milk in the breast. The lobes are located deeper inside the breast, under the ducts. About 8% of breast cancers are lobular in origin. If the cancer is LCIS (lobular carcinoma in situ) the cancer is limited within the lobe and has not spread. Lobular cancer may be removed during a lumpectomy; if the tumour margins are clear of cancer, follow-up treatment may include radiation. If lobular cancer has spread into nearby breast tissue (invasive cancer) then a mastectomy may be needed, and chemotherapy may also be recommended (National Breast Cancer Centre, 2007; Senkus, et al., 2013).

Motivational salience (MS): Motivational salience is a sub-component of appearance investment, and refers to the individual's efforts or motivation in appearance management behaviours in order to improve their attractiveness (Cash & Grasso, 2005; Cash, Melnyk, & Hrabosky, 2004). Motivational salience is considered to be the less potentially dysfunctional aspect of appearance investment, compared with the other sub-component, self-evaluative salience (Cash, Melnyk, & Hrabosky, 2004;

Cash, Phillips, Santos, & Hrabosky, 2004; Jakatdar, Cash, & Engle, 2006; Ip & Jarry, 2008; Moreira, Silva, & Canavarro, 2010).

Negative affect: the experience of a negative feeling or emotion. Negative affect is considered as a general factor of subjective distress, and subsumes a broad range of negative mood states including fear, anxiety, hostility, scorn and disgust (Watson, Clarke, & Carey, 1988).

Positive affect: the experience of a positive feeling or emotion. Positive affect refers to the extent to which an individual subjectively experiences positive moods such as joy, interest and alertness (Miller, 2011).

Psychological distress: "Distress is a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (National Comprehensive Cancer Network, 2013). It is a concept most commonly operationally defined as a score on a self-reported patient outcome measure.

Quality of life (QoL): describes the range of broad range of impacts that cancer has on psychological and physical health, functional status, symptoms, and other aspects of life such as family relationships and spiritual or existential concerns (Institute of Medicine and National Research Council of the National Academies, 2004). Many survivors continue to experience negative effects of cancer and/or cancer treatment,

after completion of primary therapy. These effects include sexual, body image and psychological concerns (Gotay & Muraoka, 1998).

Radiation therapy: uses controlled doses of radiation to destroy cancer cells, and is usually given after surgery to the breast. Radiation therapy is a localised treatment, meaning that it only treats specific areas of the body. (National Breast Cancer Centre, 2007).

Self-compassion: is an ability to show understanding towards one's personal disappointments, that includes interconnected elements of self-kindness, mindfulness and common humanity (Neff, 2003a; Neff, 2003b).

Self-evaluative salience (SES): Self-evaluative salience is a sub-component of appearance investment, and refers to the importance an individual places on their physical appearance as a basis for their personal self-worth (Cash & Grasso, 2005; Cash, Melnyk, & Hrabosky, 2004). It appears that in illnesses such as cancer, self-evaluative salience may be a vulnerability factor for the individual (Moreira, Silva, & Canavarro, 2010), but very little is known due to lack of research in this area. Self-evaluative salience has been associated with more distorted body image cognitions, more body image dissatisfaction, lower self-esteem and greater interference with psychosocial functioning (Cash, Melnyk, & Hrabosky, 2004; Cash, Phillips, Santos, & Hrabosky, 2004; Jakatdar, Cash, & Engle, 2006; Ip & Jarry, 2008; Moreira, Silva, & Canavarro, 2010).

Self-regulation of negative affect: the ability to effectively manage and cope with negative emotions and distress to maintain normal functioning (De Ridder & Kuijer, 2006; Thompson, 1994).

Unstructured writing: Unstructured writing does not outline its structure or the constraints it obeys. In other words, the structure is not made explicit, and has sometimes been described as "free writing". Although all writing content by its very nature contains some inherent structure, Pennebaker-type writing has been described as largely unstructured (Unterhitzenberger & Rosen, 2014). This is in contrast to structured writing that obeys one or more explicitly stated constraints that serve a defined purpose.

Part One: Background and review of relevant literature

Part One of the thesis outlines the background of the four empirical studies which are contained in Part Two of the thesis. Part One brings together three major fields: 1) breast cancer and its impact on body image, 2) self-compassion, and 3) therapeutic writing. The intersections of these domains are discussed and study aims are developed for investigation.

1. Chapter One: Breast cancer and body image

Chapter One outlines the nature of breast cancer in women and associated considerations in body image. More specifically, breast cancer and adverse treatment side-effects are discussed, taking into account both physical and psychological impact. Current gaps in knowledge with regard to assisting survivors with interventions are explored while acknowledging the concurrent complexity of body image disturbance related to illness.

1.1. Breast cancer

Cancer is an illness characterised by an uncontrolled division of abnormal cells, and breast cancer is defined as tumour in the breast associated with genetic, lifestyle and environmental factors (National Breast Cancer Centre, 2007). Breast cancer is the most prevalent diagnosed cancer among women with nearly 1.7 million women diagnosed worldwide in 2012 (World Cancer Research Fund International, 2014), representing a quarter of all cancers in women. With continuing improvements in early detection and treatment approaches, and 5-year survival rates of almost 90% (Runowicz, et al., 2015), there are increasing numbers of long term breast cancer survivors (Ferlay, et al., 2013). Diagnosis and treatment for breast cancer can be a traumatic event for some people with consequent distress lasting for several years post treatment (Corwin, Wall, & Koopman, 2012; Kornblith & Ligibel, 2003). There are indications that a subset of these survivors will develop moderate to severe psychopathology (Thewes, Butow, Girgis, & Pendlebury, 2004), hence issues pertaining to survivor wellbeing are becoming an area of increasing importance.

1.1.1. Incidence of breast cancer in Australia

Australia is included in the top 20 countries which have the highest breast cancer rates worldwide (Ferlay, et al., 2013), therefore the needs of survivors are a justified area of investigation. Breast cancer represents 28% of reported cancer cases in Australian females, with the majority of women being diagnosed at 40-69 years of age (Australian Institute of Health and Welfare AIHW, 2012). The risk of a woman living in Australia being diagnosed with breast cancer before the age of 85 is 1 in 8 (Australian Institute of Health and Welfare AIHW, 2012).

1.1.2. Side-effects of breast cancer treatment

Breast cancer treatment commonly involves a number of medical interventions over an extended duration, typically surgery, and then a combination of adjuvant treatments including chemotherapy, radiation and hormonal treatments (Aebi, Davidson, Gruber, & Castiglione, 2010) , in addition neoadjuvant treatment may be applied in some cases. The risk of adverse long term effects after breast cancer is associated with a number of factors, including: a) type of treatment received; b) duration and dose of treatments (increased cumulative dose and duration of therapy increase the potential risk); c) type of chemotherapy used; d) use of hormone treatment; and, e) age of patient during the treatment (Runowicz, et al., 2015). Treatments produce a number of side-effects both individually and in combination, with a broad impact upon the recipient's body. Body image alteration has been recognised as an area of concern for a substantial sub-set of women, with reports of up to 50% of breast survivors experiencing body image problems (Fobair, et al., 2006; Runowicz, et al., 2015). Treatment effects can include both visible and non-visible changes which can have a combination of physical and emotional consequences.

Visible physical changes from surgical procedures may result in partial or complete loss of one or both breasts with accompanying scarring, poor alignment of breasts or asymmetry, swelling, need for a prosthesis, and in some cases a need for additional surgery for purposes of breast reconstruction (Andersen & Johnson, 1994; Crane-Okada, 2008; Kadela-Collins, et al., 2011; Swenson, 2002; Vadivelu, 2008). Chemotherapy can induce appearance-based challenges for the woman including hair loss, weight fluctuation, skin and fingernail discolouration, and hot flushes related to early onset menopause (Carelle, et al., 2002). Radiation treatment, often given in combination with other treatments, can cause noticeable skin reactions and

discolouration (Lundstedt, et al., 2012). Those women who also undertake hormone based treatment, may experience further problems involving additional treatment-induced weight gain, fat re-distribution and hot flushes (Baum, 2002). In the longer term, women who have undergone extensive removal of lymph nodes in the axilla, and radiation treatment to the chest wall and axilla, and taxane chemotherapy may develop lymphoedema, a swelling of the arm due to inadequate lymphatic drainage, resulting in physical and psychological concerns (Alcorso & Sherman, 2016). Such visible physical changes are often accompanied by non-visible changes following breast cancer treatment including: fatigue, changes to activity endurance, pain, nausea, vomiting, digestive problems, loss of fertility, ongoing neurological changes and/or a general experience of feeling unwell (Avis, Crawford, & Manuel, 2005; Lundstedt, et al., 2012; Pinto & Azambuja, 2011). Furthermore, women often report being uninformed about the occurrence of some side-effects and functional impairments, and may experience surprise that such difficulties may remain as part of their lives (Binkley, 2012).

1.1.3. Psychological consequences of bodily changes during treatment

Adverse physical changes to a woman's body are often accompanied by emotional challenges in the form of psychological distress. Distress is a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, associated physical symptoms, and medical treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to greater difficulties which may be disabling, such as adjustment disorders, depression, anxiety, panic, social isolation, and existential crisis (National Comprehensive Cancer Network, 2013). Psychological distress

encompasses many constructs (such as negative affect, stress, depression, anxiety), and is most commonly operationally defined as a score on a self-reported patient outcome measure. Measurement instruments that cover the constructs of psychological distress are discussed further in Section 3.3.2 (Measures used for empirical studies).

Emotional challenges can be related to a number of different factors, and empirical evidence indicates that approximately 30% of breast cancer survivors experience distress that is associated with body changes related to their treatment (Scott, Halford, & Ward, 2004). Negative bodily changes are often not within the woman's domain to control, particularly with regard to the number of side effects experienced or their severity (Tacon, 2011). For example, initial weight fluctuation and longer term weight gain after cancer treatment are common, and this can impact a woman's lifestyle, stress levels and mood (Helms, O'Hea, & Corso, 2008; Makari-Judson, Judson, & Mertens, 2007). Similarly, early onset menopause, decreased physical fitness, increased pain or limited limb mobility can interfere with a variety of life areas including sexuality, job productivity, leisure activities, house duties, sleep quality, independence levels and general life satisfaction (Collins, Nash, Round, & Newman, 2004; Fobair & Spiegel, 2009; Henson, 2002). Incidence of such problems can be high, with evidence indicating 17-33% of women may experience body related problems some or most of the time within seven-months of diagnosis (Fobair & Spiegel, 2009).

The specific nature of bodily changes in breast cancer can further contribute to subsequent adverse impacts upon a woman's broader sense of femininity. Loss of a breast, hair and/or fertility may be viewed as symbols of feminine qualities, and therefore, losses in aspects of womanhood and sexual attractiveness (Helms, O'Hea,

& Corso, 2008; Manderson & Stirling, 2007; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). There is also evidence that attempts to restore feminine appearance by surgical breast reconstruction can lead to long term feelings of regret (Sheehan, Sherman, Lam, & Boyages, 2007).

A woman's age at time of diagnosis and the type of treatment used, are factors which can further influence treatment impact. The combination of declining average age of diagnosis of breast cancer in some countries (Chen, Liao, Chen, Chan, & Chen, 2012), and improved survival outcomes (Ferlay, et al., 2013), contributes to younger women facing the prospect of earlier onset of bodily changes for a longer period of time, thus making the process of adjustment an issue of critical importance. Younger women, commonly classified as being 50 years or under at diagnosis, have been identified as having more frequent or more severe psychological outcomes, and therefore, are considered a high risk population (Howard-Anderson, 2012; Paterson, Lengacher, Kristine, Kip, & Tofthagen, 2015). Younger women are often treated for more aggressive breast cancers, and hence require more rigorous treatment regimens which can be particularly distressing (Axelrod, et al., 2008; Johnson, Chien, & Bleyer, 2013). Distinct concerns regarding premature menopause, menopausal symptoms, infertility, weight gain, physical inactivity and related psychological distress are particularly relevant for younger women, and this population have been identified as a target population for psychological symptom relief interventions (Howard-Anderson, 2012). A systematic review of 36 studies found that younger women are more concerned about appearance, experience greater distress related to physical changes due to adjuvant treatment, and are more open to consideration of breast reconstruction, with younger age being identified as a predictor of worse body image (Paterson, Lengacher, Kristine, Kip, & Tofthagen, 2015). In very young women (aged

less than 35 years), and those from ethnically diverse backgrounds, the impact upon quality of life and associated distress may even more severe (Smith, 2009).

Difficulties in body image may also be associated with, or predictive of, other problems in the breast cancer survivor. Women who are less satisfied with their body image are up to two and a half more times likely to also experience sexual difficulties (Panjari, 2011). Regarding body image and sexuality, 80% of women aged 34-49 years covered up their bodies for intimate relations compared to 58% of women in an older age range (>65 years), (Andrzejczak, Markocka-Maczka, & Lewandowski, 2013). Associations have also been found with regard to mood, with body image being a significant predictor of depressed mood in breast cancer survivors (Galiano-Castillo, et al., 2014). Furthermore, body image concerns have been linked to anxiety, depression, fatigue, fear of reccurrence, impairment in social functioning and negative impact upon relationships (Paterson, Lengacher, Kristine, Kip, & Tofthagen, 2015). Conversely, women with less negative conceptualization of their body image after treatment have been found to cope better with their cancer experience (Han, Grothuesmann, Neises, Hille, & Hillemanns, 2010).

1.1.4. Adjustment to bodily changes in survivorship

Adjustment to rapid, multiple bodily changes can be a particularly complex challenge. Evidence suggests that despite an immediate focus to address side-effects and symptoms during treatment, it may be particularly difficult for a woman to implement strategies during a period which is so physically and emotionally demanding (Chen, Liao, Chen, Chan, & Chen, 2012). Individuals who have faced a serious life threatening illness, such as cancer, have been considered to be in a depleted state regarding their personal resources (Kaplan & Berman, 2010), or according to Baumeister's theory to be in "ego-depletion" (Baumeister, Muraven, &

Tice, 2000). Many treatment regimens are difficult, time-consuming, costly, and require people to do things they find unpleasant, thus placing demands on personal resources over time (Terry & Leary, 2011). In such a context, the individual may be less able to function effectively, such as being able to regulate emotions or exert volition (Baumeister, Muraven, & Tice, 2000). Studies suggest that difficulties in adjustment are likely to be most prevalent in the immediate post-treatment period and gradually subside within a one to two year period (Brandberg, et al., 2008; Ganz, Kwan, Stanton, Bower, & Belin, 2011; Fingeret, Teo, & Epner, 2014). However, for a subset of women, ongoing difficulties related to bodily changes can persist for longer periods (Falk Dahl, Reinersten, Nesvold, Fossa, & Dahl, 2010; Hartl, et al., 2003) and this issue is receiving greater attention in research literature (Fingeret, Teo, & Epner, 2014). Some researchers conceptualise the experience of post-breast cancer body change as a reaction with pervasive traumatic stress-like symptoms (Frierson, Thiel, & Anderson, 2006). There have been suggestions that due to the intensity of the cancer experience, some women may undergo classical conditioning with a range of treatment-associated stimuli (such as visible bodily changes), whereby these stimuli can trigger emotional responses long after treatment completion (Kornblith & Ligibel, 2003), indicating a need for early identification and effective interventions. So despite the fact that many survivors may be medically well, a significant proportion of women may experience difficulties with adjustment, depletion of personal resources and prolonged psychological distress, particularly in regard to perception of their altered physical appearance or body image (Scott, Halford, & Ward, 2004).

Qualitative research has provided additional information about the influence of the body upon an individual's functioning during breast cancer treatment. Amongst breast cancer survivors, three major themes related to body image after treatment have

been investigated (Hefferon, Grealy, & Mutrie, 2010). Individuals report fear of the new altered body, in particular dealing with their recent losses and new bodily vulnerabilities. Survivors have also reported a common theme of dealing with negative effects of treatment, especially chemotherapy, in which their own body may feel "alien" and uncomfortable due to weight gain and sickness. Such changes may leave the woman ashamed, and embarrassed, while trying to come to terms with her new body. Lastly, a common theme of reconnection with one's body, by which a woman attempts to establish a positive connection with her changed body, is an important process in her personal growth (Hefferon et al., 2010). Survivors are involved in an illness process involving large changes, through which their sense of physical, gender and self-identity are altered, and then re-established, during the course of their breast cancer treatment (Hefferon et al., 2010). As women negotiate their new bodily identities, some may need particular assistance with bodily acceptance strategies (Grogan & Mechan, 2016). Understandably, such a process is also likely to impact, and makes demands upon, personal coping resources. Unfortunately, breast cancer related body image changes are not typically discussed or addressed by health professionals (Jorgensen, Garne, Sogaard, & Laursen, 2015). Furthermore, relevant support and interventions may not be routinely available within healthcare systems, and existing psychosocial care may be reactive rather than preventive (Mouradian, 2001). As such, there may be little opportunity for early identification and intervention. Greater understanding of the difficulties that women face during treatment, and a focus on enhancement of their new relationship with their changed bodies, in a cost-effective manner could assist survivor body image adjustment.

1.1.5. Gaps in knowledge and interventions to assist survivors

A variety of services to assist breast cancer survivors with post-treatment bodily changes are becoming available. The American Society of Clinical Oncology Breast Cancer Survivorship Care Guidelines recommend that the primary care physician or general practitioner assess for presence of body image concerns, and refer for psychosocial care as indicated (Runowicz, et al., 2015). Commonly offered approaches include cognitive behavioural therapies (CBT), psycho-sexual interventions offered by a mental health professional, educational workshops, cosmesis-focussed interventions, exercise programs, and peer support groups which are in addition to medical feedback received by the woman's doctor (Emilsson, Svensk, Olsson, Lindh, & Oster, 2012; Fingeret, Teo, & Epner, 2014). Despite such programs, within the first year following breast cancer diagnosis (Pauwels, Chadrlier, Bourdeaudhuij, Lechner, & Van Hoof, 2013) and beyond (Brunet, Sabiston, & Burke, 2013; Galiano-Castillo, et al., 2014; Montazeri, et al., 2008; Sackey, Sandelin, Frisell, Wickman, & Brandberg, 2010), women frequently express unmet needs regarding how to cope with the impact of bodily changes. Furthermore, systematic reviews of younger women with breast cancer have provided evidence of limited effectiveness with body image interventions offered for this population (Paterson, Lengacher, Kristine, Kip, & Tofthagen, 2015).

Another avenue by which women may wish to address adverse body image changes is through breast reconstruction. Reconstructive surgery can be performed by autologous flap reconstruction, implant reconstruction or a combination of these methods, and has been viewed as a potential means of restoring cosmetic 'normality', thus reducing associated psychological distress (Sheehan, Sherman, Lam, & Boyages, 2007). Some studies suggest that breast reconstruction may improve body image,

femininity, and sexuality, positively affecting the patient's sense of well-being and quality of life, and as such may help to offset disfigurement from cancer surgery (Dean, Chetty, & Forrest, 1983; Elder, et al., 2005; Metcalfe, Semple, & Narod, 2004). However, surgical approaches are not without risks or potential complications. Difficulties can occur with the surgical donor site, infection, sizing, scarring, implant rupture, and changes to bodily sensation (Liu, et al., 2014). Furthermore, women who choose to undergo reconstruction may find themselves facing an even longer period of appearance altering procedures, and may discover that body image difficulties still persist at completion (Chua, DeSantis, Teo, & Fingeret, 2015; Sackey, Sandelin, Frisell, Wickman, & Brandberg, 2010). Qualitative research has identified personal reasons why some women may choose not to undergo reconstruction including: additional healing and hassle, unwillingness to have unnecessary cosmetic procedures, and perceiving reconstruction negatively (Holland, Archer, & Montague, 2014). Furthermore, research on women's satisfaction with their decision to reconstruct or not, following mastectomy, reveals no significant differences in satisfaction over time; therefore suggesting that reconstruction is not a 'universal panacea' for emotional and psychological recovery after mastectomy, and should not be promoted as such (Harcourt, et al., 2003; Kornblith & Ligibel, 2003; Sheehan, Sherman, Lam, & Boyages, 2008). More importantly, surgery alone may not necessarily improve a woman's relationship with her body or her body image (Dahl, Reinertsen, Nesvold, Fossa, & Dahl, 2010; Jorgensen, Garne, Sogaard, & Laursen, 2015). Studies with non-oncology populations suggest that fear of negative evaluation may be a factor in a woman's attitude towards breast surgery (Dunaev, Schutz, & Markey, 2016). Evidence suggests that women may still feel self-conscious about their body image regardless of whether or not they have had breast reconstruction

surgery (Harcourt, et al., 2003), and as such, psychological matters related to post-treatment appearance still need to be addressed.

Despite the potentially life threatening nature of breast cancer, issues related to appearance remain an ongoing concern for many women. Information on physical changes, body image and sexual wellbeing is considered a high priority issue by most women with breast cancer (Ussher, Perz, & Gilbert, 2012). However, inherent power inequalities within the patient – health professional relationship may be especially pertinent when dealing with the sensitive and emotive topic of body image (Mouradian, 2001). Worries related to body image may not be volunteered by the individual due to embarrassment and psychological discomfort (Fingeret, 2010). Furthermore, the majority of women prefer this information to be presented in written form via booklets or websites, rather than verbally or face to face (Ussher, Perz, & Gilbert, 2012). Such needs, if left unrecognised or untreated, have the potential to persist and contribute to distress, anxiety or depression, which then may further hinder general quality of life in many areas such as work, social and relationships (Fingeret, Teo, & Epner, 2014). In serious and chronic health conditions such as breast cancer, a self-management approach for longer term issues is needed, and requires the survivor to involve themselves in behaviours to assist in their physical and psychological care (Schulman-Green, et al., 2011). Resources to encourage self-management by patients of these concerns that can be introduced by a variety of health professionals, such as cancer care nurses, have been considered to be a particularly important issue in survivorship care (Paterson et al., 2015). Evidence-based information and support strategies to assist women in coping with bodily changes have been identified as critical needs for survivors, and are recognised as translational research priorities (Eccles & al., 2013; Harrison, Young, Price, Butow, & Solomon, 2009).

1.2. Relevance of body image in health care

Although any health related intervention will invariably involve the body in one way or another, research on the topic of body image has only expanded greatly during the past 20 years (Annunziata, Giovannini, & Muzzatti, 2012). Earlier research on body image focussed on aspects primarily related to eating disorders, weight reduction and body shape issues, however, currently there is greater recognition of its importance in medical and allied health practices due to its impact upon the larger context regarding an individual's quality of life (Annunziata, et al., 2012; Falk Dahl, Reinersten, Nesvold, Fossa, & Dahl, 2010; Hopwood, Fletcher, Lee, & Ghazal, 2001).

1.2.1. Complexity in definition of body image

It is recognised that defining body image is complex, multi-factorial and highly subjective, with further difficulties caused by a confusing plurality of terms (Thompson, 2004). More than 15 different terms are used to describe body image in research including weight satisfaction, size perception, body satisfaction, appearance satisfaction, appearance evaluation, appearance orientation, body esteem, body concern, body dysphoria, body dysmorphia, body schema, body perception, body distortion, body image disturbance, and body image disorder (Annunziata et al., 2012; Thompson & Heinberg, 1999). Thomas Cash, a recognised expert in the field, defines body image as the multifaceted psychological experience of embodiment, which encompasses body-related self-perceptions and self-attitudes, including thoughts, beliefs, feelings and behaviours (Cash, 2004).

1.2.2. Theoretical context of body image disturbance

In addition to various ways of defining body image, the construct itself can be viewed as consisting of different interrelated subcomponents as reflected in various relevant theories, including Higgins' Self-Discrepancy theory, Baumeister's Escape

theory, and Cash's Body Image theory. More recently, emphasis has also been placed on greater understanding of positive body image approaches to assist with distress reduction and promotion of resilience (Casellas-Grau, Vives, Font, & Ochoa, 2016; Wood-Barcalow & Tylka, 2010).

Disturbance of body image may occur during subjective processes in which negative thoughts, feelings and behaviours regarding one's body may be present, resulting in dissatisfaction with oneself (Fingeret, Teo, & Epner, 2014; Stokes & Frederick-Rescasino, 2003). Evidence suggests that female body dissatisfaction occurs throughout adult life as women gradually move away from the societal young, thin ideal as they age (Frederick, Peplau, & Lever, 2006; Tiggemann, 2004). However, a chronic focus on one's appearance as a discrepancy from an ideal body can bring negative psychological consequences to women regardless of their age (Engeln & Salk, 2014).

Higgins' Self-Discrepancy and Baumeister's Escape theories are relevant in understanding body image disturbance. Higgins states that consequences arise when individuals compare one self-state to another self-state, and find that a discrepancy exists between the two (Higgins, 1987). Body dissatisfaction due to discrepancies between one's perceived, actual, and ideal images, have been found to be associated with behaviours that attempt to reduce discrepancies, such as altered eating, increased exercise or undertaking cosmetic procedures (Vartanian, 2012). For example, a desire to diet or lose weight has been associated with a larger body image discrepancy (Brodie & Slade, 1988; Furnham, Badmin, & Sneade, 2002). There is also evidence to suggest that the larger the discrepancy, the greater the resultant psychological distress, with research indicating the more obese a woman is, and further away from the Western thin ideal, the more distress she is likely to experience (Friedman,

Reichmann, Costanzo, & Musante, 2002). Apart from behaviours to reduce discrepancies, affect regulation strategies may also be used by the individual to cope with body image discrepancy. According to Baumeister's Escape theory, when individuals are confronted with aversive self-awareness, such as recognition of a discrepancy between one's actual and ideal self, they are motivated to escape that self-awareness (Vartanian, 2012). This can be attempted in a number of ways, such as substance use, self-harm, binge eating or other forms of emotional avoidance. Furthermore, greater awareness of one's actual body compared to one's ideal body, can trigger negative self-evaluation which may increase one's unhelpful emotion regulation strategies (Vartanian, 2012). Escape theory has been applied particularly to eating disorders, in which individuals experience aversion to the awareness of their perceived personal inadequacies, faults or other deficiencies. There is evidence that binge eaters suffer from chronically high levels of self-awareness and may also narrow their cognitive focus to avoid broader, logical thought (Heatherton & Baumeister, 1991). Individuals characterised by high levels of self-awareness, and a narrow cognitive focus on the immediate present, may respond to perceived failures by self-evaluation focussed on negative body perceptions (such as feeling fat or ugly), which then fuels disordered eating (Heatherton & Baumeister, 1991). As such, body image evaluation, self-discrepancy, and a narrowness of cognitive focus are likely to have an important role in contributing to an individual's suffering and distress.

Body image dissatisfaction is further explained by Cash's body image theory which discusses two subcomponents - appearance evaluation and appearance investment. Appearance evaluation refers to the emotional and cognitive level of *satisfaction* with one's appearance, and whether there is a discrepancy between self-perceived bodily characteristics and desired characteristics. In contrast, appearance

investment refers to the cognitive-behavioural *importance* placed upon appearance and physical attributes by the individual (Cash, 2011). Appearance related self-schemas are considered to be the foundation of appearance investment, and are assumptions or beliefs about the importance of one's appearance in life (Cash & Pruzinsky, 2002). With dysfunctionally high levels of investment, appearance is seen as central to an individual's self-worth, which is distinct from adaptive valuing of one's appearance (Cash, Melnyk, & Hrabosky, 2004). These two components of body image are essentially uncorrelated, and it is important to distinguish satisfaction with appearance from investment in appearance (Thompson, 2004). Using this perspective, it is recommended that both appearance evaluation and appearance investment be assessed in the individual (Cash, 2011).

Appearance investment has been a poorly understood factor with regard to body image disturbance. Research has mostly focussed on evaluative appearance dissatisfaction associated with self-ideal discrepancies, rather than appearance investment (Carraca, et al., 2011; Cash & Pruzinsky, 2002). However, although body image disturbance is best predicted by taking into account both evaluative and investment aspects, as the evaluation component alone is not sufficient to produce poor body image (Cash, 1994). Evidence suggests that dysfunctional investment in appearance has more adverse consequences to one's psychological health than evaluative dissatisfaction, in which the latter on its own is not considered a strong indicator of distress (Carraca, et al., 2011). It has been found that investment when measured as cognitive errors associated with body image cognitions, predicted quality of life and disturbed eating attitudes above and beyond evaluative body image (Jakatdar, Cash, & Engle, 2006). Furthermore, there is empirical support that high levels of dysfunctional appearance investment, rather than body dissatisfaction, are

more likely to encourage adoption of controlled regulations (i.e. pressured, forced or coerced behaviours) to change appearance by losing weight, which subsequently contributes to decreased psychological wellbeing (Carraca, et al., 2011). Carraca and colleagues suggest that whereas body image satisfaction is an important aspect, the salience or meaning of appearance to one's personal self is pivotal.

More recently, there has been a call for a change in theoretical direction in relation to body image research. In oncology there is a growing interest in positive psychological functioning (Casellas-Grau, Vives, Font, & Ochoa, 2016). This is in contrast to the major focus on body dissatisfaction in the general literature, with only a small amount of research literature examining the positive constructs related to body image (Andrew, Tiggemann, & Clark, 2016). Therefore, due to a pathology focus in the past (Williams, Cash, & Santos, 2004), potentially new positive-focused sources of understanding and intervention for body image have been largely neglected. Positive body image is described as having love, respect, and acceptance for one's body, with such individuals treating their bodies with care and appreciation for its function (Tylka, 2011). Research exploring body appreciation shows that it is a concept which goes beyond the mere absence of body dissatisfaction (Wood-Barcalow & Tylka, 2010). Body appreciation involves an understanding of what the body is able to do, its functionality, what it represents, its unique features, together with a broad conceptualisation of beauty with less emphasis on physical appearance as central to one's self-worth (Tiggemann & McCourt, 2013; Tylka & Wood-Barcalow, 2015; Wood-Barcalow & Tylka, 2010). Individuals who are higher in body appreciation and positive body image are able to feel confident with their bodies and are more able to resist unrealistic, unhelpful social ideals by filtering information in a body protective manner (Tylka, 2011; Tylka & Wood-Barcalow, 2015). Another

approach which is in its infancy is the application of self-compassion to issues of body image (for a detailed discussion see section 2.1.8. Self-compassion and its relationship to body image). Positive body image has been seen as both a stable and malleable characteristic, having both trait- and state-like qualities (Tylka & Wood-Barcalow, 2015). Furthermore, preliminary evidence suggests that positive body image is likely to be protective of physical health and psychological wellbeing, thus increasing one's resilience, (Tylka & Wood-Barcalow, 2015); however, actual responses after perceived threats to body image also need to be investigated. Suggestions have been made for researchers to study real-world outcomes related to positive aspects of body image such as: attentiveness to the needs of the body, use of modifiable health behaviours to reduce health risk, early self-detection of disease through appropriate body monitoring, and increased health behaviour compliance (Andrew, Tiggemann, & Clark, 2016; Tylka, 2011). At the same time, negative aspects of body image cannot be ignored in the field of health promoting behaviours. For example, there are indications that body image concern may be a frequent barrier to breast and other cancer screening for women (Clark, et al., 2009), and therefore, negative body image needs to be addressed together with enhancement of positive body image. There are suggestions that both "upward spirals" of positive body image fostering growth, and "downward spirals" perpetuating negative body image distress could exist (Tylka & Wood-Barcalow, 2015). The discussion in this section indicates a need for translation from theoretical exploration to applied studies of both positive and negative body image in health care areas.

1.2.3. Alteration in body image during illness

Body image concerns of the general population, and associated personal disappointments related to one's appearance with resultant impacts on psychological

wellbeing, have been documented in the literature (Grogan, 2008; Grogan, 2012; Jarry & Berardi, 2004; Thompson & Heinberg, 1999). Such concerns may be different, and potentially additive to bodily changes that have occurred due to medical reasons. The discussion below examines the specific contribution and impact of medical factors to body image difficulties. Features of body image concerns amongst non-oncology populations are reviewed in the following section (Section 1.2.4), according to age group.

During illness or injury, additional factors come into effect with regard to body image, and resultant impacts frequently go beyond the purely physical realm. The diagnosis of illness and commencement of treatment can add further challenges and complexity for the individual. Organic disease and injuries that distort the body structure have also been shown to alter one's personal image of the body, and further interfere with the entire self-image (Bronheim, Strain, & Biller, 1991). Heightened awareness of the body has been reported as an outcome of physical illness (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007). Some illnesses, injuries or treatment side-effects are sudden in their onset, and the abrupt nature of changes may present additional difficulties. It has been suggested that gradual changes of a disease process may allow for a gradual adaptation to changes in body image, and may be less psychologically traumatic than a sudden insult to the body (Samonds & Cammermeyer, 1989). During and after the experience of illness and/or its treatment, an individual's altered physical body can induce a conflicted cognitive state of two equally important outlooks (Hefferon et al., 2010); one's human vulnerability and mortality, *as well as* a reminder of being alive and having hope in future (Goldenberg, Kosloff, & Greenberg, 2006; Hefferon et al., 2010). Therefore, those who receive medical treatment – especially multiple medical treatments - and undergo sudden

bodily alteration may need specific psychological assistance with adjustment to physical changes.

In cancer patients disease and treatment-related changes differ in their degree of observability, permanence, controllability and extensiveness (White, 2000), thus adding further issues for consideration. Moreover, the term 'body image' in cancer has not captured the complexity of the issues involved, and as such, researchers have generally failed to integrate findings from mainstream psychology to psychosocial oncology research and practice (White, 2000). Body image dimensions are largely inseparable from one's feelings, and also need to take into account one's personal investment (or importance) placed upon appearance attributes, and all these concepts need to be taken into consideration in oncology research and practice (White, 2000). White has constructed a heuristic model of important body image dimensions of which an adapted version is shown below (Fig 1.1. A heuristic model of important body image dimensions). White's model illustrates the close relationship between automatic thoughts and images, emotions and compensatory behaviours as final outcomes in relation to body image difficulties which are often the point of intervention for an oncology clinician

White's model can be understood further using a common example of cancer-related weight gain. A woman may experience an increase in her weight due to cancer treatments, and this change in appearance can activate her schemas, for example "Attractive women must be slim". The woman's schemas can influence her level of investment in appearance as described by Cash (Cash, 2011), and the extent of ideal-actual body image discrepancy experienced as described by Higgins (Higgins, 1987). An example might be "It is important for me to be slim to be attractive and liked", and "My body is very different to how it should look". These aspects, in turn, are likely to

influence situation specific negative assumptions, for example, "People are staring at me because I've gained so much weight". These assumptions are then likely to influence the woman's body image cognitions such as "I am ugly", body image related emotions, such as fear and sadness, and compensatory behaviours, such as avoidance (e.g. not attending social events)

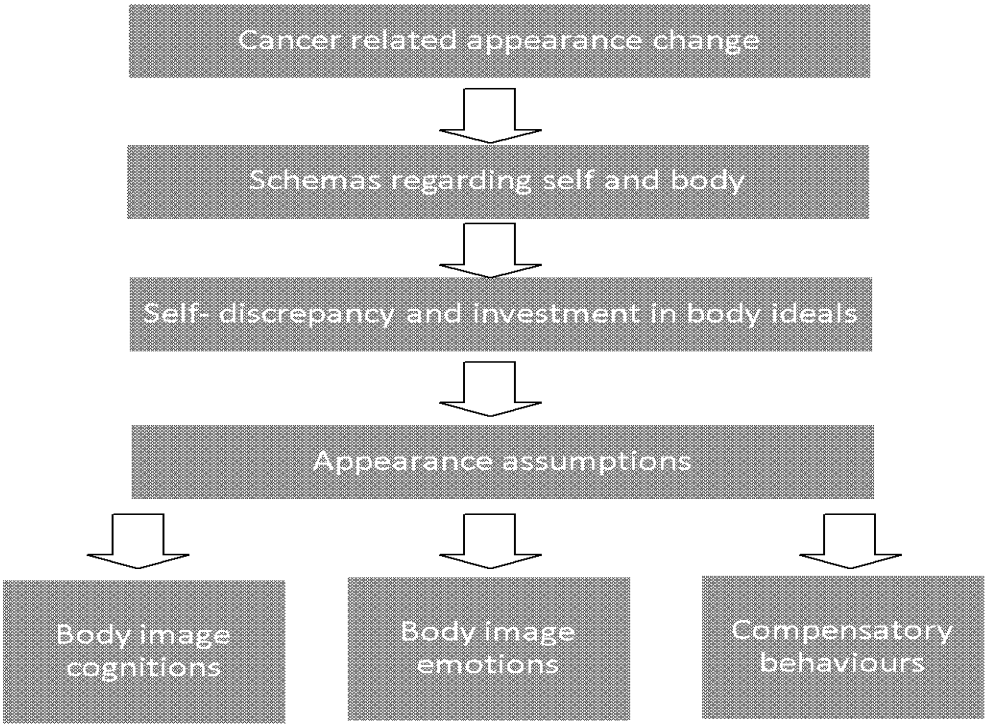


Figure1.1. A heuristic model of important body image dimensions (adapted from White, 2000)

Appearance investment appears to be a critical factor in breast cancer survivors due to the level of attention and importance a woman may direct towards any body image changes. From Cash's theory, this appearance investment is further broken down into two main facets: self-evaluative salience and motivational salience (Cash & Labarge, 1996). Self-evaluative salience refers to the importance an individual places on her physical appearance as a basis for her personal self-worth,

whereas motivational salience refers to the individual's efforts in appearance management behaviours in order to improve her attractiveness (Cash & Grasso, 2005; Cash, Melnyk, & Hrabosky, 2004). From research using a variety of community samples, motivational salience is regarded as the less dysfunctional component, with self-evaluative salience associated with more distorted body image cognitions, more body image dissatisfaction, lower self-esteem and greater interference with psychosocial functioning (Cash, Melnyk, & Hrabosky, 2004; Cash, Phillips, Santos, & Hrabosky, 2004; Jakatdar, Cash, & Engle, 2006; Ip & Jarry, 2008; Moreira, Silva, & Canavarro, 2010). A further component regarding bodily integrity or wholeness has also been suggested as a possible additional factor to be considered in personal appearance investment for this population (Carver, et al., 1998).

Given the challenges of illness and adverse bodily changes for a woman with breast cancer, it has been suggested that enhancement of her personal resources may assist with adaptation and adjustment to body image changes. Potential interventions may be focussed on physical aspects of the woman's cancer survivorship experience, such as health and exercise programs, social resources including support groups, and psychological resources such as resilience or cognitive therapy programs (Phillips & Feguson, 2013). There is evidence that self-compassion may be a particularly important additional personal psychological resource to develop in both younger and older age groups, due to its associations with psychological health (Barnard & Curry, 2011; Neff, 2011; Phillips & Feguson, 2013). Self-compassion is the ability to show self-directed kindness in times of difficulty (Neff, 2003a) and is discussed in detail in Chapter 2. Potential applications of self-compassion could be directed at a woman's cognitions, emotions, and behaviours, consistent with White's model (2000). Self-compassion has been associated with body image improvement, hence demonstrating

specificity to body image difficulties (Albertson, Neff, & Dill-Shackleford, 2014). Given that positive body image might be more related to health-promoting behaviours, whereas negative body image may be more related to health-compromising behaviours (Andrew, Tiggemann, & Clark, 2016), a psychological approach that addresses both of these aspects would be optimal for a woman's wellbeing. Self-compassion has shown promise regarding assisting one's openness to health promoting behaviours (Terry & Leary, 2011; Terry, Leary, Mehta, & Henderson, 2013), improvement of motivation (Breines & Chen, 2012), reducing experiential avoidance (Costa & Pinto-Gouveia, 2013), increasing acceptance of personal responsibility for mistakes (Leary, Tate, Adams, Allen, & Hancock, 2007), and promoting personal improvement after difficult experiences (Zhang & Chen, 2016). Self-compassion as a concept and personal resource will be discussed further in Chapter 2. Existing approaches to addressing body image difficulties are discussed below.

1.2.4. Age and body image intervention

Women are likely to have differing body image concerns based on their stage in life, and this has been reflected in relevant research and interventions. Body image dissatisfaction have been reported in girls as young as seven years of age (McCabe & Ricciardelli, 2003), but most existing research is based on young women in their 20s and 30s, as they are a convenient sample for university based student research (Grogan, 2012). Younger women tend to be most dissatisfied with their lower torsos; they compare their bodies unfavourably to thin media models, and are unhappy about post-pregnancy weight gain (Grogan, 2008; Grogan, 2012). Cognitive-behavioural interventions typically focus on modifying an individual's thoughts and subsequent behaviours regarding an area of difficulty, and are a widely utilised approach in

psychological treatments (Beck, 1991). Cognitive-behavioural-based treatments have been shown to be an effective intervention to assist in younger women's body image issues, especially encouraging women to focus on body function and fitness, rather than body appearance (Jarry & Berardi, 2004). Other approaches indicated for younger women's body image difficulties include improving media literacy to allowing rejection of unrealistic flawless images, improvement of self-esteem, and use of exercise programs to improve fitness (Grogan, 2012). There are indications that internet delivery of interventions for young women may be particularly effective given their high levels of access to online activities and their comfort in using this type of delivery format (Stice, Rohde, Durant, & Shaw, 2012).

Much attention has been placed on body image difficulties amongst adolescents and young adult females, however, body image problems in midlife (i.e., 35-55 years) or older, have received relatively less investigation (Lewis-Smith, Diedrichs, Rumsey, & Harcourt, 2015). Such age groups face unique challenges related to this life stage (e.g. menopause, appearance changes due to ageing) which means that research from younger age groups does not necessarily address these women's concerns, (Lewis-Smith et al., 2015). Furthermore, health problems such as breast cancer, and other chronic illnesses are more likely to affect women in midlife, than in younger years. A recent review indicates that psychotherapeutic group therapy approaches for mid-life women (aged 35-55 years) from general community samples, have been found to produce sustained body image improvements, whereas exercise based programs have been less effective (Lewis-Smith et al., 2015). While demonstrating effectiveness in addressing body image concerns both in community samples and women diagnosed with breast cancer, long recognised drawbacks to group interventions include that they are time, labour and resource intensive, and

potentially demanding in terms of participant attendance (Kissane, et al., 1997; Lewis-Smith, et al., 2015).

Existing research on body image dissatisfaction in older women, such as those aged 60 years or over, is scarce (Rakhkovskaya & Holland, 2015). There have been suggestions that importance of body shape, weight and appearance diminishes with age, therefore, potentially decreasing appearance investment, making this population distinct from younger women (Tiggemann, 2004). Conversely, other research suggests continuation of body image difficulties, with an ongoing preoccupation with weight and appearance, with heightened awareness of advancing age and perceptions of body failure (Clarke & Griffin, 2008). In a recent study, the majority of older adults, aged 60 years and over, reported dissatisfaction with their weight, shape or appearance, with women reporting higher body dissatisfaction than men. Furthermore, perceptions that one's physical health has negatively impacted one's appearance were significantly associated with greater body dissatisfaction (Rakhkovskaya & Holland, 2015). As such, they recommend appropriate screening for individuals who may have experienced physical effects of illness on appearance (Rakhkovskaya & Holland, 2015). More research regarding body image in older women is clearly needed. The importance of this issue is likely to increase as the worldwide population of older adults continues to grow in a social context that which is largely youth oriented and devalues aging (Knight, 2012). In particular, with increasing rates of survivorship of body image compromising medical conditions such as breast cancer, the demand for effective intervention is likely to become even greater with time.

2. Chapter Two: Self-compassion

Self-compassion is a novel approach in the field of psychology and this chapter outlines the background of this concept, main theories of understanding, and relevance to psychological wellbeing. The approaches taken by Neff and Gilbert are discussed, as well as self-compassion-based intervention and possible future directions for specific difficulties.

2.1. Self-compassion and its relevance to the needs of survivors

2.1.1 Definition of self-compassion

The importance and potential of self-compassion has only recently been acknowledged in Western psychology (Gillath, Shaver, & Mikulincer, 2005); however, it is a fundamental component of Buddhist beliefs, psychology and practice that is many centuries old. Buddhist philosophy is inclined to look at compassion as a motivational construct, or an attentional sensitivity to suffering, in which an individual's personal intention is paramount (MacBeth & Gumley, 2012). Within Buddhist beliefs, the practice of compassion is seen as a way of helping individuals to train their minds. This can lead to a general improvement in wellbeing and ability to cope with difficult emotions, which then enhances the ability to cope with challenges in life (Pauley & McPherson, 2010). Similar to other Buddhist-based approaches that have been adopted by Western psychology, such as mindfulness activities (Sharf, 2015), Emotionally Focused Therapy (EFT) (Karris & Caldwell, 2015), and Acceptance and Commitment Therapy (ACT) (Fung, 2015), self-compassion is being researched and translated to psychological practice in both clinical and non-clinical settings.

The English word compassion is derived from Latin, *com* meaning "together with" and *pati* meaning "to suffer with" (Burnell, 2009). In a broad way, compassion can be understood as a combination of knowing the suffering of others, adoption of non-judgemental acceptance, having a sense of connection, and trying to intentionally alleviate the suffering (Gilbert, 2005). It is seen as the opposite of cruelty, which is the intention for creating suffering and harm (Gilbert, 2005). Furthermore, in addition to compassion for others, it can be extended to oneself in times of difficulty, and self-

compassion can be particularly relevant when suffering arises from one's own losses, mistakes, failures or personal inadequacies (Neff, 2011).

Psychology has applied the concept of compassion to understanding people's emotional states, and is examining whether development of self-compassion is beneficial for alleviation of psychological distress and regulation of negative affect (Reyes, 2012). There are two main viewpoints regarding self-compassion as a construct in Western psychology: 1) social psychological approaches (Neff, 2003a; Neff, 2003b; Neff, 2011), and, 2) evolutionary neuroscience-based approaches (Gilbert, 2005; Gilbert, 2009a; Gilbert & Procter, 2006).

2.1.2. Social psychology approach to self-compassion

Self-compassion has been conceptualised by Neff, who initially studied the construct as an alternative to self-esteem for promotion of well-being (Neff, 2011). Self-esteem refers to a self-attitude in which self-worth is conditional on perceived personal competence and attainment of desired states and ideals. In contrast, self-compassion is a self-attitude that is non-judgemental towards one's inadequacies and failures, and in which self-worth is unconditional (Karanika & Hogg, 2015; Neff & Vonk, 2009). Since self-esteem incorporates conditional self-worth, it is non-protective against self-deficits, and thus self-compassion represents a healthier form of self-acceptance (Karanika & Hogg, 2015; Neff & Vonk, 2009). Neff views self-compassion as comprising three main components which mutually interact and overlap: Self-kindness versus self-judgement, common humanity versus isolation, and mindful awareness versus over-identification/entanglement (Neff, 2003a; Neff, 2003b; Neff, 2011). The Self-Compassion Scale is a measure of dispositional levels of compassion directed towards oneself to reflect the self-compassion components (Neff, 2003a). The scale has demonstrated adequate psychometrics properties (Neff, 2003b;

Neff, Pisitsungkagam, & Hsieh, 2008; Williams, Dalgleish, Karl, & Kuyken, 2014). However, emerging evidence questions the 6-factor structure in the original scale (Neff, 2003a; Neff, 2003b), indicating that a 2-factor structure of positive and negative items is more appropriate (Phillips & Feguson, 2013). The Self-Compassion Scale is discussed further in the thesis section which describes measures used for empirical studies.

Self-kindness is the ability to be caring, gentle and understanding with one's self, rather than being harshly judgemental and critical (Neff, 2011). Using such an approach, one's personal flaws, inadequacies and mistakes are addressed in a gentle, understanding manner, and the emotional tone of one's language used towards the self is soft and supportive (Neff, 2011). Rather than ongoing rumination and criticism for one's inadequacies, self-compassion incorporates the understanding that human beings are imperfect and that we cannot always be exactly the type of person we would like to be. During difficult times, self-compassionate individuals are able to provide themselves with warmth, soothing and comfort, rather than adopting a cold, harsh, stoic approach (Neff, 2011). However, self-kindness is also not a licence simply to do anything one would wish without consideration of consequences, or to be self-indulgent. Often self-kindness may mean facing difficult situations and emotions, as well as having courage to address the sources of one's suffering. This may involve various actions such as thorough self-examination, taking personal responsibility for one's decisions, learning from one's mistakes, asking for forgiveness, making amends, putting in greater efforts to address one's shortcomings, not avoiding necessary tasks, or making any number of personal changes that lead to a decrease in suffering (Leary et al., 2007; Neff, 2011; Neff, Rude, & Kirkpatrick, 2007; Sirois, Kitner, & Hirsch, 2015).

The concept of common humanity, in self-compassion, is the understanding that all people experience loss, failure, make mistakes and feel inadequate in some way or another. As such, imperfections are seen in a broad, inclusive perspective as something that is shared, and is considered to be a normal part of the human experience (Neff, 2011). As such, difficulties and suffering can foster a sense of connection, and possibly enable communication with others, rather than isolation using a singular "why me?" perspective (Neff, 2003a; Neff, 2011). This approach challenges the sense of isolation and disconnection that can occur if an individual adopts a viewpoint that it is abnormal, shameful or even a punishment to experience hardships in life (Neff, 2003a; Neff, 2008; Neff, 2011). Theoretically, a common humanity perspective can assist the individual to consider both their own difficulties and the difficulties of others, enhancing inclusiveness and a sense of belonging to the human community. Common humanity is theorised to be distinct from self-pity. Although both engage with difficult emotions, self-pity involves creation of a distinction between self and others, exaggeration, self-absorption, or using a perspective of inferiority/superiority regarding the difficult circumstances. A "poor me" approach denies that life is difficult at times for everyone, and that many people suffer in a number of different ways, creating separation which is the opposite of common humanity (Neff, 2003a; Neff, 2003b; Neff, 2011).

Mindful awareness involves having a stance which is balanced and clear about the present moment. Mindful individuals observe their thoughts as thoughts, and feelings as feelings in an accurate, non-judgemental, receptive mind state (Neff, 2008). In this way, the individual neither ignores, exaggerates nor ruminates on difficult aspects of one's life (Brown & Ryan, 2003). As avoidance of painful emotions intensifies them in the longer term (Neff & Vonk, 2009), mindfulness could

be considered essential for adjustment and wellbeing. Mindful awareness is said to be a necessary step to acknowledging one's personal pain. It is believed to enable taking on a meta-perspective with clarity, objectivity and context. This process is thought to be disrupted by self-judgement, avoidance, excessive problem solving, or simply being carried away by one's own story line which Neff describes as "over-identification" (Neff, 2003b; Neff, 2011).

An 8-week training program to enhance self-compassion has been developed (Germer & Neff, 2013; Neff & Germer, 2013), which is based along mindfulness training formats, similar to that of Kabat-Zinn (Kabat-Zinn, 1982). A limitation of mindfulness training approaches is that they devote relatively little time to explicitly teaching skills of self-compassion, and focus primarily on teaching mindfulness techniques (Neff & Germer, 2013). In contrast, the Mindful Self-Compassion (MSC) Program (Germer & Neff, 2013; Neff & Germer, 2013), works to enhance self-compassion directly, rather than focussing on mindfulness. This program shares similar methodology to that of Kabat-Zinn, and includes facilitator led education, various guided meditations, group discussion, silent retreat practice, and a number of home activities (formal and informal meditation practices), and also teaches basic mindfulness skills (Neff & Germer, 2013). In addition, specific elements such as use of self-compassionate language, soothing touch, affectionate breathing (Germer & Neff, 2013; Neff & Germer, 2013) are incorporated in the MSC, which is regarded as a "hybrid" intervention in that it is appropriate for the general population and also for some clinical populations (Neff & Germer, 2013). The MSC program has demonstrated promising results in non-clinical populations, with randomised controlled trials using wait list controls showing increased self-compassion, greater compassion for others, improvements in mindfulness, greater life satisfaction, with

decreases in depression, anxiety, stress and emotional avoidance (Neff & Germer, 2013; Germer & Neff, 2013). There has also been an increased focus on development of a shorter intervention suitable for university students, with a brief three week version of the group program demonstrating positive outcomes in relation to self-compassion, optimism and self-efficacy in a randomised controlled trial (Smeets, Neff, Alberts, & Peters, 2014). Such results hold promise for the future development of brief interventions using self-compassion without potential loss of effectiveness.

2.1.3. Evolutionary neuroscience approach to self-compassion

Gilbert has taken a somewhat different approach to self-compassion than Neff, as his focus investigates evolutionary clusters of emotions that are involved in the mammalian caregiving system (Gilbert & Procter, 2006). Gilbert has based his approach on the work of Depue and Morrone-Strupinsky (Depue & Morrone-Strupinsky, 2005) and Le Doux (LeDoux, 1998), who have identified three evolved core affect systems entailing emotions that serve the function of: 1) threat detection and generation of defensive safety strategies; 2) seeking of resources for survival and reproduction; and, 3) contentment, satisfaction, calming and settling (Gilbert, 2009a; Gilbert, 2014; Gilbert, 2015). These three systems are discussed below.

The threat and self-protection focused system at its most basic level involves emotions to alert and assist an animal to respond to threats. When activated, the system responds with a number of threat based emotions such as anger, anxiety and disgust, shame, and related behaviours of fight, flight, freeze and submission, with the motive of keeping oneself safe (Gilbert, 2001; Gilbert, 2015; LeDoux, 1998). Due to its life preservation focus, this is the most dominant affect processing system, and can give rise to the *negativity bias* that ensures an individual's greater focus on aversive events and negative stimuli, in memory, cognitions and decision making (Baumeister,

Bratslavsky, Finkenauer, & Vohs, 2001). Threat activation tends to suppress positive emotion, as interest is lost in enjoyable activities when faced with threats (Veale & Gilbert, 2014). It is the intensity, frequency and duration with which this system is activated that can lead an individual to seek psychological assistance (Gilbert, 2015).

The drive-seeking and acquisition focused system is associated with emotions related to obtaining resources related to survival (e.g., food) and reproduction (e.g., mate selection), which when successful are usually experienced as energising and positive. Usually these are experienced as "feel good" emotions derived from anticipation, achieving, acquiring, consuming and competitive success (Gilbert, 2015). Some scenarios by which this system may be activated include competitive sports, promotions, finding a sexual partner, acquiring new possessions or gambling. There are suggestions that Western society is overly focussed on a "have it all" attitude and may be overstimulating this system (Pani, 2000). Problems with this system may manifest as being overly "driven", having an excessive need to be busy, experiencing problems with addictions or impulse control difficulties.

The soothing-affiliative affect system is a state of peacefulness, contentment or wellbeing, which may be seen when an individual is not threat focussed or striving for resources. The positive emotions in this system are not contingent upon obtaining resources, success or achievement, and are not excitement-based (Gilbert, et al., 2008). Such a system of safety, calming and soothing has evolved to facilitate affiliation and attachment between members of groups. In humans if an individual is distressed, the care, kindness, and support of others can help to create calm. People in kind, caring relationships feel safe, soothed, relaxed, have reduced stress hormone and experience improvements to their immune systems (Gilbert, 2009a). If the functioning of this system is problematic, the individual may feel separated, alone, disconnected,

misunderstood and unsafe (Gilbert, 2015). Evidence suggests that a secure attachment during childhood with affiliative bonds, social connection and safeness as conferred by the presence of supportive others, is important in the development of this system (Veale & Gilbert, 2014). Furthermore, the presence of such affiliative connections have been shown to be crucial to regulation of emotion, noting that individuals respond very differently to threats when they are supported, than if they are alone or criticised (Gilbert, 2015).

In order to perform compassionate behaviours the individual first needs to develop the attributes of compassion (Gilbert, 2009a; Gilbert, 2009b). Gilbert states that attributes of compassionate behaviour are: "care for well-being", "sensitivity towards distress", "sympathy", "distress tolerance and acceptance", "empathy", and "non-judgement" (Gilbert, 2009a). A "care for well-being" entails a genuine concern for well-being that is directed towards the self, which is not based upon obtaining social approval or praise. It is the opposite of self-neglect. "Sensitivity" involves self-awareness so that an individual can choose to attend to their physical sensations, emotions and cognitions, as well as being aware of any potentially self-sabotaging reactions. "Sympathy" is an emotional reaction, which involves the ability to be genuinely moved by one's suffering and an understanding of one's pain. It is the opposite of denying or dissociating from one's suffering. "Tolerance" is the ability to stay and face one's emotions as they occur, and "acceptance" involves no longer fighting emotions, instead changing focus to come to terms with them. "Empathy" involves a cognitive approach that is related to tolerance; an ability to connect with personal emotions to truly understand one's processes and experiences. "Non-judgement" involves engagement with one's emotions and behaviours without belittling, disparaging or distortion. It does not entail that everything is acceptable;

rather that self-correction is possible without attacking and condemning oneself. Gilbert states that these attributes necessary for self-compassion can be enhanced by skills training involving imagery, reasoning, attention, sensory training, and practice of compassionate behaviours, in an environment of warmth (Gilbert, 2009a). He has called his approach CFT – Compassion Focussed Therapy (Gilbert, 2010), and it has been primarily designed for use with clients with clinical problems. The primary focus of CFT is to help clients effectively access their soothing affect system, to facilitate the experience of affiliative emotions, and to enable down regulation of an overactive threat system. (Gilbert, 2010). Gilbert's view is that fear, shame and other stressors work to activate the threat system in times of danger which has conferred an evolutionary advantage for survival (Gilbert, 1989). However, some people with such intense negative emotions, and an inability to self-soothe, can have difficulty in being compassionate and experiencing feelings of affiliation (Gilbert & Irons, 2004). Traditional cognitive behavioural strategies seek to identify and challenge faulty cognitions, and may inadvertently reinforce people's perception of themselves as fundamentally flawed (Van Vliet & Kalnins, 2011). A central difficulty is that such individuals may also have trouble generating *believable* alternate helpful cognitions during processes such as CBT-based thought challenging, and therefore the development of self-kindness can assist with client engagement (Gilbert & Procter, 2006). The compassion focused therapist may be seen as an attachment figure who offers corrective emotional experiences for clients (Gilbert, 2010). As such, Gilbert's approach involves an interweaving of varied theoretical views such as physiological threat systems, neuro-chemical self-soothing systems, and attachment styles (Gilbert, 2014; Gilbert & Irons, 2004; Rockcliff, Gilbert, McEwan, Lightman, & Glover, 2008), which also translates to a treatment approach that is multi-focal requiring various forms of therapist input.

A central CFT skill is the development of self-compassionate visualisation in which an individual learns to create a unique ideal image of a compassionate being to which they can relate (Lee, 2005; Gilbert & Procter, 2006; Gilbert, 2009a; Van Vliet & Kalnins, 2011). The individual practices visualisation of a kind being whose facial expressions and soothing tone communicate caring, understanding and acceptance. Whenever the individual's thoughts return to habitual self-criticism, then the image of the compassionate being can be recalled as many times as needed (Van Vliet & Kalnins, 2011). However, a possible difficulty for some people is that they may have no memory or experience of kind, caring people in their past, and this might be an additional source of grief (Gilbert & Irons, 2004; Gilbert & Procter, 2006; Gilbert, 2010). CFT also uses other experiential exercises, such as compassion-focused attention, engagement in self-compassionate behaviours and dialogue which is held within the safety of a therapeutic relationship (Gilbert, 2005; Gilbert & Procter, 2006; Gilbert, 2010). A systematic review using 14 studies indicate that CFT shows promise in the treatment of mood disorders, especially with individuals high in self-criticism, however, more high quality randomised controlled trials of this therapeutic approach are needed (Leavis & Uttley, 2015)

Although, Neff and Gilbert have approached the concept of self-compassion from different viewpoints, their definitions share the commonalities of kindness, warmth, attunement and a desire for betterment, with a belief that one's self-compassion levels can be enhanced or cultivated. Psycho-education is an important foundation and can help the individual understand their emotions and reactions. Both self-compassion approaches focus on the client's "here & now" alleviation of suffering, expansion of the individual's viewpoint, and creation of new understanding. Skilful self-soothing is emphasised by both Neff and Gilbert as a cornerstone of their

methodologies, and this is made explicit when teaching self-compassion skills (Germer & Neff, 2013; Gilbert, 2010; Gilbert & Procter, 2006; Neff & Germer, 2013).

Both Neff and Gilbert have well-researched self-compassion group training programs, which have been used for skill enhancement or therapeutic intervention. Neff has found that self-compassion can be manipulated through group format structured activities over an 8-week period, and has obtained evidence for enhancement at one year follow up (Neff & Germer, 2013), with further investigations continuing through her Mindful Self-Compassion (MSC) training programme. Neff's program is guided by facilitators who aim to model self-compassion to participants. Facilitators guide participants through experiential activities either by formal meditation practices (loving-kindness, affectionate breathing), and informal practices (soothing touch, self-compassionate writing). Participants are expected to undertake home practice of skills for approximately 40-minutes per day. Likewise, Gilbert has shown that self-compassion can be enhanced through training by using his Compassion Focussed Therapy (CFT) approach with clinical populations (Braehler, et al., 2013). Although CFT programs may be modified for needs of specific groups of participants, typical activities may include keeping a personal diary of self-criticism/self-reassurance, identification of shame, use of self-compassionate reflection, self-compassionate reasoning, development of self-compassionate behaviours and practice of self-compassionate imagery over a 6-week period (Gilbert & Irons, 2004). Likewise, as in Neff's MSC training, Gilbert's CFT also requires the facilitator to demonstrate self-compassionate warmth, and therefore be a role model and guide for group participants (Gilbert & Irons, 2004). Some researchers have begun integrating approaches from both Gilbert and Neff, finding

them compatible to use together, and further combining self-compassion interventions with existing psychotherapeutic techniques (Karris & Caldwell, 2015).

From this point onwards in the thesis, self-compassion and related research will be considered from a combined perspective, and discussion of outcomes will not make distinctions between Gilbert and Neff's theoretical viewpoints. Further discussion about the treatment benefits of self-compassion based approaches will be explored in the following sections.

2.1.4. Evidence for psychological benefits associated with self-compassion

Evidence is mounting that self-compassion is a significant variable in numerous aspects of psychological difficulties. Self-compassion is a robust predictor of negative affect, depression and anxious symptom severity, when compared to other possible predictors such as mindfulness (Van Dam, Sheppard, Forsyth, & Earlywine, 2011; Woodruff, et al., 2014). It has been suggested that higher levels of self-compassion can represent an internalization of a healthy attitude that therapists often attempt to instil in their clients, and hence may be a critical factor against development of psychological difficulties (Van Dam et al., 2011). A meta-analysis by MacBeth and Gumley (2012) of 14 studies found strong, negative correlations between self-compassion and measures of psychopathology (depression: r=-.52, anxiety: r=-.51, stress: r=-.54). This is a starting point in understanding the benefits of self-compassion, however, it must be kept in mind that wellbeing is not necessarily just a lack of psychopathology (Greenspoon & Saklofske, 2001; Wang, Zhang, & Wang, 2011), and this may particularly be true of people who have chronic medical conditions, such as cancer survivor populations.

Self-compassion has also been directly linked with overall wellbeing. In their meta-analysis of k=79 studies using mostly non-clinical participants with a total

sample size of N=16,416, Zessin and colleagues confirmed a significant, positive relationship between self-compassion and wellbeing (using a combination of subjective and psychological wellbeing) (*r*=.47), as well as evidence for a causal relationship between these variables. Manipulations of both longer and shorter term self-compassion caused a statistically significant increase in wellbeing (Zessin et al., 2015). They recommend more research take place to clarify possible mechanisms for these changes. One such mechanism may be the positive association between self-compassion and health promoting behaviours, such as healthy eating habits, sleep, exercise, and stress management (Dunne, Sheffield, & Chilcot, 2016; Sirois, Kitner, & Hirsch, 2015). However, Zessin and colleagues point out that their meta-analysis could not clarify the relationship between self-compassion and wellbeing in view of specific critical stressful life events, such as illness, bereavement or other losses (Zessin et al., 2015). Evidence from populations who suffer from chronic health conditions such as arthritis, suggest that self-compassionate people may use more adaptive approaches such as active coping, positive reframing and acceptance strategies for better outcomes, and fewer maladaptive approaches, compared with less self-compassionate individuals (Sirois et al., 2015). As such, individuals high in self-compassion may have a greater ability to accept and integrate negative experiences through reducing self-evaluative distress, and experience their setback as less threatening (Neff & Dahm, 2015), and may have increased coping through awareness, reflection and flexibility rather than persisting with ineffective or self-damaging approaches (Kato, 2012) Hence, there is an identified need for further investigation of the role of self-compassion, and how it may contribute to wellbeing for coping with serious life events, such as cancer.

2.1.5. Role and enhancement of self-compassion

There has been widespread investigation into the possible mechanism of being compassionate, and thus increasing potential for enhancement. A compassionate individual is able to direct compassion to the self and others. Self-compassion has been acknowledged as a characteristic that exists both as a trait and as a state. In their review MacBeth and Gumley (2012) discuss both of these aspects, arguing that compassion generally has been seen as a distinct affective state that arises from the witnessing of distress and which motivates a subsequent desire to provide help. They report that compassion is also thought to constitute an evolutionary advantageous trait that evolved as part of a caregiving response to vulnerable offspring. Furthermore, compassion has been seen as a desirable trait to assist in relations with non-kin (MacBeth & Gumley, 2012).

The trait and state aspects of self-compassion are relevant to translational and intervention programs. Research has confirmed that self-compassion is a relatively stable personality trait that can also be induced or fostered as a state (Sirois et al., 2015). As discussed earlier (Sections 2.1.1, 2.1.2, 2.1.3), Neff and Gilbert have both recognised that although self-compassion is a relatively stable trait, it can be induced as a state, and further enhanced through training. According to Neff, self-compassion is considered to be a second-order trait that arises from a combination of sub-traits, rather than a pre-existing trait (Neff, Kirkpatrick, & Rude, 2007). Neff has found that self-compassion can be manipulated through group format structured activities over an 8-week period, and has obtained evidence for retention of enhancement at one year follow up (Neff & Germer, 2013), with further investigations continuing through her Mindful Self-Compassion (MSC) training programme. Likewise, Gilbert has shown that self-compassion can be enhanced through training using his Compassion

Focussed Therapy (CFT) approach with clinical populations (Braehler, et al., 2013). As the research of self-compassion is still in its early stages, the understanding of state and trait measures, and how they may affect each other, is not yet clearly distinguished. Therefore it is of value to continue to investigations into both state and trait aspects of self-compassion to improve understanding of its role in psychological treatments.

Furthermore, there is ongoing investigation as to whether self-compassion exerts its influence as a mediator or moderator, and evidence has been found for both points of view. Mediation can be understood as a process that underlies an observed relationship between an independent and dependent variable by the inclusion of a third proposed variable known as a mediator or intermediary variable. A mediator can assist in explaining how or why a particular process occurs (Baron & Kenny, 1986). There is broad evidence that self-compassion mediates the relationship between attachment and mental health in general and oncology populations (Raque-Bogdan, Ericson, Jackson, Martin, & Bryan, 2011; Sherman & Arambic, 2016). A study of undergraduate students using a cross-sectional questionnaire demonstrated that self-compassion partially mediates the relationship between mindfulness and happiness (Hollis-Walker & Colosimo, 2011), with cultivation of a self-compassionate attitude possibly safeguarding against the pernicious effects of negative feelings. With regard to body image, self-compassion has been found to mediate the relationship between shame and drive for thinness in both clinical and general populations (Ferreira, Pinto-Gouveia, & Duarte, 2013), and to partially mediate the relationship between body dissatisfaction and depression (Wasylkiw, MacKinnon, & MacLellan, 2012). More recently, a study using 580 female undergraduate students has shown that self-compassion mediates the relationship between maladaptive perfectionism and body

image dissatisfaction (Barnett & Sharp, 2016), Furthermore, there is evidence that self-compassion could be an important regulator of emotion in the link between body image disturbance and subsequent psychological quality of life in general populations by acting as a mediator in this relationship (Duarte, Ferreira, Trindade, & Pinto-Gouveia, 2015). As such, self-compassion may be an important variable that intervenes, or is accessed, in particular situations in relation to psychological health and body image.

On the other hand, a moderator variable changes the strength of an effect, or relationship between two variables (Baron & Kenny, 1986). A moderator may increase, decrease or change the direction of an existing relationship. A study of 306 female undergraduate students indicated that self-compassion may act as a moderator in lessening the relationship between mental health risks and clinical symptomatology (Liss & Erchull, 2015). Leary and colleagues produced early evidence that self-compassion acts as a moderator of the relationships between distressing events and negative self-feelings (Leary et al., 2007). Self-compassion has been found to moderate the relationship between rumination and stress (Samaie & Farahani, 2011), and also to moderate the relationship between precursors of depression and the experience of depression (Wong & Mak, 2013). Findings have provided evidence that self-compassion is a moderator of the relationship between physical health and subjective well-being in the elderly (Allen, Goldwasser, & Leary, 2012). Self-compassion also has been shown to moderate the relationship between body mass index (BMI) and eating disorder pathology (Kelly, Vimalakanthan, & Miller, 2014), and to moderate the recollection of critical comments about eating from parental figures and the experience of body surveillance/body shame (Daye, Webb, & Jafari, 2014). Self-compassion has been found to moderate the inverse relationship between

body related threats (such as body comparison and appearance contingent self-worth) and body appreciation (Homan & Tylka, 2015). A study using 75 women diagnosed with breast cancer found a significant moderating effect of self-compassion on the body image – distress relationship in this population (Sherman, Woon, French, & Elder, 2016). As such, self-compassion appears to influence existing relationships between psychological health and body image. Given evidence from multiple contexts, it is possible that both a mediating and moderating relationship with self-compassion may be present in the area of body image disturbance and distress.

Since self-compassion may act in a number of ways, there are also various possible roles of self-compassion in therapeutic interventions. Albertson and colleagues have found use of self-compassion meditations improved a variety of measures of body image and distress in women with self-identified body image concerns, with effects maintained at three-month follow-up (Albertson, Neff, & Dill-Shackleford, 2014). Medium to large effect sizes were obtained in this study suggesting that self-compassion may have an important influence on aspects of body image distress, and the authors speculate that even brief exposure may be enough to impact psychological wellbeing (Albertson et al., 2014). The rehearsal, delivery and receipt of self-compassionate thoughts, feelings and behaviours has been shown to specifically reduce self-criticism with female undergraduate students (Falconer, et al., 2014). It has been suggested that when people feel under *threat* (from judgements of others or their own judgements) there can be an intense critical self-focus specifically on aversive consequences, thereby further increasing negative affect in the individual (Leary & Guadagno, 2011). In other words, one can be critical to oneself, focus on unwanted outcomes, then feel distressed, depressed and beaten down as a consequence, which Irons and colleagues see as a form of "internal self-harassment"

(Irons, Gilbert, Baldwin, Baccus, & Palmer, 2006). Conversely, when people feel *safe*, negative emotions typically abate, and individuals become less critically self-focussed while adopting a broader perspective, which can lead to greater positive emotions (Leary & Guadagno, 2011). It is entirely possible to act kindly to oneself even in the presence of unfavourable circumstances, failure or loss, and be less entangled in negative self-concepts (Marshall, et al., 2015). Self-compassion being associated with fewer avoidance strategies, would indicate a greater willingness to engage with uncomfortable thoughts and emotions, as well as enhancing the natural exposure process regarding stressful or difficult events (Thompson & Waltz, 2008). Engaging in a self-compassionate stance would be particularly advantageous during periods of great emotional turmoil when the prospect of overcoming absorption in self-criticism, intense feelings of shame, and negative self-evaluation is seemingly insurmountable (Daye, Webb, & Jafari, 2014). The management of negative emotions and not being overwhelmed by them, rather than an absence of distress, may be a key adaptive task in the process of adjustment to diagnosis and treatment of chronic illnesses such as cancer (Moss-Morris, 2013). In this way, enhancement of self-compassion can be seen as an effective way to address negative affect and facilitate broader adjustment.

Evidence suggests that self-compassion interventions are not particularly difficult to implement (Adams & Leary, 2007) and quickly show effectiveness (Albertson et al., 2014). Despite the group-based formats of many current self-compassion programs (e.g. CFT, MSC), enhancement interventions can produce results even when largely self-administered in the absence of a formal therapeutic relationship (Johnson, 2013; Liss & Erchull, 2015). At this point, self-compassion enhancement programs are in their infancy, and the longer term duration and stability

of self-compassion training is unknown. However, evidence suggests that manipulation and enhancement of self-compassion may be particularly relevant for women and this is discussed further in Section 2.1.7 (Self-compassion and women).

2.1.6. Safety of self-compassion

As with any new therapeutic approach, questions have been asked regarding the safety and possible adverse effects of self-compassion-based interventions, particularly if used without clinician supervision. Initial research has provided evidence that unsupervised self-compassion based enhancement interventions can be used without adverse effects (McEwan & Gilbert, 2016). This pilot study involved use of a non-clinical student population to engage alone in online self-compassion imagery exercises, over a two week period. Results were measured at the conclusion of the study and again at 6-month follow up, which found a significant improvement in self-compassion and self-reassurance, while also producing reductions in self-coldness, self-criticism, depression and anxiety. Out of 45 participants, only two reported negative experiences of sadness or pity in response to the self-compassion imagery intervention (McEwan & Gilbert, 2016). The authors suggest this issue could be ameliorated by clearer instructions, and point out that the vast majority of participants experienced improvement without adverse effects. Moreover, participants who might be considered most in need (i.e., higher self-critics) showed the largest improvement in scores of psychological distress. It was concluded that online unsupervised practice of self-compassion focussed interventions are understandable, safe and beneficial, and that future studies need to explore whether more at risk populations would also experience such results (McEwan & Gilbert, 2016).

2.1.7. Self-compassion and women

Research suggests that self-compassion interventions are likely to be particularly relevant and beneficial for women. Historically, females are generally more likely to report mood disorders and anxiety than males, with factors such as hormonal differences, gender-based coping styles, and social expectations regarding masculinity/femininity being considered possible influences (Casper, Belanoff, & Offer, 1996; Seeman, 1997). Meta-analysis indicates that women use more rumination and avoidance strategies regarding their personal health (Tamres, Janicki, & Helgeson, 2002) and score higher in neuroticism (Lynn & Martin, 1997) than men. Furthermore, epidemiological research has shown that eating disorders such as anorexia and bulimia are more common amongst women (Hoek, 2006; Striegel-Moore & Bulik, 2007). Body checking behaviours and engagement in body avoidance is also more likely to be found in female, rather than male binge eaters (Grilo & Masheb, 2005; Grilo, et al., 2005; Reas, Grilo, Masheb, & Wilson, 2005). Dissatisfaction with one's body image is often seen as a correlate of eating disorders, and has been viewed by some as a predominately "female disorder" (Furnham, Badmin, & Sneade, 2002).

Gender differences in psychological distress and body image have been also found in general populations, which has implications for self-compassion interventions. Individuals who are more invested in their physical appearance have been shown to experience more frequent and more intense body image distress, especially for women (Muth & Cash, 1997). Feelings of one's body being inferior, unattractive or defective, with a harsh perception of one's shortcomings, may be associated with critical and punitive responses towards the self (Duarte, Pinto-Gouveia, & Ferreira, 2014). Significant associations have been found between body

image difficulties, self-criticism and depressive symptomatology, with these processes potentially contributing to a self-perpetuating cycle for the woman (Duarte, et al., 2014; Kelly, Vimalakanthan, & Carter, 2014). Considering the prevalence of self-critical body image difficulties amongst women, it has been suggested that non-evaluative self-compassionate competencies may be particularly suited to address emotional distress and promote effective self-regulation as either a preventative or treatment strategy, (Duarte, et al., 2014; Kelly, Vimalakanthan, & Carter, 2014). Self-regulation refers to the processes by which an individual pays attention to their emotions, manages the intensity and the duration of emotional arousal, and transforms the meaning and nature of feeling states when faced with distressing situations (Thompson, 1994). Gender differences in self-regulation of negative affect have been found, and it is acknowledged that women are more likely to engage in self-focused rumination than men (Mor & Winquist, 2002; Nolen-Hoeksema & Corte, 2004). Self-compassion has been recognised to enhance personal self-regulation by decreasing interference from negative affective states (Terry & Leary, 2011), and therefore may be particularly suited to use by females.

Studies amongst student populations have found that females generally report lower levels of self-compassion than males (Neff, 2003b; Neff & McGeehee, 2010; Neff, Pisitsungkagam, & Hsieh, 2008), and the large majority of individuals who have participated in self-compassion training have been female (Neff & Germer, 2013). A recent meta-analysis found that nearly two-thirds of participants, in the 79 self-compassion studies reviewed, were female (Zessin et al., 2015). Such findings have led Neff and colleagues to speculate that the concept of self-compassion may be more appealing to females than males (Smeets et al., 2014), potentially by more specifically addressing their constellation of needs and concerns.

Given that breast cancer is a predominantly female disease, with an adverse impact upon the body, use of self-compassion may be particularly apt as an intervention suited to this population. Studies using other populations who have chronic illness such as arthritis, suggest that self-compassion may be especially beneficial for women who are facing health problems as it promotes the use of personal adaptive strategies while minimising the use of maladaptive approaches (Sirois et al., 2015). The role of self-compassion and its possible relationship to the body disturbance will be explored further in the sections below.

2.1.8. Self-compassion and its relationship to body image disturbance

Given the pervasiveness and difficulty in treating body image concerns amongst non-clinical populations (Pearson, Follette, & Hayes, 2012), further consideration should be given to self-compassion as a potential novel intervention (Goss & Allan, 2014). As discussed elsewhere (see 1.2.4), a variety of body image interventions exist, but these have shown mixed effectiveness, and those that have produced sustained improvements are often time, labour and resource intensive group programs (Lewis-Smith et al., 2015). Self-compassion based therapies for body image disturbance are in their infancy, however, there is some evidence supporting the effectiveness of relatively brief interventions with improvements in body appreciation, and reductions in contingent self-worth based on appearance (Albertson et al., 2014).

It has been proposed that self-compassion may interrupt the processes by which negative thoughts about the body lead to negative consequences (Liss & Erchull, 2015). Self-compassion may have a unique contribution in assisting individuals with self-observation. Body image interventions, such as mindfulness or exposure in CBT, typically require individuals to undertake various types of body

observation and associated experiences (sensations, thoughts, emotions), which may be done imaginally or in vivo (Cash, 1997; Cash & Grant, 1995; Delinsky & Wilson, 2006). For example, exposure to looking at one's body in a mirror as part of a desensitisation process to assist in body image has been used with eating disordered women (Key, et al., 2002), however, the authors also acknowledge that such an intervention can cause intolerable distress for some people, and must be used with caution. On a broader level, self-observation interventions with general populations may be a problematic approach for some individuals experiencing body image disturbance, as higher levels of observation have also been associated with less body acceptance and greater psychopathology (Prowse, Bore, & Dyer, 2013). More specifically, higher levels of observation may be detrimental if an individual is prone to inaccurate judgements or hypervigilance about their body or appearance (Prowse et al., 2013). Therefore, simply using existing interventions that further focus one's tendency towards observation of additional aversive body changes could increase psychological distress and lower body acceptance even further. Self-compassion may have a unique role in fostering a sense of care and tenderness towards the self while experiencing difficult thoughts and emotions about one's body (Albertson, et al., 2014). Thus the explicit use of self-warmth and kindness, which self-compassion emphasizes, may be of particular importance in relation to body image.

2.1.9. Self-compassion for body image changes in breast cancer survivors

Self-compassion may have an important role to play in relation to body image alteration in breast cancer survivors. Evidence already suggests that the general impact of self-compassion, when used for clinical psychological disorders, can be far reaching (Pauley & McPherson, 2010). Specifically, self-compassion has been associated with lower negative emotions in real, remembered or imagined situations,

together with cognitive styles that enhance an individual's ability to cope with negative events (Leary et al., 2007). These associations, together with less avoidance of traumatic stimuli (Thompson & Waltz, 2008), suggest that self-compassion may have a role in facilitating exposure to difficult or aversive situations, and in this way assists in improving an individual's adjustment. As such, a self-compassionate approach may help to counter the development of unhelpful affective, cognitive and behavioural patterns amongst breast cancer survivors. Self-compassion is positively associated with health promoting behaviours in general populations, suggesting that self-compassionate people are more likely to engage in helpful activities such as exercising, eating healthily, sleeping well, relaxing, and thus caring for their physical wellbeing (Dunne, Sheffield, & Chilcot, 2016). Furthermore, self-compassionate people are more likely to seek medical assistance sooner than people who are lower in self-compassion (Terry, Leary, Mehta, & Henderson, 2013). Specifically with oncology populations, self-compassion has been associated with less depression and stress, and increased quality of life (Pinto-Gouveia, Duarte, Matos, & Fraquas, 2014). As such, self-compassion is a potentially untapped resource that could be used to enhance a woman's efforts in coping with the side-effects of breast cancer treatment and adherence to medical advice or behaviour change strategies, and thus would be of value in meeting the needs of cancer survivors in promoting adaptation to these personal changes.

Individuals higher in self-compassion have been shown to be more accepting of their problems and better able to keep negative situations in perspective compared to individuals with less self-compassion, suggesting that self-compassion may act as a psychological resource to face life's challenges (Pauley & McPherson, 2010), and therefore promote emotional resilience. Conversely, those lower in self-compassion

are likely to experience greater difficulties in managing these same situations. It is possible that major difficult life events, such as a diagnosis of breast cancer, would further draw on a person's self-compassion resources. Evidence suggests that those who are in poorer physical health, or have greater challenges to their wellbeing, may require higher levels of self-compassion to cope with these situations (Raque-Bogdan, Ericson, Jackson, Martin, & Bryan, 2011). Indeed, physical ill health may trigger a decrease in self-compassion (Dunne, Sheffield, & Chilcot, 2016), possibly through additional demands on this resource, as an individual deals with sudden losses (Fobair & Spiegel, 2009; Rosenberg, et al., 2013) and feelings of isolation (Casati, Toner, De Rooy, Drossman, & Maunder, 2000) due to their condition. Since female breast cancer survivors experience unique difficulties in affective (e.g., feeling feminine and attractive), behavioural (e.g., avoidance of others because of appearance), and cognitive aspects (e.g., satisfaction with appearance post-treatment) (Hopwood et al., 2001), these women are faced with a new set of multiple body-based challenges. Given that women generally experience more self-evaluation and greater social pressure regarding their appearance (Fitzsimmons-Craft, et al., 2012; Franzoi, et al., 2012), combined with additional demands of breast cancer treatment upon her body, potentially a great need for self-compassion arises at this point. At the same time a woman's personal resources, including self-compassion, may be in a depleted state (Kaplan & Berman, 2010). This could be particularly problematic for those who may have had few previous encounters with warmth and support, and as such become much more prone toward self-criticism at times of distress, rather than self-compassion (Kelly, Carter, & Borairi, 2014). In other words, one could argue that life circumstances (i.e., breast cancer and its side-effects) have placed a uniquely high demand on the woman for self-compassion, but she may not have the internal resources to meet this. This could be partly because her threat systems are overactive

while her soothing systems are underactive; so by not being able to employ a self-compassionate perspective the women may instead try to regulate her feelings of distress and inadequacy by maladaptive strategies (Kelly, Carter, & Borairi, 2014). Common problematic coping strategies found amongst breast cancer patients include avoidance, disengagement and self-blame (Malik & Kiran, 2013), which ultimately provide limited or no long term relief for the woman.

A breast cancer survivor who has experienced adverse bodily impacts, but who is also low in self-compassion, could struggle with many existing body image interventions such as physical exercise interventions, cosmetic interventions, CBT, unstructured expressive writing, or mindfulness-based approaches as the development of a compassionate relationship with one's body may not be explicitly taught. Interventions whose sole focus is exercise or cosmetic improvement which have been previously described in the literature (Kendrick, 2008; Pitts, 2004; Turner, Hayes, & Reul-Hirche, 2004), although offering much needed information and practical help, may not address a woman's established maladaptive coping strategies or ability to self-soothe. CBT approaches, although widely acknowledged as an effective treatment for many psychological issues including body image alteration (Fingeret, Teo, & Epner, 2014; Lewis-Smith, et al., 2015; Rumsey & Harcourt, 2004), may be problematic for women who are low in self-compassion. Such individuals are likely to have difficulty with traditional cognitive challenging in coming up with believable alternative helpful thoughts, and may be shamed in seeing themselves and their thoughts as fundamentally flawed (Gilbert & Procter, 2006; Van Vliet & Kalnins, 2011). Breast cancer survivors with low levels of self-compassion may also experience difficulty in engaging with expressive writing to address their body image difficulties. Thus far, research has not been conducted to specifically assess the

effects of unstructured writing to address cancer-related body image disturbances. The lack of research may reflect evidence that unstructured expressive writing appears to have mixed effectiveness in addressing body image problems in a variety of other non-oncology contexts (Truxillo, 2001; Earnhardt, Martz, & Ballard, 2002; Stice, Shaw, Burton, & Wade, 2006; Johnston, Startup, Lavender, Godfrey, & Schmidt, 2010; Lafont & Oberle, 2014). As such, an unstructured expressive writing approach is uncertain to prove effective for women struggling with body image disturbance related to breast cancer treatment. Furthermore, although mindfulness-based approaches have been acknowledged as effective with cancer survivors (e.g. Lengacher, et al., 2009), certain aspects of mindfulness appear to have a more complicated relationship with body image, particularly the skill of observation. In non-cancer populations, higher levels of observation have been associated with less body acceptance and greater psychopathology, and increased observation may be particularly detrimental if an individual is prone to habitual misjudgement or hypervigilance (Prowse, Bore, & Dyer, 2013). One may speculate that this effect could be magnified in breast cancer survivors who have acquired actual adverse changes to their body and have moved even further away from their ideal body. If a standard body image intervention requires a survivor to increase her self-observation after cancer treatment, as in typical mindfulness activities or CBT based desensitization/exposure (Aguirre-Camacho, et al., 2016; Fingeret, Teo, & Epner, 2014; Stewart, 2004), the woman is likely to be faced with new negative changes to observe. If she has had pre-existing difficulties with misjudgement or hypervigilance, increased observation of her own additional negative bodily changes may potentially lead to even greater increases in psychological distress and decreases in bodily acceptance. As such, the demand on a woman's self-compassion may be greater than ever before. The explicit use of self-warmth and kindness towards the self, which self-

compassion emphasizes, may be of particular importance in relation to the intensely personal experience of body image change after breast cancer treatment.

3. Chapter Three: Therapeutic writing and research development

This chapter explores the history of unstructured expressive writing as developed by Pennebaker in the mid-1980s. The benefits and limitations of expressive writing in general populations and cancer survivors are discussed. The concept of self-compassion based writing is introduced as a novel approach to therapeutic writing, and existing forms of self-compassion based writing are evaluated.

The concept of a writing-based self-compassion research project is introduced, with associated aims and graphical representation, and is operationalised by use empirical measurement instruments.

3.1. Therapeutic Expressive writing

3.1.1 History of expressive writing as developed by Pennebaker

Unstructured expressive writing has been used since the 1980s in the general population to assist in coping with difficult events (Baike & Wilhelm, 2005; Smyth, 1998). This approach asks individuals to choose a traumatic or upsetting experience and to write freely about their deepest thoughts and feelings (Pennebaker & Beall, 1986). The original Pennebaker intervention involved four occasions of writing over four consecutive days, with sessions of approximately 20 minutes each (Pennebaker & Beall, 1986). However, the rationale of this format appears to be entirely arbitrary and was largely based upon initial availability of laboratory room bookings for the researchers (Chung & Pennebaker, 2008). Writing instructions have historically been quite general, whereby the participant can select the traumatic situation on which to focus, a typical example of a Pennebaker prompt is shown below:

> *"...I would like you to write your very deepest thoughts and feelings about the most traumatic experience of your entire life or an extremely important emotional issue that has affected you and your life. In your writing, I'd like you to really let go and explore your deepest emotions and thoughts. You might tie your topic to your relationships with others, including parents, lovers, friends or relatives; to your past, your present or your future; or to who you have been, who you would like to be or who you are now. You may write about the same general issues or experiences on all days of writing or about different topics each day. All of your writing will be completely confidential. Don't worry about spelling, grammar or sentence structure. The only rule is that once you begin writing, you continue until the time is up." (Baike & Wilhelm, 2005, p. 338)*

Such writing is unstructured and self-directed, with no further prompting provided. Pennebaker typically used a factual (i.e., non-emotive) writing condition as a contrasting control group to his expressive writing participants, and found evidence of

physical and psychological health benefits over time for writing intervention participants (Pennebaker, 1993). However, there is no consensus amongst researchers and clinicians on the therapeutic mechanisms involved or optimal "dose" of writing, and wide variations in methodology exist (Smyth, 1998). Instructions for expressive writing typically ask participants to write for one to five consecutive days, for 15 to 30 minutes on each occasion, with no feedback given (Pennebaker & Chung, 2011). However, questions have been raised whether repeated or lengthy writing sessions are necessary (Smyth & Pennebaker, 2008), with evidence of positive effects occurring in single session writing (Greenberg, Stone, & Wortman, 1996; Fernandez & Paez, 2008; Henry, Schlegel, Talley, Molix, & Bettencourt, 2010).

3.1.2 Benefits of expressive writing

Benefits of unstructured expressive writing have been broad and impressive, encompassing many physical, social and psychological areas of wellbeing (Baike & Wilhelm, 2005). In Pennebaker's early studies with college students, he found evidence of improved grades, better health, and greater adjustment to college (Pennebaker, 1993); with benefits being maintained at the 4-month follow-up point (Pennebaker & Beall, 1986). Health-related benefits in a variety of contexts have been demonstrated, including objective measures such as improvement in blood pressure (Davidson, et al., 2002), liver function (Francis & Pennebaker, 1992), lung function (Smyth, 1998), and immune system functioning (Booth, Petrie, & Pennebaker, 1997; Pennebaker, Kiecolt-Glaser, & Glaser, 1988; Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004). Fewer days of hospitalisation have also been associated with expressive writing in female chronic pain populations, (Norman, Lumley, Dooley, & Diamond, 2004), as well as benefits in self-reported health outcomes, such as fewer visits to the doctor and physical symptoms (Cameron & Nicholls, 1998; Park &

Blumberg, 2002). Effects of unstructured expressive writing upon physical symptoms and behavioural outcomes have been favourable, and understandably have been of interest for adoption by various settings as a patient intervention (Baike & Wilhelm, 2005).

However, the effectiveness of unstructured expressive writing upon psychological outcomes has been less clear. Expressive writing has been associated with lower levels of emotional distress, including improved mood (Paez, Veasco, & Gonzalez, 1999; Pennebaker, Kiecolt-Glaser, & Glaser, 1988), depressive symptoms (Lepore, 1997), and post traumatic intrusion (Klein & Boals, 2001). Even so, it has been noted that the effect of unstructured expressive writing for psychological outcomes has not been as robust or as consistent as those found for physical health outcomes (Baike & Wilhelm, 2005). This was clearly illustrated with a meta-analysis that found significant effects for the benefits of expressive writing for physical health outcomes in medically-ill populations (d =0.21, p = 0.01), but no significant psychological health outcomes in psychiatric populations (d = 0.07, p = 0.17) (Frisina, Borod, & Lepore, 2004). Various contributing factors and inconsistencies have been suggested to account for these different impacts of expressive writing, including use of different populations who have diversified concerns, different methodologies, and different approaches to measurement of results (Zhou, Wu, An, & Li, 2015), so it may be more helpful to look at the effects of unstructured expressive writing upon the needs of physically unwell populations who are likely to be a more unified group due to demonstrated common health concerns.

Early reviews of unstructured expressive writing found greater benefit in medically well populations (Smyth, 1998), often using students; however, later investigation of various specific clinical populations have also demonstrated positive

effects (Smyth, 1998). Expressive writing has been explored for various medical conditions such as asthma (Harris, Thoresen, Humphreys, & Faul, 2005), heart disease (Manzoni, Castelnuovo, & Molinari, 2011), rheumatoid arthritis (Broderick, Smyth, & Kaell, 2004), HIV (Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004), cystic fibrosis (Taylor, Wallander, Anderson, Beasley, & Brown, 2003), irritable bowel syndrome (Halpert, Rybin, & Doros, 2010), poor sleep (Harvey & Farnell, 2003), geriatric populations (Klapow, et al., 2001) and associated care givers (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2007). Given that expressive writing techniques have shown promise in a number of physical health conditions, further investigation of expressive writing methods is justified in the field of oncology.

3.1.3 Expressive writing in cancer populations

Expressive writing also been adapted for certain populations by the use of tailored writing prompts, including for oncology populations where the prompt has been cancer-related. Such studies usually require the participant to write about their *illness experience* and to describe their associated deepest thoughts and emotions (Bruera, Wiley, Cohen, & Palmer, 2008; Cepeda, et al., 2008; Corter & Petrie, 2011; Craft, Davis, & Paulson, 2012; Henry, Schlegel, Talley, Molix, & Bettencourt, 2010; Laccetti, 2007; Low, Stanton, & Danoff-Burg, 2006; Stanton, et al., 2000; Stanton, et al., 2002). A typical modified expressive writing prompt for a cancer participant is presented below:

> *"... You have been asked to write about your deepest thoughts and feelings regarding breast cancer for 20 minutes on four consecutive days. Thoughts include when something happened, what is going on as far as treatment etc. Feelings are how you feel about these events i.e. sadness, anger, fear etc. Please try to incorporate both of these in your writing. There is no structure to how you write or what time of day... (Craft, Davis, & Paulson, 2012, p. 309)*

Different control conditions have been used by various researchers in unstructured expressive writing for people diagnosed with cancer. Comparison groups to expressive writing conditions have included any combination of: no writing or wait list, neutral/factual writing, or a self-selected traumatic event which may not be related to the cancer diagnosis (Craft, Davis, & Paulson, 2012). These comparison conditions have themselves been associated with inconsistent results. For example, some "factual" writing conditions about breast cancer, have shown benefits similar to that of expressive writing (Craft et al., 2012), whereas in other studies mixed effects have been observed, such as benefits for only subsets of participants (Low, Stanton, Bower, & Gyllenhammer, 2010), and in others, expressive writing has been clearly superior when compared to factual writing about breast cancer (Stanton, et al., 2002).

Increasingly the use of expressive writing is being evaluated in the field of psycho-oncology. A review (Merz, Fox, & Malcarne, 2014) found 13 oncology expressive writing studies, nine being breast cancer specific, indicating interest in this approach for breast cancer survivors. As in other areas of unstructured expressive writing, a variety of "dose" structures have been used with breast cancer survivors. Most of these follow the traditional four occasions of writing, but one and three occasions of writing have also been used with this population (Merz, et al., 2014).

The original Pennebaker format using four consecutive days of writing (Pennebaker & Beall, 1986) has demonstrated a variety of benefits on quality of life measures (physical, social, emotional and functional wellbeing), with participants who were *specifically* directed to write about their breast cancer either factually or expressively (Craft, et al., 2012). The control (no writing) and self-selected trauma writing groups did not confer the same benefits, therefore, highlighting that specificity of the writing prompts may be an important factor in effectiveness. The Craft study

used two time points measuring effectiveness at 1- and 6-months, and showed retention of benefits during this period (Craft, et al., 2012). However, this format demonstrated a relatively low overall retention rate of 58% of participants, which may be problematic for an intervention which is intended for initial broad use amongst the population. Therefore, an intervention approach that is acceptable for a greater percentage of the breast cancer survivor population as an initial supportive intervention was sought for this thesis.

The effectiveness of single session home-based writing format has been studied with breast cancer survivors (Henry, Schlegel, Talley, Molix, & Bettencourt, 2010). A home based writing intervention has two advantages: first, to eliminate the need to travel for an intervention; and second, to provide a greater opportunity for comfort by writing in the privacy of one's home. In the Henry study, participants were instructed to write in a single session without interruption for 20-30 minutes in a private place, using a modified Pennebaker prompt that focussed on *positive* outcomes of the participants' cancer experience as below:

> *"What we would like you to do is write about any positive thoughts and feelings about your experience with breast cancer. We realise that women with breast cancer experience a full range of emotions, but we would like you to focus on some positive emotions, thoughts, and life changes that have come out of your experiences. For example, some women feel that they have gained important lessons out of their experience with cancer. In this writing exercise, we want you to try and write about any positive thoughts, experiences, and feelings that you have encountered over the course of your cancer, from the time you were diagnosed until now. You might also tie your positive thoughts and feelings about your experiences to other parts of your life – your childhood, people you love, who you are, or who you want to be. Ideally, we would like you to write without stopping for 20 minutes. If you run out of things to say, just repeat what you have already written until the 20 minutes are up. Don't worry about grammar, spelling, or sentence structure. Don't worry about erasing things or crossing things out, just write*

> *freely." (Henry, Schlegel, Talley, Molix, & Bettencourt, 2010, p. 751)*

Participants were monitored for improvements in physical health, depressive symptomatology and affect, at two time points (three and nine months), after completion of the writing activity. Henry and colleagues found that physical symptoms, depressive symptoms and overall mood were significantly improved in the experimental group at the 3-month point, compared to a control group who did not engage in a writing exercise. However, at the 9-month point both groups were the same, suggesting that benefits of the *positively focussed* single expressive writing session weakened somewhere between the 3-9 months post-writing. The reason for this drop-off in effect may be related to the need for more writing sessions to sustain benefits over time, or that the chronic nature of trauma in oncology (e.g. ongoing fears of reoccurrence), is different from a one-off traumatic or difficult event (such as having an accident). Henry and colleagues concluded that expressive writing at various time points during the cancer experience may be helpful to cope with the chronicity of the problems faced by breast cancer survivors. It is noteworthy that this study with one session of writing had a 70% retention rate and positive post-intervention feedback from the majority of participants, thus displaying a high level of consumer acceptability. The researchers concluded that their results indicated that the intervention was a practical and rewarding intervention for this population (Henry, et al., 2010).

3.1.4 Limitations of expressive writing

Despite widespread use and popularity of unstructured expressive writing, a variety of limitations have been observed over time. Some of these have been within the structure of expressive writing itself, whereas other problems have been related to its use in specific areas.

In general, large inconsistencies in outcomes have been found with studies of unstructured expressive writing. Meta-analyses have supported findings that expressive writing is generally associated with benefits to physical and psychological health (Frisina, Borod, & Lepore, 2004; Frattaroli, 2006; Harris, 2006; Mogk, Otte, Reinhold-Hurley, & Kroner-Herwig, 2006). However, widely differing levels of significance have been observed, with effect sizes ranging between 0.07-0.21, which are lower than the 0.47 observed in earlier reviews (Smyth, 1998). Inconsistencies and variations in results obtained have indicated that closer scrutiny needs to be given to potential influencing factors such as use of prompts, mechanisms of action, characteristics of the population being studied, and generalizability of results outside experimental environments. It is essential to understand the factors that may contribute to the effectiveness of expressive writing, and how to maximise the benefits of this approach, (Lu & Stanton, 2010). Apart from issues of methodology and participant characteristics, it has been suggested that potentially "inborn limitations" of unstructured expressive writing itself may have a part to play (Zhou, Wu, An, & Li, 2015). Historically, the traditional Pennebaker activity asks participants to write "randomly" according to the initial prompt, and its potentially variable effects suggest this to be a function of experimental parameters and the specificity of psychological processes actually targeted by the activity (Lu & Stanton, 2010). Although the prompt encourages emotional expression, it can be argued that the writer is left with little guidance in how to approach their writing topic, manage associated emotions, or process their distressing events in a therapeutic way. As such, the writing activity itself may benefit from refinement and improvement in structure to provide greater support for the writer. Pennebaker and Smyth themselves admit there was no serious inspection of the assumptions on which unstructured expressive

writing was based, and there are a number of valid questions about the original procedures (Smyth & Pennebaker, 2008).

In addition, unstructured expressive writing has shown to have limited effectiveness in specific areas. Although beneficial effects upon physical health indicators were evident even early in the use of the technique, Pennebaker found that the same effect was not found upon all experimental outcomes, notably health-related behaviours such as diet, sleeping pill use, exercise, caffeine intake or alcohol consumption (Pennebaker, Kiecolt-Glaser, & Glaser, 1988). There was little examination or speculation by Pennebaker and colleagues as to why this might be the case. In terms of chronic illness and cancer survivorship, health related behaviours are of critical importance in terms of wellbeing and risk reduction (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Denmark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000), and thus this limitation may be a major setback of standard unstructured expressive writing as a potential intervention for breast cancer survivors where issues related to weight reduction, exercise or dietary choices impacting on body image may be involved.

Furthermore, the evidence with regard to writing for body image, eating disorders and associated difficulties appears less straightforward, with unstructured expressive writing studies mostly reporting similar results to that of control conditions (Earnhardt, Martz, Ballard, & Curtin, 2002; Johnston, Startup, Lavender, Godfrey, & Schmidt, 2010; Lafont & Oberle, 2014; Stice, Shaw, Burton, & Wade, 2006; Truxillo, 2001). In general, it has been acknowledged that body image disturbance may be particularly difficult to treat given the broader ongoing social pressures on women regarding their appearance (Pearson, Follette, & Hayes, 2012). Suggestions as to why body image disturbance may respond differently to unstructured expressive writing

include that body image disturbance is more diffuse than an incidence of trauma (Earnhardt, Martz, Ballard, & Curtin, 2002), and that body image narrative may already be under the strong influence of the media (Lafont & Oberle, 2014). This limitation of traditional unstructured expressive writing presents particular challenges for applications with breast cancer survivors who experience adverse bodily alteration as a result of their treatment (Fingeret, Teo, & Epner, 2014).

3.1.5 Limitations of expressive writing in breast cancer

Despite promising results from individual studies, traditional expressive writing may have limited usefulness amongst breast cancer survivors as a whole. A meta-analysis undertaken by Zhou and colleagues, on the effectiveness of expressive writing specifically with this population, found results that were largely disappointing (Zhou, Wu, An, & Li, 2015). No significant effects of writing (using either an expressive or benefit finding prompt) were found on psychological health with breast cancer participants at any time point. A significant effect was found for reducing negative somatic symptoms at the 3-month point, but not afterwards, indicating that any benefits upon physical health may be short lasting. It was concluded that the "non-lasting momentum" of standard expressive writing interventions needs to be explored, and the authors caution the widespread use of this method in the clinical setting (Zhou, et al, 2015). This demonstrated limited effectiveness of expressive writing on psychological distress is particularly important, and may be a hindrance to using this method to assist breast cancer survivors in managing treatment-related psychological distress.

3.1.6 Limitations of expressive writing as a standalone intervention

There has been increased acknowledgement of the limitations of standalone unstructured expressive writing, leading to investigation of combined approaches,

with positive reappraisal recognised as also providing some benefit in writing activities (Stanton, et al., 2002). However, in writing about positive aspects of difficult situations, benefit-finding or positive reappraisal has been less thoroughly studied and more poorly understood than expressive writing (Low, Stanton, & Danoff-Burg, 2006). A combined approach using expressive writing and reappraisal may appear confused, and be contradictory regarding methods and outcomes; that is, expressive writing encourages people to openly express all their felt emotions, whereas positive reappraisal asks people to focus specifically on reinterpreting potentially negative situations in more positive ways (North, Meyerson, Brown, & Holahan, 2012). Such an approach could potentially be confusing to implement clearly with clients, and pose difficulties in disentangling results from a research point of view, so alternative methods of combination approaches need to be explored further.

There is evidence that approaches which combine emotional acceptance with derivation of new meaning may be particularly effective (North, Meyerson, Brown, & Holahan, 2012). Individuals are encouraged to have a willingness to experience all emotions without trying to change, avoid or control them (Hayes, 1994), while also deriving a new meaning, perspective or outlook from their negative experiences (Folkman, 2008). It could be argued self-compassionate writing may be an approach which effectively addresses the potential limitations of unstructured expressive writing, as it encourages expression, awareness, investigation, and acceptance of all emotions in a context of kindness. In addition, self-compassion also considers the wider influences upon the negative experience, and the commonality of difficult experiences with others, thus adopting a broader perspective rather than a purely self-focussed one, and therefore gently encourages reappraisal of the individual's difficult

event. Again, this is done in an atmosphere of warmth and sensitivity. As such, self-compassion is not simply emotional expression, and not just positive re-evaluation, and is more than the sum of its parts as these actions are conducted in a larger context of kindness. A valid criticism of typical writing interventions, whether they employ expression of negative experiences or positive evaluations, is that there is no broader consideration of the tone or larger context of the writing (Low, Stanton, & Danoff-Burg, 2006). This may be particularly true of populations such as breast cancer survivors where the adverse event (cancer) can be considered a life threatening condition, and which is likely to be still influencing women's health, relationships and thoughts about the self and the future, although their active treatment may be finished (Low, Stanton, & Danoff-Burg, 2006). Given that such health events may be less clear cut, and are less likely to have a final and complete resolution, adopting kindness as the longer term tone during ongoing uncertainty and adaptation may be particularly influential for breast cancer survivors.

Combined approaches, using more than a single standalone technique, have already been adopted elsewhere in psychology. For example, Acceptance and Commitment Therapy (ACT) interventions encourage an individual to be open to and accept the reality of their situation, while at the same time also reappraising and initiating changes to improve their lives, with the help of a supportive therapist (Hayes, Strosahl, & Wilson, 1999). There is evidence that writing interventions which integrate acceptance and provide explicit permission to express difficult emotions, while also encouraging individuals to review their negative experiences may be more effective than either strategy alone, and that both of these aspects may be essential to decrease distress and facilitate a change in thinking (North, Meyerson, Brown, & Holahan, 2012). As such, conducting writing in the context of warmth, kindness and

compassion, may further facilitate this process, and will be explored in Section 3.2.1: Expressive and self-compassion focussed writing, below.

3.2. Use of self-compassion in therapeutic writing

3.2.1 Expressive writing and self-compassion focussed writing

Self-compassion may address the limitations of expressive writing through its specific actions. Given the incidence of unclear outcomes of expressive writing with body image, it has been suggested that self-compassion may be uniquely placed to therapeutically assist in this area (Goss & Allan, 2014), due to its benefits in assisting with body shame, self-criticism, and affect regulation in studies with eating disorders. There is a need to directly compare unstructured and compassion-based writing for body image alteration after breast cancer. The question of whether differences exist between standard (unstructured) expressive writing and modified writing formats have already been asked in other fields (Boals, Murrell, Berntsen, & Southard-Dobbs, 2015). Examples of self-compassion based writing do exist, but no application of this approach has been located that specifically addresses body image. (Existing self-compassionate writing is discussed in more detail in section 3.2.3)

3.2.2 Structuring of self-compassion based writing

Investigation as to whether self-compassionate structuring can improve the effectiveness of current written format interventions with regard to body image difficulties is needed. Self-compassionate writing specifically encourages an individual to adopt a compassionate perspective towards themselves as they write about events (Gilbert & Irons, 2005). Although expressive unstructured and self-compassion based writing appear similar, they may work differently. There is no consensus on how unstructured expressive writing "works" (e.g., Baike & Wilhelm,

2005), but evidence suggests that self-expression, cognitive processing, and construction of a cohesive narrative regarding difficult events, may all play a part. It is likely that self-compassionate writing would contain these same elements, but in addition, the adoption of a self-compassionate focus makes the "tone" or "warmth" of one's writing an influential factor. The experience of personal "warmth" in turn can assist the individual to self-soothe while undertaking challenging activities (Gilbert & Irons, 2005; Gilbert & Proctor, 2006), such as writing about difficult events (Imrie & Troop, 2012). Self-compassionate writing is a method by which we can help train the person to process their experiences differently, in a caring and supportive way (Gilbert & Irons, 2005), which goes beyond emotional expression. However, some individuals report difficulties in generating self-compassionate statements spontaneously (Gilbert & Proctor, 2006; Pauley & McPherson, 2010), and therefore, may need some guidance for achieving this type of writing. Furthermore, individuals high in self-criticism can find it particularly difficult to access a self-supportive narrative or create affiliate feelings towards themselves, thus being more likely to respond with cognitive biases and distortions (Leaviss & Uttley, 2015). To prevent ongoing unhelpful narratives, self-criticism or cognitive distortions, such individuals would be likely to benefit from appropriate, specific prompting to enhance their self-compassion during writing.

3.2.3. Existing self-compassion based writing activities

Existing forms of self-compassionate writing activities and examples used by Gilbert, Neff, and others will be examined below. The overall goal is to assist the individual to generate, experience, and apply a compassionate perspective to their own situation, with each approach having their individual strengths and weakness. However, none of these self-compassion based writing activities have thus far

specifically focused on body image difficulties experienced by breast cancer survivors.

Gilbert and colleagues have been including compassionate letter writing as part of their compassion training programs, usually held in groups or as part of a treatment with a therapist. Gilbert emphasises that letter writing must not be detached, cold or dismissive, and the therapist is expected to assist the client in reviewing their letter writing and guiding them to adopt a more compassionate style (Gilbert & Procter, 2006). In this approach the individual spends some time practicing a soothing breathing rhythm or compassionate imagery, to orientate themselves to a compassionate focus before commencing the writing (Gilbert, 2009b). Expressive writing as developed by Pennebaker is acknowledged to be beneficial for some people, and such an intervention from a compassionate point of view, can be useful in shifting a person's perspective as they generate the courage to engage with something that is difficult (Gilbert, 2009b). A variety of different methods to undertake compassionate writing exist, including writing from the "compassionate part of self", writing compassionately to someone else who they imagine is going through the same difficulties, or writing a dialogue that they might imagine coming from their ideal compassionate image (Gilbert, 2009b; Gilbert & Procter, 2006). As such, there are a variety of explanations, directions and prompts available for participants who undertake compassion focused writing in this manner, and an example of a prompt is given below:

> *Getting Started*
>
> *There is nothing rushed in letter writing – just take your time. We find that sometimes people sit staring at a blank page not sure what to write because they are "over thinking" in their heads of "what to write"; how to write or worried about spelling – or telling themselves they can't write. This is the evaluative mind trying to*

> *work it all out in advance. There is no right or wrong here and you might have a number of starts before you get into flow. So it is useful to start with: "Dear (your name), I know you have been feeling..." and then almost let the pen right (sic) itself. Just write what you would really like somebody who's really kind and understanding to say to you.*
>
> *If you're struggling with flow just write whatever comes into your mind. The key here will be to try to work around a tendency to self monitor and judge if you're doing it right or not – that judging can make it more difficult for you. Just write – you can always throw it away if you don't like it and you can have as many attempts as you want. It's useful to just start writing regardless of whether or not you know what you're going to write – in fact, in many ways, it's a good idea not to work it out in advance...*
>
> *"Training Our Minds in, with and for Compassion: An introduction to concepts and compassion-focused exercises" by Paul Gilbert. Online resource (http://www.compassionatemind.co.uk/downloads/training_materials/3.%20Clinical_patient_handout.pdf)*
>
> *Accessed 10th December 2015*

Others have adapted Gilbert's approach as a short self-compassion induction for experimental intervention. Rowe and colleagues have simplified the self-compassionate prompt instructing undergraduate students and community samples to "visualise and write about being completely compassionate and warm towards yourself". Participants were told to write about the prime theme on paper on one occasion, for 10 minutes, and then to take the paper with them when finished, to maximise chances that participants would be uninhibited in what they wrote (Rowe, Shepstone, Carnelley, Cavanagh, & Millings, 2016). It was found that even such a brief exposure resulted in higher willingness to engage in a challenging activity (mindfulness training), compared to a control condition (writing about a shopping trip). Although self-compassionate priming and prompting are relatively novel

procedures, they could have important implications in rendering challenging activities more accessible (Rowe, et al., 2016).

Neff has incorporated self-compassionate writing as part of her Mindful Self-Compassion (MSC) group intervention and other trainings. A suggested three part format for self-compassionate writing is given on Neff's website, and appears below:

> *Part One: Which imperfections make you feel inadequate?*
>
> *Everybody has something about themselves that they don't like; something that causes them to feel shame, to feel insecure, or not "good enough." It is the human condition to be imperfect, and feelings of failure and inadequacy are part of the experience of living a human life. Try writing about an issue you have that tends to make you feel inadequate or bad about yourself (physical appearance, work or relationship issues…) What emotions come up for you when you think about this aspect of yourself? Try to just feel your emotions exactly as they are – no more, no less – and then write about them.*
>
> *Part Two: Write a letter to yourself from the perspective of an unconditionally loving imaginary friend*
>
> *Now think about an imaginary friend who is unconditionally loving, accepting, kind and compassionate. Imagine that this friend can see all your strengths and all your weaknesses, including the aspect of yourself you have just been writing about. Reflect upon what this friend feels towards you, and how you are loved and accepted exactly as you are, with all your very human imperfections. This friend recognizes the limits of human nature, and is kind and forgiving towards you. In his/her great wisdom this friend understands your life history and the millions of things that have happened in your life to create you as you are in this moment. Your particular inadequacy is connected to so many things you didn't necessarily choose: your genes, your family history, life circumstances – things that were outside of your control.*
>
> *Write a letter to yourself from the perspective of this imaginary friend – focusing on the perceived inadequacy you tend to judge yourself for. What would this friend say to you about your "flaw" from the perspective of unlimited compassion? How would this friend convey the deep compassion he/she feels for you, especially for the pain you feel when you judge yourself so harshly? What*

would this friend write in order to remind you that you are only human, that all people have both strengths and weaknesses? And if you think this friend would suggest possible changes you should make, how would these suggestions embody feelings of unconditional understanding and compassion? As you write to yourself from the perspective of this imaginary friend, try to infuse your letter with a strong sense of his/her acceptance, kindness, caring, and desire for your health and happiness.

Part Three: Feel the compassion as it soothes and comforts you

After writing the letter, put it down for a little while. Then come back and read it again, really letting the words sink in. Feel the compassion as it pours into you, soothing and comforting you like a cool breeze on a hot day. Love, connection and acceptance are your birthright. To claim them you need only look within yourself.

(http://self-compassion.org/exercise-3-exploring-self-compassion-writing/) Accessed 7th December 2015

Closer examination of Neff's approach is warranted, as well as comparison with Gilbert's writing method. The first part of the Neff intervention involves writing about one's imperfections and feeling the associated emotions. Some parallels may be seen with this part and Pennebaker's expressive writing method regarding self-disclosure (Pennebaker, 1997). However, Pennebaker's approach emphasises "letting go" and little self-censorship, and expresses no concern about the appearance or grammatical quality of the writing (e.g., spelling, sentence structure or other mistakes), instead strongly encouraging continued writing for a specified period of time. Neff's instructions above also emphasise exploration of difficult issues, however, with initial careful consideration of one's emotions first before commencing writing. Hence, Neff's approach focuses on careful reflection on one's experiences first, and differs from expressive writing which emphasises continued writing for a set period of time (Pennebaker, 1997). Although similar in some ways, the two approaches differ in the amount of personal reflection expected prior to writing and

the actual writing process itself (i.e., specified period of time, care in how the writing is constructed), and this may affect what is expressed by the participant.

Neff's second part encourages the individual to write a letter to the self from the perspective of an unconditionally caring imaginary friend. Such an approach is likely to foster the generation of a personalised, warm message of care, concern and encouragement to the individual, and furthermore promote the experience of receiving compassion. This section has similarities with the self-compassionate visual imagery and writing style used by Gilbert and colleagues, and as such may encounter similar limitations. Some individuals could struggle to take the perspective of an unconditionally kind friend, if they have no prior experience of such an encounter, and thereby potentially triggering additional sadness and grief (Gilbert, 2010; Gilbert & Irons, 2004; Gilbert & Procter, 2006). Furthermore, the instructions in this section are relatively lengthy, and may be challenging for some individuals to comprehend and implement, possibly leading to misunderstanding and further difficulties. This aspect may be problematic if the activity is being undertaken alone, rather than in a group or as part of a therapy program.

The third and final section of Neff's writing activity encourages the individual to connect with the experience of compassion that has been generated through the earlier sections. As such, this section allows the individual to reflect upon, and also derive comfort from, the end result of their letter writing. However, there is a possibility that some people may not have had an experience of compassion generated by the writing activity, or they may have experienced sadness or grief instead. Such individuals may reach a conclusion that they are deficient, defective or a failure in some way as a consequence. Therefore, there is a potential for the Neff style of self-compassionate writing activity to be distress-producing for a subset of individuals.

Furthermore, the activity does not include suggestions as to length or duration of self-compassionate writing. Although this approach may be attractive to some, who could use the freedom to engage in a lengthy way, but for others it may entail an unknown period of distress and struggle if no experience of compassion is generated.

Following on from earlier work undertaken by Gilbert and Neff, other researchers have developed various versions of self-compassionate writing instructions or prompts. An example of a hybrid unstructured Pennebaker writing activity and self-compassionate prompting is given by Shapira and Mongrain (Shapira & Mongrain, 2010). In this study, general community participants recruited via Facebook were provided with instructions for engaging in an exercise that aimed to promote a supportive, caring and compassionate stance towards the self. Participants were asked to think about a distressing event that left them feeling upset, and then to write a one paragraph letter to themselves in the first person about the situation (Shapira & Mongrain, 2010, p. 380). The following instructions were provided to participants:

> *To start writing your own letter, try to feel that part of you that can be kind and understanding of others. Think about what you would say to a friend in your position, or what a friend would say to you in this situation. Try to have understanding for your distress (e.g. I am sad you feel distressed...) and realize your distress makes sense. Try to be good to yourself. We would like you to write whatever comes to you, but make sure this letter provides you with what you think you need to hear in order to feel nurtured and soothed about your stressful situation or event. This letter may take 5-15min to write, and there is no "right" or "wrong" way of doing it.*

Participants were asked to undertake this activity daily for seven days, and then to undergo post-testing at 1-week, 1-, 3-, and 6-months later. These writing instructions were relatively brief, and aimed to assist the participant to find a perspective which

might be beneficial in times of difficulty. However, despite this, and a financial incentive provided by the researchers, the drop-out rate for the entire study was high (79.7%) (Shapira & Mongrain, 2010), indicating possible problematic aspects with user acceptability. Although the activity was described as being self-compassion based, no actual testing of self-compassion levels was undertaken during the study period. As such, it is unknown where there was any impact of the activity upon individual's state or trait levels of self-compassion.

A structured self-compassion based writing activity that is more closely modelled according to the theoretical components of compassion as described by Neff, was developed by Leary and colleagues (Leary, Tate, Adams, Allen, & Hancock, 2007). In particular, Leary hypothesized that an experimentally-induced state of self-compassion would attenuate negative affect related to difficult experiences about which participants chose to write. Leary's intervention involved a single occasion of writing. Participants were asked to "think about a negative event that you experienced in high school or college that made you feel badly about yourself – something that involved failure, humiliation or rejection" and then to describe the event, providing details as to what had led up to the event, who was present, precisely what happened, and how they felt and behaved at the time (Leary, Tate, Adams, Allen, & Hancock, 2007, p. 899). Participants who had been allocated to the self-compassion condition were then asked to write further according to three self-compassion based prompts: 1) how other people may have experienced similar difficult events (common humanity); 2) an expression of kindness, understanding and concern, similar to what would be expressed to a friend who had undergone the same experience (self-kindness); and, 3) to describe one's feelings about the event in an objective and unemotional fashion (mindfulness). Other active writing conditions

used in the study were self-esteem induction, Pennebaker expressive writing, and a control condition in which participants simply described the negative event. At immediate post-test assessment, participants in the structured self-compassion writing condition described significantly lower negative affect than participants in the other writing conditions (which did not differ from each other). Leary and colleagues' study demonstrated that a single occasion of structured self-compassionate writing had a significant immediate effect in lowering negative affect. Such a simple, brief intervention displayed potential for adaptation to the concerns of a specific population. Furthermore, the duration of benefits obtained by the structured self-compassionate writing was unknown, and therefore invited further research.

Considering the objective of rigorously testing such a novel self-compassion based writing intervention, a step-wise set of aims was developed which are discussed in the following section.

3.3. Outline of empirical research

3.3.1. Summary of aims

The primary aim of this thesis was to examine the nature of self-compassion in the context of body image changes after breast cancer treatment and during the survivorship period. The main assertion made in this thesis is that self-compassion is an important factor, in which a deficit is significantly associated with body image disturbance and psychological distress in female breast cancer survivors. For survivors with ongoing body image problems, self-compassion needs to be measured and interventions introduced that may help to enhance this internal resource.

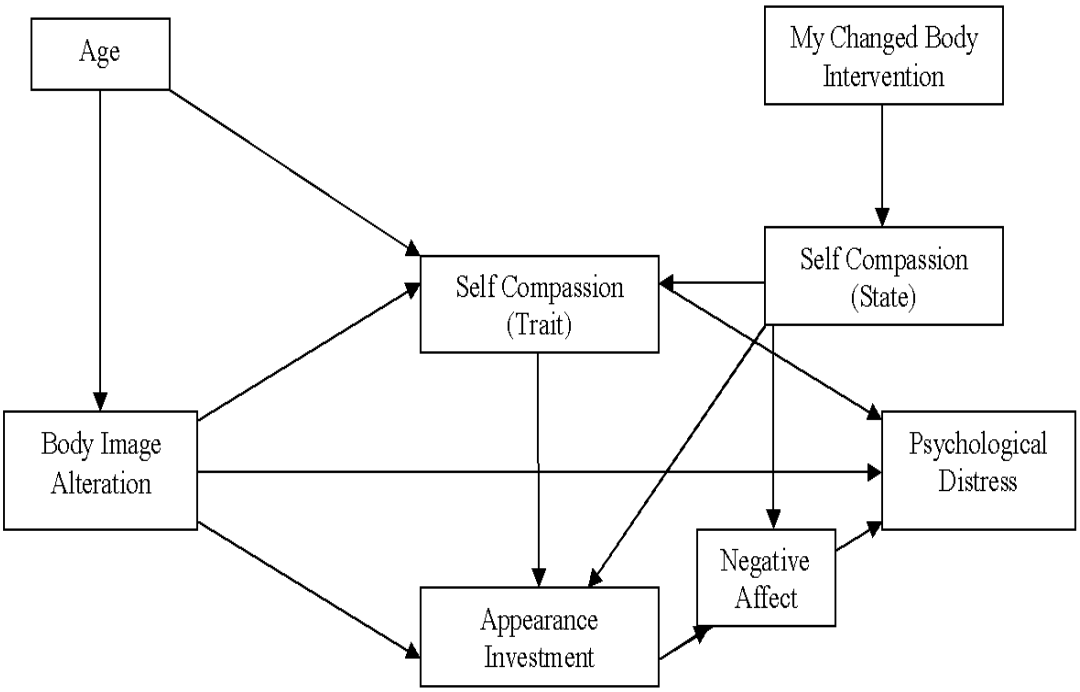
Investigation was conducted in a stepwise manner by demonstrating that:

1. Self-compassion is associated with body image disturbance and related psychological distress in breast cancer survivors (Study I).
2. A self-compassionate state can be triggered and enhanced by a structured writing activity regarding post treatment body image difficulties (Study II)
3. A self-administered, self-compassion based writing activity is acceptable to both consumers and breast cancer health professionals (Study III).
4. Self-compassion levels can be improved in the short- to medium-term by an online structured writing activity regarding post-treatment body image difficulties (Study IV).

The figure below is graphical representation of variables of main interest in this thesis, and their hypothesized relationships. Broadly, it was decided to investigate the possible roles of self-compassion in a population of breast cancer survivor, as discussed in the aims listed earlier. Furthermore, given that it has been recognised that amongst persons with equivalent body discontent, women who are more invested in

their physical appearance will experience more frequent and intense psychological distress (Muth & Cash, 1997), it was also decided to include appearance investment as a variable in this model.

Figure 1. Graphic representation of hypothesized variable relationships



Information about each of the main variables of interest was collected empirically: age (demographic information), body image disturbance (Body Image Scale), trait self-compassion (Self-Compassion Scale), appearance investment (Appearance Schema Inventory Revised), negative affect (The Positive and Negative Affect Schedule), and psychological distress (Depression, Anxiety, Stress Scale). These instruments are discussed in more detail in the following section (3.3.2. Measures used for empirical studies). No measure was available at time of study development

that specifically measured self-compassion as a state. Therefore, a novel measure was devised by the researchers to measure self-compassionate attitude as a state, and this is further discussed in Chapter 5 (Empirical study II).

3.3.2. Measures used for empirical studies

Below is a list of psychological instruments designed to measure aspects of emotional distress, impact of cancer, affect, body image and self-compassion that were utilised throughout investigations undertaken during this thesis.

3.3.3. Measures related to emotions and impact of cancer treatment

3.3.3.1.The Depression Anxiety Stress Scale (DASS21)

The original Depression Anxiety Stress Scale (DASS) is a 42-item self-administered instrument designed to measure the severity of three negative emotional states: depression, anxiety and stress (Lovibond & Lovibond, 1995). The DASS21 is a short form of the original DASS with half the number of items and a shorter administration time (Henry & Crawford, 2005), and has been considered by some to be a superior instrument (Antony, Bieling, Cox, Enns, & Swinson, 1998).

The DASS21 has three subscales according to the three negative emotional states being measured. The depression subscale focuses on self-identification of low mood, low motivation and low self-esteem. The anxiety subscale focuses on self-identified physiological arousal, panic and fear. The stress subscale focuses on self-identified tension and irritability. Participants rate questions such as, "I felt that I wasn't worth much as a person" on a 4 point scale (0 "did not apply to me at all" to 3 "applied to me very much, or most of the time"). These subscale scores are converted to the DASS normative data by multiplying the total scores of each subscale by two, and can then be compared to the clinical cut off scores in the DASS Manual

(Lovibond & Lovibond, 1995). This then allows comparison of whether an individual's depression, anxiety or stress score falls within normal or clinical (mild, moderate, severe or extremely severe) ranges.

The DASS21 has high reliability (Cronbach's alpha is 0.96, 0.89, 0.93, for depression, anxiety, stress respectively), a factor structure consistent with the allocation of items to subscales, and exhibits high convergent validity with other measures of anxiety and depression (correlations with Beck Depression and Beck Anxiety Inventories 0.74 and 0.81 respectively), (Henry & Crawford, 2005). The DASS21 has been utilised with both general and clinical populations, and has been used frequently in studies involving cancer patients (Loh, Chew, Lee, & Quek, 2011; Sheehan, Sherman, Lam, & Boyages, 2007; Stafford, et al., 2015).

3.3.3.2. The Positive and Negative Affect Schedule (PANAS)

The Positive and Negative Affect Schedule (PANAS) is a 20-item self-report scale designed to measure positive and negative affect (Watson, Clark, & Tellegan, 1988). Negative affect is epitomized by subjective distress and unpleasurable engagement, for example, characterised by sadness and lethargy, while positive affect reflects pleasurable engagement with the environment, characterised by emotions such as enthusiasm and alertness (Watson & Clark, 1984). These items were derived from studies of an earlier mood checklist (Zevon & Tellegen, 1982). Participants are asked to rate their experience of a range of emotions on a 5-point Likert scale (1 "very slightly or not at all", 2 "a little", 3 "moderately", 4 "quite a bit", 5 "very much"). The PANAS has been shown to be effective at differentiating depression and anxiety in clinical samples, with positive affect being specifically related to depression, but not anxiety, and negative affect being highly related to both (Dyck, Jolly, & Kramer, 1994). Watson and colleagues (Watson, Clark, & Tellegan, 1988) have used a variety

of timeframes with the PANAS ranging from "right now" to "during the last year", however, a one week timeframe has been most commonly applied in clinical studies (Dyck, Jolly, & Kramer, 1994; Jolly, Dyck, Kramer, & Wherry, 1994; Kuiper, McKee, Kazarian, & Olinger, 2000) and most commonly researched (Crawford & Henry, 2004).

The reliability and validity of the PANAS has been found to be moderately good, with Cronbach's alpha coefficient reported as 0.86 to 0.90 for the Positive Affect Scale, and 0.84 to 0.87 for the Negative Affect Scale. Test-retest correlations over 8 weeks were 0.47 – 0.68 for positive affect and 0.39 – 0.71 for negative affect (Watson, Clark, & Tellegan, 1988). Correlations between the Negative Affect Scale and another measure of general distress (Hopkins Symptom Checklist) have been reported between 0.65 – 0.74 (Watson, Clark, & Tellegan, 1988).

The PANAS is a measure of affect and can also be used as a supplement to other measures of anxiety and depression such as the DASS (Crawford & Henry, 2004). The PANAS has been employed as an outcome measure in studies with cancer survivors (Ganz, et al., 2002), and also self-compassion based intervention programs (Bluth, Gaylord, Campo, Mullarkey, & Hobbs, 2015; Phillips & Feguson, 2013).

3.3.4 Measurement of body image

3.3.4.1 Body Image Scale (BIS)

The Body Image Scale (BIS) is a brief, psychometrically robust self-administered 10-item instrument designed to be applicable to measure body image in individuals who have received any form of breast cancer therapy (Hopwood, Fletcher, Lee, & Ghazal, 2001). The BIS has undergone extensive psychometric testing with breast cancer patients, using datasets from seven UK treatment trials/clinical studies. The BIS has displayed high within scale reliability (0.93), discriminant validity

between breast conserving and mastectomy patients, good clinical validity based on response prevalence, sensitivity to change, and consistency of scores from different breast cancer treatment centres (Hopwood, Fletcher, Lee, & Ghazal, 2001).

The BIS contains affective, behavioural and cognitive items, with five items covering general body image issues (feeling self-conscious, dissatisfied when dressed, difficulty looking at oneself naked, avoidance of others because of appearance, dissatisfaction with body). The other five items focus specifically on the impact of cancer treatment upon body image (feeling less physically attractive, less sexually attractive, less feminine, experiencing the body as less whole, being dissatisfied with scarring). Each item is scored on a four-point scale (0 "not at all", 1 "a little", 2 "quite a bit", 3 "very much"). Items are summed and higher scores reflect greater body image disturbance. A clinical cut-off score is not available for the BIS, (Hopwood, Fletcher, Lee, & Ghazal, 2001), however, it has been suggested that a score of 10 indicates a threshold of body image dissatisfaction (Hopwood, et al., 2000). The BIS, and derivatives from this instrument, have been used extensively in breast cancer research (Falk Dahl, Reinersten, Nesvold, Fossa, & Dahl, 2010; Gomez-Campelo, Bragado-Alvarez, Hernandez-Lloreda, & Sanchez-Bernardos, 2015; Sheehan, Sherman, Lam, & Boyages, 2008).

Furthermore, the BIS is applicable to patients with any type of cancer, stage of the disease or treatment situations, and can be used for both male and female patients. Its use has increased in recent years, becoming a reference measurement in international research, and it has been adapted for a number of different languages. Four out of the ten BIS items comprise the body image subscale of the EORTC Breast Cancer Module (QLQ-BR23), complementing quality of life assessment in clinical

trials or psychosocial research (Gomez-Campelo, Bragado-Alvarez, Hernandez-Lloreda, & Sanchez-Bernardos, 2015)

3.3.4.2 Appearance Schema Inventory Revised (ASI-R short form)

Appearance Schema Inventory Revised (ASI-R short form) was developed as an instrument to measure body-image investment, i.e., the importance, influence and meaning of one's appearance to the individual (Cash, Melnyk, & Hrabosky, 2004). This instrument was based on an earlier questionnaire, the Appearance Schema Inventory ASI (Cash & Labarge, 1996), which aimed to measure "dysfunctional" schematic investment in appearance (Rusticus & Hubley, 2005).

The ASI-R has 20 self-report items with two subscales; Self-Evaluative Salience (SES) (12 items), and Motivational Salience (MS) (8 items). Self-Evaluative Salience reflects the extent to which individuals measure their self-worth by their appearance, and Motivational Salience reflects the extent to which individuals involve themselves in appearance management behaviours. The items are scored on a 5-point scale (1 "strongly disagree" to 5 "strongly agree") with a mean of all 20 items used to form a composite score of body image investment. The two subscales can also be used separately to form self-evaluation and motivational scores, with self-evaluation levels particularly being reflective of dysfunctional investment in one's appearance (Cash, Melnyk, & Hrabosky, 2004).

The ASI-R has been reported to have good psychometric properties. Reliability estimates were considered satisfactory with Cronbach's alpha for the ASI-R's composite score being 0.88 for women and 0.90 for men, with subscales ranging 0.82 – 0.90 for women, and 0.84 - 0.90 for men (Cash, Melnyk, & Hrabosky, 2004). Furthermore, the ASI-R composite scores have been correlated with various similar measures assessing body image dimensions, and also associated with measures of

self-esteem, perfectionism, and Body Mass Index (Cash, Melnyk, & Hrabosky, 2004). Validity evidence by correlations with subscales of the Multidimensional Body-Self Questionnaire – MBSRQ (Cash & Pruzinsky, 1990) which is a widely used measure of body image, has also occurred. The Self-Evaluative Salience subscale was significantly negatively correlated with the MBSRQ's Body Satisfaction and Appearance Evaluation measures (-0.36 to -0.43), which supports the claim that this subscale assesses dysfunctional investment in appearance (Rusticus & Hubley, 2005). The ASI-R has been more recently used with body image research in breast cancer populations, as body image investment has been associated with decreased quality of life and increased depression, as well as being predictive of self-consciousness and body shame (Chua, DeSantis, Teo, & Fingeret, 2015; Hahn, Segawa, Kaiser, Cella, & Smith, 2016; Moreira & Canavarro, 2010; Sherman, Woon, French, & Elder, 2016)

3.3.5 Measurement of self-compassion

3.3.5.1 Self-Compassion Scale

Currently, the Self-Compassion Scale (SCS) is the main self-report instrument to measure self-compassion (Lopez, et al., 2015). This scale is based on the definition of self-compassion as conceptualised by Neff (Neff, 2003a; Neff, 2003b) and acts to measure trait self-compassion. The three components of self-compassion (i.e. mindful awareness, self-kindness, common humanity) are each measured by both negative and positive items thus producing six factors in total. The resulting factors are known as mindful awareness vs. over-identification, self-kindness vs. self-judgement, and common humanity vs. isolation (Neff, 2003b). These subscales are added together to form a total score of self-compassion which can be used by researchers or clinicians. The SCS has been demonstrated to be a reliable measure with high internal consistency of the total scale ($\alpha = 0.93$), with evidence for the presence of a higher order self-compassion factor, and good consistency of the subscales among college

students and others (Neff, 2003b; Neff, Pisitsungkagam, & Hsieh, 2008; Williams, Dalgleish, Karl, & Kuyken, 2014). Evidence also exists for the scale's validity with a significant negative relationships with rumination (-0.50) and neuroticism (-0.40), and positive relationship with self-esteem (0.59) (Neff, 2003b; Neff, Rude, & Kirkpatrick, 2007). The SCS has significantly predicted mental health outcomes through negative correlations with the Beck Depression Inventory (-0.51) and the Speilberger Trait Anxiety Inventory (-0.65) (Neff, 2003b). Convergent validity has also been demonstrated, with a strong association (0.70) found for self reported and partner reported scores with the SCS amongst couples in long-term romantic relationships (Neff & Beretvas, 2013). A strong relationship has also been reported (0.77) between independent coders using SCS items to rate the level of self-compassion displayed in brief verbal dialogues (Sbarra, Smith, & Mehl, 2012). However, more recently there have been questions raised about its factor structure (Lopez, et al., 2015). A new instrument called the Self-Compassion and Self-Criticism Scales (SCCS) has been very recently developed to investigate the association between self-compassion and self-criticism in hypothetical scenarios, (Falconer, King, & Brewin, 2015). However, very few studies exist which have used this instrument (Falconer, King, & Brewin, 2015; Falconer, et al., 2016) and its applicability to oncology populations is unknown. The SCS, and its translations, remain the most researched self-report instrument for the construct of trait self-compassion and is used widely for research in this field (Zessin, Dickhauser, & Garbade, 2015).

No measure was available at the time of study development that specifically measured self-compassion as a state. A novel measure was devised by the researchers to measure self-compassionate attitude (SCA) as a state, and this is further discussed in Chapter 5 (Empirical study II).

3.3.6. Measures of secondary interest

3.3.6.1.Body Appreciation Scale (BAS)

The Body Appreciation Scale (BAS) was developed to measure positive aspects of body image, considered to be neglected by available research in the field (Avalos, Tylka, & Wood-Barcalow, 2005). The BAS goes beyond investigating self-satisfaction with the body, by focussing on and measuring body appreciation. Body appreciation is also understood to include feelings of gratitude towards the body, bodily love, consideration of one's inner state as reflecting outer demeanour, and embodiment of a wider conceptualisation of beauty (Frisen & Holmqvist, 2010; Wood-Barcalow & Tylka, 2010). In this way, body appreciation is not simply seen as the absence of negative body image or the experience of self-perceived attractiveness (Tylka & Wood-Barcalow, 2015).

The BAS is a 13-item self-report scale focussing on body appreciation (e.g. "Despite my flaws, I accept my body for what it is") with responses being scored on a 5-point Likert scale (1 "never", 2 "seldom", 3 "sometimes", 4 "often", 5 "always"). The items are averaged, and higher scores reflect greater body appreciation. The developers have reported unidimensionality of the scale, as well as good construct validity and internal reliability (Cronbach's alpha 0.91-0.94), (Avalos, Tylka, & Wood-Barcalow, 2005). Higher BAS scores were strongly associated in a positive direction with a greater tendency to evaluate one's appearance favourably (r = 0.68, p<0.001), and in a negative direction with body preoccupation (r = -0.79, p < 0.001) and body dissatisfaction (r = -0.73, p<0.001). Such findings provide additional support for the convergent validity of the BAS (Avalos, et al., 2005). The BAS has been recommended as a research tool for investigation of predictors and outcomes of positive body image (Avalos, et al., 2005). Body appreciation has been associated with positive appearance evaluation, self-esteem, positive affect, life satisfaction and

self-compassion (Avalos, et al., 2005; Swami, Stieger, Haubner, & Voracek, 2008; Tylka & Kroon Van Diest, 2013), and hence is an appropriate instrument for investigation of positive body image changes.

The BAS is a relatively recent scale and recommendations have been made for use with various populations, including people undergoing cancer treatment (Webb, Wood-Barcalow, & Tylka, 2015). Studies using the BAS to investigate cancer related behaviours are rare (Andrew, Tiggemann, & Clark, 2016), and indicates a knowledge gap in this area. Information about body appreciation and the breast cancer patient is needed.

This instrument was used in Empirical study II (Chapter 5) as a baseline measure.

3.3.6.2.Impact of Event Scale – Revised (IES-R)

The Impact of Event Scale–Revised (IES-R) is a 22-item self-report measure of current subjective distress in response to a specific traumatic event, and is a revised version of the original IES (Weiss & Marmar, 1997; Horowitz, Wilner, & Alvarez, 1979). The revised instrument is comprised of three subscales which form the major symptom clusters of post-traumatic stress as classified by Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994), namely intrusion, avoidance and hyperarousal. The intrusion subscale comprises eight items related to intrusive thoughts, nightmares, intrusive feelings and images associated with the traumatic event. The avoidance subscale also comprises eight items related to avoidance of thoughts, feelings and situations. The hyperarousal subscale is comprised of six items focussing on hypervigilance, anger, irritability, difficulties in concentration, and arousal upon exposure to reminders of the event. The participant is asked to report the degree of distress experienced for each item in the past seven days

on a five-point scale (0 “not at all”, 1 “a little bit”, 2 “moderately”, 3 “quite a bit”, 4 “extremely”). Higher scores are representative of greater distress.

The scale displays high internal consistency (Creamer, Bell, & Failla, 2003), with a range of 0.79-0.92 (Corcoran & Fishcher, 1994). With regard to content validity, a review has found a mean correlation of 0.63 between the instrument and 11 studies of traumatized populations (Sundin & Horowitz, 2002). Evidence suggests that the IES-R may be sensitive to a more general construct of traumatic stress especially in those individuals with lower symptom levels (Creamer, Bell, & Failla, 2003). There is a high degree of correlation between the IES-R and the PTSD Checklist, with a cut off score of 33 providing the best diagnostic accuracy (Creamer, Bell, & Failla, 2003). Both the original IES and IES-R have a history of use in breast cancer research (Lindberg & Wellisch, 2004; Stanton, et al., 2005; Thewes, Meiser, & Hickie, 2004)

This instrument was used in Empirical study IV (Chapter 7) as a secondary outcome measure.

Part Two: Empirical studies of self-compassion in breast cancer survivors

Self-compassion is relatively recent concept in psychology, and its functions are still not completely understood (see Section 2.1.5. for detailed discussion). Therefore, it was decided to investigate self-compassion in different ways through empirical studies in this thesis, to further understand its potential roles as state / trait, and, mediator / moderator in breast cancer survivor populations. The following empirical studies will touch each of these areas.

Part Two of the thesis contains a series of four consecutive empirical studies which aimed to investigate the relevance of self-compassion in relation to body image (Study I), pilot test the potential of a self-compassion based writing intervention (Study II), translate the intervention to an online format acceptable to consumers and their health care workers (Study III), and evaluate in a randomised controlled study the online format self-compassion based writing intervention with breast cancer survivors (Study IV).

4. Chapter Four: Empirical Study I

4.1. Empirical Study I

Title: **My Changed Body: Breast cancer, body image, distress and self-compassion**

This chapter aims to explore the role of self-compassion in relation to body image disturbance after breast cancer treatment, and to determine the relevance of self-compassion for this population. From a theoretical perspective and available information from prior studies, it was proposed that low self-compassion may be associated with increased psychological distress. This approach was guided by research from Wasylkiw and colleagues (Wasylkiw, MacKinnon, & MacLellan, 2012), indicating that self-compassion may act as a mediator with regard to body image issues. Therefore, it was proposed that body image would exert an indirect influence on psychological distress through self-compassion in a breast cancer population. Investigation of trait self-compassion as a potential mediator, as measured by Neff's Self-Compassion Scale, was the focus of this study.

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My changed body: breast cancer, body image, distress and self-compassion

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Abstract

***Background*: Bodily changes after breast cancer treatment can lead to long-term distress. Self-compassion, the ability to be kind to oneself, is an internal resource that may enhance a woman's ability to adjust to cancer-related bodily changes. The aim of the present study was to test the hypothesis that self-compassion mediates the relationship between body image and distress, controlling for alternate plausible mediators.**

***Methods*: Members of a nationwide breast cancer consumer network were invited to participate. A total of 279 women who had finished active cancer treatment completed the online survey. Assessments included the Body Image Scale; Self-compassion Scale; Depression, Anxiety and Stress Scale and items measuring perceived normative pressure and comfort with one's weight. Possible mediating effects of proposed variables on the body image–distress relationship were assessed.**

***Results*: Tests using a bootstrapping approach with multiple mediators were significant for self-compassion on distress. Body image disturbance was indirectly associated with distress through low self-compassion.**

***Conclusions*: Body image disturbance and lower self-compassion were associated with increased psychological distress among these breast cancer survivors. This study provides preliminary evidence for a mediating role of self-compassion between body image disturbance and psychological distress, suggesting a potentially protective effect of higher levels of self-compassion for women at risk of experiencing body image disturbance.**

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Introduction

Breast cancer treatment typically involves several interventions over an extended duration, usually entailing initial surgery, followed by adjuvant therapy that may include a combination of chemotherapy, radiation therapy and hormonal treatments [1]. These treatments alone, and in combination, produce a number of different side effects. With regard to body image-specific outcomes, breast surgery involving partial or complete loss of one or both breasts may result in poorly aligned breasts and breast asymmetry, extensive scarring and alteration to breast and/or nipple sensation, need for a breast prosthesis, possible changes to limb mobility and lymphoedema [2–6]. Chemotherapy presents challenges including hair loss, weight fluctuation, skin and fingernail discolouration and hot flashes related to early-onset menopause [7]. Radiation treatment, which may be given alone or in combination with chemotherapy, can cause skin reactions and discolouration, as well as potential slow progressing long-term neurological changes [8]. For women undertaking a programme of chemoprevention using hormone treatments, further difficulties may arise including treatment-induced weight gain and hot flashes [9].

Such multi-factorial negative bodily changes are often not within the individuals' domain to control, particularly in terms of extent of adverse impact or severity [10], with further attempts to restore appearance possibly leading to prolonged feelings of regret [11]. These changes may also adversely impact a woman's sexuality [12,13]. Taken together, there is considerable evidence that breast cancer survivors may experience protracted psychological distress, particularly as this relates to negative changes in the individual's perception of her physical appearance or body image [14] despite the fact that the woman may be medically well.

Body image reflects a direct personal perception and self-appraisal of one's physical appearance, whereby negative thoughts and feelings related to one's body indicate a disturbance of body image and lead to dissatisfaction with one's self [15]. A high personal investment in one's body image can act as a source of self-worth [16]. Because women generally have a focus on body image-related evaluation and investment [17], a diagnosis of breast cancer is likely to further exacerbate this propensity [18]. Indeed, the loss of a breast is inherently linked to a woman's identity, sexuality and sense of self [19], with approximately one-third of breast cancer survivors expressing distress that is directly related to disturbed body image after successful cancer treatment [14], particularly younger women [20]. Furthermore, long-term patterns of weight gain after cancer treatment are common [21,22], creating additional bodily challenges.

A number of models can be applied to understanding the development of body image distress following cancer treatment. Fox and Corbin [23] propose that physical self-worth

can be divided into domains including body attractiveness, physical strength, physical conditioning and physical competence. Clearly, breast cancer and its treatment can affect all of these domains. Self-discrepancy theory [24] states that one's self concept is a relationship between the actual and ideal-state representations; breast cancer treatment can increase the discrepancy between how one would like to appear and how one actually is. A prolonged state of high discrepancy could manifest as ongoing tension and distress [24].

Self-compassion, the ability to kindly accept oneself or show self-directed kindness while suffering [25,26], is one internal resource that may impact on a woman's coping processes. Neff [27] has defined self-compassion as comprising three components: self-kindness (versus self-judgement), mindful awareness of one's emotions (versus over-identification) and understanding the universality of human suffering (versus isolation of self) using a six-subscale measure. Evidence from non-oncology populations suggests that self-compassion is associated with psychological well-being [28,26]; therefore, this internal resource may assist a woman to deal sensitively with the many bodily changes she has rapidly experienced following her cancer diagnosis. Such a rapid alteration in body image is likely to acutely test a woman's ability to cope with multiple losses and physical changes. Furthermore, any discrepancies regarding how she wishes to appear and how she actually appears are likely to be widened. In this situation, a woman with higher levels of compassion towards herself is more likely to have the capacity to counter any self-criticism and self-blame, responses which commonly arise among individuals experiencing psychological distress, particularly depression and anxiety [29,30]. Moreover, self-directed compassion may mitigate the frequency and automaticity of negative thoughts about one's appearance [31], as it has been shown to be negatively related to both social physique anxiety and self-evaluations [32]. Berry *et al.* [33] further extend this concept and propose a sub-domain of 'body self-compassion' in which individuals extend a kind, non-judgmental attitude to their body and perceived physical imperfections, limitations and setbacks. Individuals who are self-compassionate are theoretically more likely to react with tolerance to changes in their body and with awareness, understanding and kindness to themselves when in emotional distress. Thus, self-compassion may mediate the adverse effects of body image disturbance on distress in women undergoing rapid, multi-dimensional changes. Evidence for the self-compassion–body image link and the potential mediating role of self-compassion is emerging [34].

The aims of the current study were to investigate the relationship between body image disturbance, self-compassion and psychological distress and to determine whether body image difficulties are associated with more distress through low self-compassion amongst women who have survived breast cancer. In addition, the potential mediators of comfort with one's weight and perceived pressure from others regarding one's weight were examined. Research in other contexts demonstrates that body image difficulties and weight dissatisfaction in women are linked [35] and that personal measures of weight dissatisfaction are associated with increased psychological distress [36,37]. As such, a woman's lack of comfort with her own post-cancer treatment weight may potentially function as a mediator of her distress.

Accordingly, the following were hypothesised: (i) increased body image disturbance and low self-compassion would be associated with increased psychological distress, and (ii) self-compassion would mediate the body image disturbance–psychological distress relationship.

Method

Sample and procedures

Participants were 279 women recruited from an Australian community-based breast cancer consumer organisation. Contact persons within the organisation sent an emailed invitation to participate in the study regarding women's body image experiences in survivorship to 885 members, resulting in a 31% response rate. Participants were required to be over 18 years of age, previously diagnosed with breast cancer and to have completed active breast cancer treatment (surgery, chemotherapy, radiation). Participants completed the anonymous questionnaire online, which should have taken 20–25 min. This research was approved by the Macquarie University Human Research Ethics Committee.

Measures

Body image

The 10-item Body Image Scale was developed to measure body image distress, including aspects of affect, behaviour and cognition, as a unitary measure [38] and has been widely utilised in oncology contexts (e.g. [11,39,40]). Participants rated on a four-point Likert scale the extent to which they agreed with statements, such as 'Have you been feeling self-conscious about your appearance?' (0 'not at all' to 3 'very much'). Summed total scores have a possible range from 0 (no distress) to 30 (high body image distress). This scale shows high item reliability ($\alpha = 0.93$) and good clinical validity and sensitivity to change. Item reliability for this scale in the present study was high ($\alpha = 0.94$).

Self-compassion

The 26-item self-report Self-compassion Scale measured compassion towards the self. Likert scale items (1 = almost never, to 5 = almost always) assessed the extent to which participants treat themselves with self-compassion during times of difficulty. The instrument consists of six subscales: Self-kindness (e.g. 'When I'm going through a very hard time, I give myself the caring and tenderness I need'), Self-judgement (e.g. 'I'm disapproving and judgemental about my own flaws and inadequacies'), Mindfulness (e.g. 'When something upsets me, I try to keep my emotions in balance'), Over-identification (e.g. 'When I'm feeling down, I tend to obsess and fixate on everything that's wrong'), Common humanity (e.g. 'I try to see my failings as part of the human condition') and Isolation (e.g. 'When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world'). A total mean score was obtained (range 1–5) in accordance with recommendations from the scale developer. The Self-

compassion Scale has good test–retest reliability ($\alpha = 0.93$) and validity [27]. In the current study, item reliability was excellent ($\alpha = 0.92$).

Psychological distress

The 21-item short form of the valid and reliable Depression, Anxiety and Stress Scale (DASS21) assessed psychological distress [41,42]. The DASS21 comprises three subscales measuring depression, anxiety and stress (i.e. nervous tension and irritability, factorially distinct from depression and anxiety). Participants rated questions such as 'I felt that I wasn't worth much as a person' (0 'did not apply to me at all' to 3 'applied to me very much or most of the time'). A total score out of 21 was calculated for each subscale and then multiplied by 2, to be comparable with full-scale DASS scores. Scores of at least 10 (Depression), 8 (Anxiety), and 15 (Stress) indicate clinical levels of distress for each subscale, respectively [43]. In the current study, item reliability was high for all subscales ($\alpha = 0.92$ for Depression; $\alpha = 0.79$ for Anxiety; $\alpha = 0.89$ for Stress).

Comfort with weight

The mean of three items scored 1 to 5 ($\alpha = 0.80$) assessed the extent to which the individual feels comfort with her weight (impact of cancer treatment on weight, weight impact on body perception, worry about weight). High scores indicate greater comfort.

Pressure from others

Four Yes/No format items ('Have you experienced any pressure from family/friends/health professionals/media—with regard to your weight?') were summed to indicate the extent to which participants felt pressured from others regarding their current weight ($\alpha = 0.71$).

Demographics

Information was gathered on participants' age, country of birth, marital status, education level, type of breast cancer treatment and duration since breast cancer diagnosis.

Statistical analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS, version 18). Pearson's correlations were used to identify the association between all variables. A sequence of linear regression models were used to assess the extent to which body image, self-compassion, comfort with weight and pressure from others were associated with psychological distress. Mediation analyses were also conducted in which the total effect of body image on each of the three distress outcomes (depression, anxiety, stress) was partitioned into direct and indirect effects, which were tested for statistical significance. Following Baron and Kenny [44], the significance of the paths from body image to each of the mediating variables (self-compassion, comfort with weight, pressure from others; the *a* paths) and from the mediating variables to the distress outcomes (the *b* paths) was tested, along with the significance of the indirect effects. The significance of the indirect effects was tested with the bootstrapping method described by Preacher and Hayes [45].

Bootstrapping is a computationally intensive method that involves repeatedly sampling from a dataset and estimating the indirect effect in each resampled dataset. By repeating this process thousands of times, an empirical approximation of the sampling distribution of *ab* is built, and this is used to construct confidence intervals for the indirect effect. Bootstrapping is considered to be superior to other tests of indirect effects [46]. The Preacher and Hayes approach [45] allows simultaneous testing of multiple mediators (self-compassion, comfort with weight, pressure from others) while adjusting all paths for the potential influence of covariates not proposed to be mediators. Rather than providing a *p*-value for the obtained estimate of the indirect effect, the Preacher and Hayes approach gives confidence intervals based on the bootstrap distribution. If the confidence interval does not contain zero, the indirect effect is said to be significant at a level corresponding to the confidence interval specified (95% in this case). Especially with smaller samples, multiple mediators and non-normal distributions, the bootstrapping method is more likely to provide unbiased estimates of the standard error of the indirect effect than the asymptotic method described by Sobel [46,47].

Results

Demographic data on participants are provided in Table 1. The mean age of respondents was 53.4 years (range, 23–73 years, SD 9.40) with the majority being Australian born, married or partnered, having completed 12 years of education and diagnosed with breast cancer within the last 5 years. All participants had undergone breast cancer surgery, with

Table 1. Sample demographic characteristics

Categorical variable	Percentage %	Number (*n*)
Marital status		
No partner	28	78
Married or partnership	72	201
Country of birth		
Australia and New Zealand	81	226
Britain/Ireland	11	31
Asia	1	3
Europe	1	2
America (North and South)	4	11
Africa	2	6
Education		
Less than 12 years	22	62
12 years	10	28
Vocational training	25	70
Some university	8	22
Bachelor's degree or above	35	97
Type of treatment		
Surgery	100	279
Chemotherapy	74	206
Radiation	72	201
Hormonal treatment	60	167
Other	12	33
Current use of hormones		
Yes	49	137
No	51	142
Time since diagnosis		
Less than 1 year	1	3
1–2 years	11	30
2–3 years	27	76
3–4 years	24	67
5 or more years	37	103

74% receiving chemotherapy, 72% undergoing radiation treatment and approximately half currently receiving hormone treatment.

The DASS21 distress mean scores were Depression 7.13 (SD 8.57), Anxiety 5.71 (SD 6.08) and Stress 10.52 (SD 8.32), respectively; these scores fall within normal ranges [43].

The mean body image score was 10.59, (SD 8.20), which indicated significantly greater body image dissatisfaction compared with scores reported by breast cancer patients in the initial validation of the scale [38] (mean = 8.07, SD = 5.02, 1 year post operatively, and mean = 9.00, SD = 4.70, 2 years post operatively) ($t(437) = 3.53, p < 0.005$). Moderate levels of self-compassion ($M = 3.27$; SD = 0.64) and discomfort with weight ($M = 2.4$; SD = 0.81) were demonstrated, along with relatively low levels of pressure from others ($M = 0.71$; SD = 1.31).

Correlations and regression analyses

Self-compassion was positively correlated with age, with older respondents more compassionate towards themselves. Age was also negatively correlated with body image difficulties, with younger women expressing more body image disturbance. As hypothesised, body image disturbance scores were positively correlated with the measures of psychological distress and pressure from others and negatively correlated with self-compassion and comfort with own weight. Self-compassion was also negatively correlated with the three distress measures, with greater levels of self-compassion associated with decreased psychological distress. Comfort with one's weight was negatively correlated, and pressure from others positively correlated, with psychological distress (Table 2).

Mediation analyses

Linear regression analyses were used to assess the relationship between body image, self-compassion and distress. The significance of the indirect effect was then tested using the bootstrapping method described by Preacher and Hayes [45].

The model for the regression analysis is shown in Figure 1. Results of the analyses and tests of potential mediating variables are shown in Table 3, with age, marital status, time since diagnosis, time since treatment completion and use of hormonal treatment as covariates. If paths *a*, *b* and *c* are significant, and *c'* is reduced compared with *c* (*the total effect*), then the Baron and Kenny [44] criteria for mediation are met. Table 3 shows that all *a* and *b* paths for self-compassion were significant. The bootstrapping test showed that the overall indirect effect and, equivalently, the overall reduction in the total effect (*c*) to the direct effect (*c'*), was significant for all three dependent variables (95% CI: Depression 0.19 to 0.46; Anxiety 0.10 to 0.27; Stress 0.15 to 0.38). For depression, anxiety and stress, the indirect

Table 2. Correlations between variables of interest

Variables	1	2	3	4	5	6	7	8	9	10
1. Age										
2. Time since diagnosis	0.29**	–								
3. Time since treatment	0.28**	0.86**	–							
4. Body image	−0.20**	−0.19**	−0.21**	–						
5. Self-compassion	0.18**	0.07	0.08	−0.16**	–					
6. Comfort with weight	0.18**	0.16**	0.16**	−0.19**	0.31**	–				
7. Pressure from others	−0.01	−0.05	−0.009	0.32**	−0.21**	−0.35**	–			
8. Depression	−0.06	−0.10	−0.10	0.39**	−0.57**	−0.30**	0.26**	–		
9. Anxiety	−0.03	−0.07	−0.10	0.26**	−0.39**	−0.21**	0.29**	0.65**	–	
10. Stress	−0.01	−0.05	−0.06	0.30**	−0.51**	−0.19**	0.21**	0.69**	0.69**	–

N = 225–279.
**Correlation is significant at the 0.01 level (two-tailed).
*Correlation is significant at the 0.05 level (two-tailed).

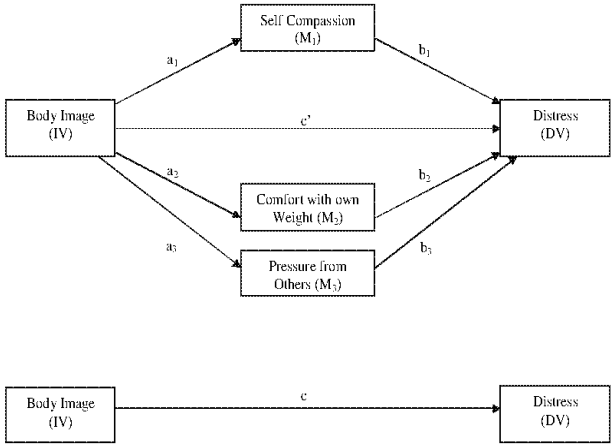

Figure 1. Graphic representation of the mediation model

Table 3. Tests of the potential mediating variables

	Effect of IV on MV (*a* path)		Effect of MV on DV (*b* path)		Direct effect (*c*′ path)[a]		Total effect (*c* path)[a]		Indirect effect (*a* × *b*)		Indirect effect (*a* × *b*)	
	β	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	SE	95% CI	
											Lower	Upper
Depression												
Self-compassion	−0.01	<0.0001	−6.17	<0.0001	0.10	0.16	0.11	<0.0001	0.22	0.05	0.11	0.33
Comfort with weight	−0.02	<0.0001	0.01	0.97	0.10	0.16	0.11	<0.0001	0.07	0.03	0.00	0.11
Pressure from others	0.02	<0.0001	1.55	0.19	0.10	0.16	0.11	<0.0001	0.03	0.03	−0.02	0.09
Anxiety												
Self-compassion	−0.01	<0.0001	−3.00	<0.0001	0.007	0.89	0.18	0.0003	0.11	0.03	0.06	0.18
Comfort with weight	−0.01	<0.0001	−0.59	0.27	0.007	0.89	0.18	0.0003	0.03	0.02	−0.03	0.08
Pressure from others	0.05	<0.0001	0.68	0.03	0.007	0.89	0.18	0.0003	0.01	0.03	−0.01	0.11
Stress												
Self-compassion	−0.01	<0.0001	−6.12	<0.0001	0.06	0.12	0.32	<0.0001	0.22	0.01	0.15	0.32
Comfort with weight	−0.01	<0.0001	−0.11	0.89	0.06	0.12	0.32	<0.0001	0.00	0.01	−0.07	0.08
Pressure from others	0.05	<0.0001	0.57	0.19	0.06	0.12	0.32	<0.0001	0.03	0.03	−0.02	0.10

IV, body image; MV, mediating variable; DV, distress; CI, confidence interval.
[a]The total and direct effects were for the single IV in each model.

effect of self-compassion was positive and significantly different from zero, indicating mediation according to the bootstrapping method [45]. For anxiety and stress, the other candidates (pressure from others, comfort with weight) did not meet the criteria for mediators when analysed simultaneously, as their confidence intervals included a zero value. However, for depression, comfort with weight met the criteria for mediation, along with self-compassion. In summary, body image disturbance was found to exert an indirect effect on distress through all of the proposed mediators, but for anxiety and stress, only self-compassion uniquely contributed to this effect.

Discussion

This is the first study to investigate the association between body image disturbance and self-compassion and its relationship to psychological distress in an oncology context, specifically among breast cancer survivors. These investigations have also allowed initial exploration of a potential mediating role of self-compassion on the body image–distress relationship.

Consistent with prior research among breast cancer survivors [48–50], the present study reports minimal psychological distress for the majority of women. Given that more than half of the sample were diagnosed with breast cancer at least 3 years prior to study participation, the low level of distress reported is unsurprising and is consistent with the view that by 12 months post-diagnosis most women will have returned to pre-diagnosis levels of distress (e.g. [50,51]). Many factors can contribute to psychological distress and its alleviation; however, in this sample, distress was associated with greater body image disturbance and lower levels of self-compassion, less comfort with weight and greater perceived pressure from others.

A considerable number of women reported experiencing body image disturbance related to their breast cancer diagnosis and treatment, consistent with other studies reporting sustained body image difficulties at 12 months post-diagnosis and beyond [52–54]. Indeed, levels of body image disturbance in this sample exceeded those reported by Hopwood [38] in the validation of the Body Image Scale. The women in the present study also had a longer time since diagnosis than the Hopwood sample [38], suggesting sustained body image disturbance. Hence, it cannot be assumed that body image disturbance experienced by breast cancer survivors will necessarily diminish with the passage of time, as has been suggested (e.g. [55,56]). Moreover, not surprisingly, greater body image disturbance was evident in women reporting lower comfort with weight and greater pressure from others regarding current weight. As hypothesised, body image disturbance was associated with increased psychological distress in breast cancer survivors, consistent with findings from other studies of cancer and breast cancer survivors (e.g. [57]), highlighting the importance of body image to overall psychological well-being [50,11,38]. These ongoing difficulties with body image in breast cancer survivors suggest that the needs of these women are not always being adequately addressed [58].

Self-compassion was inversely associated with distress, so that women experiencing greater self-compassion also experienced lower distress. This is consistent with emerging evidence from non-oncology populations that self-compassion is a robust predictor of lower depressive and anxious symptomatology, improved quality of life [59] and mental health in general [60]. Furthermore, some of those who are in poorer physical health or have greater challenges to their well-being might require higher levels of self-compassion [60]. It may be possible that on occasion of rapid multi-factorial body image disturbance, additional demands are placed on the individual's self-compassion resources. Although these cross-sectional data preclude any causal inferences, these findings suggest that women who are experiencing distress and who are unable to view themselves in a self-compassionate manner may be creating a self-perpetuating cycle that exacerbates and prolongs their distress.

As predicted, the results obtained confirmed the association between body image disturbance, self-compassion and psychological distress, demonstrating a significant indirect effect through all mediating variables investigated. Key to this finding, however, was that only self-compassion contributed to the indirect effect uniquely for anxiety and stress measures of psychological distress. Hence, the unique

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circumstances of the breast cancer survivor's body image changes may prove to be a salient context in which self-compassion needs to be considered. With reference to the mediation model, it can be seen that the negative link between body image disturbance and self-compassion may result in a reduction of a resource that assists in alleviating psychological distress. Although the present study data preclude examination of causal mechanisms, it can be surmised that breast cancer survivors who have poor body image may be more likely to be depressed, anxious or stressed because of their lower levels of self-compassion, given the negative relationship between self-compassion and distress. Therefore, it may be argued that especially at the post-treatment phase, a woman's self-compassion may need to be reinforced or enhanced to lessen the impact of body image disturbance.

Although this research provides evidence for the potential mediating role of self-compassion on body image, the mediating effects of the other potential factors of comfort with one's own weight and perceived pressure from others did not contribute uniquely to this effect for anxiety and stress. As such, prior body image-related research findings generated from non-oncology populations, such as eating disorder contexts or studies on adolescents [35–37], may not necessarily be applicable to breast cancer survivors. Differences in age, the type of bodily changes, presence of treatment side effects and overall general health may be possible influencing factors accounting for the lack of unique contribution of these variables to the mediating effect.

The level of self-compassion that the woman is able to display becomes a crucial factor and, it can be argued, an essential point of intervention to address body image dissatisfaction following breast cancer treatment. In other words, simply attempting to address body image difficulties without considering the role of self-compassion is likely to have limited benefits. For women with low levels of self-compassion, survivor programmes that focus solely on cosmetic improvements or physical exercise, although informative, may not produce the desired outcomes in terms of distress reduction. Self-compassion enhancement may be one of the 'active ingredients' that need to be included in effective body image intervention. Because of its likely impact in the area of rapid multi-factorial bodily change, it can be argued that if a woman's self-compassion is low, then psychological distress is likely to be problematic. This finding is consistent with emerging evidence that self-compassion can buffer against rumination, which can make people vulnerable to anxiety and depression [26]. In non-oncology populations, interventions designed to promote self-compassion [61–63] have proven effective in reducing depression, anxiety, self-criticism, shame and negative emotions in general while increasing self-soothing. Hence, this approach may potentially be applied to the needs of breast cancer survivors.

There are a number of limitations to the current research that need to be considered. Information was only collected via self-report measures. These data were based on a self-selected group of women who were previously diagnosed with breast cancer. It is possible that women who were experiencing ongoing distress and body image concerns may have been more likely to participate in such a study. Information was not collected on the women's sexual orientation, and this issue may limit the generalisability of the results obtained. In addition, the participants were all English speaking, had access to computers and were mostly Australian born; thus, they were not necessarily representative of all women diagnosed with breast cancer. The generalisability of these findings is limited but is nevertheless similar in composition to prior research among similar cancer populations (e.g. [11]). Finally, the present study is limited by the cross-sectional nature of the data, and more research is needed utilising a prospective design to further investigate the potential mediating role of self-compassion upon distress.

As the first study to investigate and confirm relationships between body image disturbance, self-compassion and psychological distress in an oncology population, our results suggest that a substantial proportion of women do not readily adjust to life after breast cancer and that ongoing distress may be associated with residual concerns resulting from changes to their physical appearance and how they perceive their bodies. The presence of low self-compassion may produce particularly negative consequences. The question of whether the observed levels of low self-compassion were pre-existing or developed post-treatment needs further exploration. In any case, it appears that self-compassion is an important factor to monitor in the breast cancer population. Further research is needed to determine a causal mediation link between body image and self-compassion and to establish whether these findings are robust across age, gender and disease types. Despite the limitations discussed above, our research provides evidence as to the importance of self-compassion with regard to post-treatment physical changes and provides a sound grounding for further exploration of appropriate clinical interventions targeting breast cancer survivors.

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Conflict of interest

No potential conflict of interest reported. This research was supported by Macquarie University being undertaken as part of a PhD programme.

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5. Chapter Five: Empirical Study II

5.1. Empirical Study II

Title: **Modifying affective and cognitive responses regarding body image difficulties in breast cancer survivors, using a self-compassion based writing intervention.**

This chapter documents the second empirical study, that investigated whether it is possible to influence affect and state self-compassion, by use of a short self-compassion based writing activity about difficult body image experiences after breast cancer treatment. The preceding empirical study documented in Chapter 4 established that there are grounds for the application of self-compassion for psychological distress related to body image changes. This chapter explores whether there are possible beneficial short term effects from writing according to self-compassionate prompts in a paper based activity. As such, the study attempted to investigate self-compassion as a trait (baseline measure), and as a state (self-compassionate attitude). Given that the main available instrument (i.e. Neff's Self-Compassion Scale) measures self-compassion as a trait, it was decided to develop a novel measure of a self-compassionate state.

Furthermore, Leary and colleagues (2007) investigated the benefits of moderating effects of self-compassion; therefore it was also decided to investigate potential moderating effects of trait self-compassion on the outcome of the intervention.

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ORIGINAL PAPER

Modifying Affective and Cognitive Responses Regarding Body Image Difficulties in Breast Cancer Survivors Using a Self-Compassion-Based Writing Intervention

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Abstract The body image-related concerns of breast cancer survivors following treatment are not always adequately addressed. Self-compassion, which is the capacity to adopt a kind, caring attitude to oneself in times of difficulty, has been linked to decreased psychological distress. The aim of this study was to determine the affective and cognitive impact of a self-compassionate writing activity regarding adverse bodily changes. Female breast cancer survivors ($N = 105$) were recruited through an Australian consumer organization and completed an initial background questionnaire including Depression, Anxiety and Stress Scale, Body Image Scale, Body Appreciation Scale and Self-Compassion Scale. Participants were then randomly allocated to either a self-compassion-focused (experimental) or unstructured writing (control) condition regarding their experiences of body image difficulties after cancer treatment. Ratings of affect and cognition were assessed immediately prior to, and following, completion of the paper-based writing activity. Multivariate analysis of covariance (MANCOVA), controlling for pre-intervention levels of affect and cognition, indicated a significant main effect for the experimental condition, $F(2, 104) = 4.70$, $p = 0.01$, and $\eta_p^2 = 0.08$. Univariate tests revealed significantly lower negative affect and greater self-compassionate attitude in experimental compared to control participants. Writing according to self-compassionate-focused prompts resulted in lower levels of negative affect and an increased self-compassionate attitude during exposure to difficult memories related to body image, compared with unstructured writing about these experiences. These findings provide preliminary evidence for the usefulness of a relatively simple and inexpensive self-compassionate writing intervention to address body image-related issues in breast cancer survivors, with potential application of this model to many other client settings.

Keywords Self-compassion · Mindfulness · Breast cancer · Body image · Psychological distress · Writing

Introduction

Breast cancer is the most common female cancer, and with continuing improvements in early detection and treatment approaches, there are increasing numbers of long-term survivors (Ferlay et al. 2010). Although effective at reducing mortality, breast cancer treatments (i.e., surgery, chemotherapy, radiation, hormone treatment) often result in unwanted physical side effects that may include alterations to breast appearance and scarring following whole or partial breast removal; arm and shoulder mobility restriction; changed nipple and breast sensation; lymphedema; hair loss; hormonal changes; treatment-induced menopause; skin pigmentation; and long term weight gain (Fobair et al. 2006; Gho et al. 2013; Hayes et al. 2010). Unfortunately, these treatment effects can lead to serious challenges to the integrity of a woman's body, and hence, her body image, with possible resultant distress (Fobair et al. 2006; Jim et al. 2007).

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Body image incorporates an individual's cognitions, feelings, behaviors and evaluations toward one's own body, which can vary along a continuum from positive to negative (e.g., Banfield and McCabe 2002; Cash and Fleming 2002; Thompson et al. 1999). It is usual for survivors to be provided with medical feedback, information from a variety of sources (e.g., exercise, dietary, cosmetic), and peer support programs after breast cancer treatment to help with various concerns, including body image. However, within the first year following breast cancer diagnosis (Pauwels et al. 2013) and beyond (Brunet et al. 2013; Galiano-Castillo et al. 2014; Montazeri et al. 2008; Przezdziecki et al. 2013; Sackey et al. 2010), women have expressed unmet needs regarding how to cope with bodily changes and reported disturbed body image. Furthermore, there is evidence that average age of breast cancer patients has been declining, with women being diagnosed at an earlier age (Chen et al. 2012; Iqbal et al. 2014). It appears that younger women are more vulnerable to body image concerns, so without effective interventions, the number of women reporting body image disturbance is likely to increase over time (Chen et al. 2012). Moreover, treatment adherence and length of survival post-cancer treatment have also been linked with body image disturbances (Annunziata et al. 2012), suggesting that this may influence general treatment effectiveness as well as survivor quality of life.

There is emerging evidence that the way in which a woman views herself and the attitude she adopts, in the context of her cancer-related situation, influences how she perceives and experiences these treatment-related bodily changes (Brunet et al. 2013; Moreira et al. 2010; Moreira and Canavarro 2010; Przezdziecki et al. 2013). Psychological approaches, such as mindfulness and self-compassion, may hold promise to further assist women to cope with such changes. Mindfulness involves paying attention and being aware of the present moment with attitudes of non-judgment, acceptance, and patience (Kabat-Zinn 2009), while self-compassion is the ability to kindly accept oneself or show self-directed empathy, while suffering, (Germer 2009; Raes 2011). More specifically, self-compassion has been defined as comprising three interacting components: self-kindness, mindful awareness, and a sense of common humanity (Neff 2003a). As such, individuals higher in self-compassion are less likely to engage in self-criticism, over-identification, and isolation (Neff et al. 2005). The practice of mindfulness itself is well established and recognized as an effective intervention (Kang and Whittingham 2010), while self-compassion has been more recently investigated but often is not explicitly taught (Neff and Germer 2013). Qualities fostered by mindfulness are considered to be necessary preconditions for the development of self-compassion, with mindful awareness of one's inner experiences of suffering being an essential step for the development of compassion toward oneself (Birnie et al. 2010). However, while mindfulness is an essential component of self-compassion, it has been pointed out that the difference between mindfulness and self-compassion lies in their respective targets, with mindfulness focusing on one's internal *experience* (sensations, emotions, thoughts), and self-compassion focusing on oneself as the *experiencer* (Neff and Germer 2013). As such, self-compassion emphasizes comforting the "self" when distressing sensations or experiences arise (Neff and Germer 2013). Historically, the development of mindfulness was understood in tandem with the development of compassion (Kang and Whittingham 2010) and the possibility that these practices assist each other needs to be further considered in relation to body image disturbances.

The potential roles of mindfulness and self-compassion in relation to body image require further examination. Mindfulness is recognized as a protective factor in body image concerns (Alberts et al. 2012; Adams et al. 2013). It entails an acceptance of one's present appearance, rather than a focus on achievement of ideals or perfection, and encourages neutral observation of reality, rather than engaging in body avoidance or harsh self-judgment (Alberts et al. 2012). Engagement in mindfulness enhances compassionate behavior; potentially, mindfulness uses an increased attention to stimuli with less personal bias, whereas compassion engages with empathic processes and pro-social emotions (Lim et al. 2015). However, certain aspects of mindfulness may have a more complicated relationship with body image, particularly the skill of observation. Higher levels of observation have been associated with less body acceptance and greater psychopathology (Prowse et al. 2013). Higher levels of observation may be detrimental if an individual is prone to misjudgment or hypervigilance (Prowse et al. 2013). Therefore, it is possible that the process of using mindfulness alone may be problematic for some individuals in relation to body image disturbance, especially in relation to self-observation. Self-compassion may have a unique role in fostering a sense of care and tenderness toward the self, while experiencing difficult thoughts and emotions about one's body (Albertson et al. 2014). Thus, the explicit use of self-warmth and kindness, which self-compassion emphasizes, may be of particular importance in relation to body image.

It appears that self-compassion may be able to offer mindfulness additional approaches with regard to cancer related body image disturbance. Self-compassion has been associated with greater cognitive flexibility (Martin et al. 2011), indicating an increased ability to adapt to life changes (Neff et al. 2005). Furthermore, self-compassion has been shown to exert an indirect effect on the relationship between body image disturbance and psychological distress among breast cancer survivors (Przezdziecki et al. 2013) and has been associated with less depression and stress and increased quality of life (Pinto-Gouveia et al. 2014) in cancer patients generally. Research among healthy non-cancer populations confirms the association between self-compassion and a healthy body

image (Wasylkiw et al. 2012) and links higher self-compassion with lower body shame and decreased disordered eating, (Breines et al. 2014). Self-compassion-based therapies for body image disturbance are in their infancy; however, there is some evidence supporting the effectiveness of relatively brief interventions with improvements in body appreciation and reductions in contingent self-worth based on appearance (Albertson et al. 2014). This is particularly noteworthy as body image disturbances appear to be widespread, to be difficult to treat, and to be resistant to a number of interventions (Pearson et al. 2012).

Self-compassion is likely to influence psychological distress in a number of ways. Overall, individuals who are high in self-compassion tend to react less strongly to negative events, have greater levels of life satisfaction, and are better able to manage health difficulties (Allen and Leary 2010; Leary et al. 2007; Neff 2003a, b; Neff et al. 2007; Terry and Leary 2011). Specifically, self-compassion has been associated with lower negative emotions in real, remembered, or imagined situations, together with cognitive styles that enhance an individual's ability to cope with negative events (Leary et al. 2007). These associations, together with less avoidance of traumatic stimuli (Thompson and Waltz 2008), suggest that self-compassion may have a role in facilitating exposure to difficult or aversive situations, and in this way, assist in improving an individual's adjustment. As such, a self-compassionate approach may help to counter the development of unhelpful cognitive and behavioral patterns among breast cancer survivors. When faced with a stressful life event, such as breast cancer diagnosis, a self-compassionate individual is purported to be more likely to have awareness of her distress in an accurate way, treat herself kindly, and be able to put her painful experiences in the broader context of life (Neff 2003a, b). Increased comfort with oneself, as opposed to embarrassment or shame, could assist the breast cancer survivor to manage her body focused activities, such as medical checkups, with decreased avoidance or distress (Ridolfi and Crowther 2013). As such, self-compassion is a potentially untapped resource that could be used to enhance a woman's efforts in coping with the side effects of breast cancer treatment and promoting adherence to medical advice or behavior change strategies, and thus, would be of value in meeting the needs of cancer survivors in promoting adaptation to these personal changes.

Evidence is growing that self-compassion is amenable to external manipulation (Leary et al. 2007; Neff and Germer 2013). Intensive interventions using self-compassion-focused psychotherapy (Gilbert 2010) have been shown to decrease self-criticism and depression among people with chronic mood difficulty (Gilbert and Proctor 2006) and to improve symptomatology in eating disorder populations (Gale et al. 2014). Formal 8-week self-compassion group-training programs incorporating meditation practice, group discussion, and home practice (Jazaieri et al. 2013; Neff and Germer 2013) have demonstrated increases in the participants' overall self-compassion (Jazaieri et al. 2013) and happiness (Neff and Germer 2013), as well as decreases in anxiety and depression (Neff and Germer 2013) among medically well populations. While effective, these intervention approaches are relatively time-, labor-, and cost-intensive, requiring therapist facilitators and participants to attend on-site sessions. A less intensive but, nonetheless, effective approach to manipulating self-compassion among medically well populations has been to use a self-compassion-focused writing exercise intervention (Leary et al. 2007; Johnson and O'Brien 2013; Zabelina and Robinson 2010). This approach requires individuals to write about a painful life event, while focusing on prompts designed to cognitively prime the three self-compassion components of self-kindness, mindful awareness, and common humanity (Neff 2003a). Self-compassion-focused writing has been shown to minimize defensiveness and distress caused by negative events and to increase an individual's willingness to accept responsibility for their actions (Leary et al. 2007). Benefits of a self-compassionate outlook are particularly effective for individuals low in trait self-compassion (Leary et al. 2007) and high in self-judgment (Zabelina and Robinson 2010).

Due to their time and cost-effectiveness, writing activities involving personal disclosure have been used in oncology populations for a number of years. A recent review (Merz et al. 2014) has found a variety of outcomes including benefits in sleep, pain, physical health, mental health, and health care utilization. However, due to wide variations in methodology, it is difficult to understand specific features of writing activities that are effective in cancer populations (Merz et al. 2014). Probable mechanisms of action include an exposure function and opportunity to develop self-regulation, when faced with a difficult memory (Merz et al. 2014). Pennebaker and colleagues (1986, 1997), who established expressive writing as a therapeutic technique, typically used an unstructured approach allowing the writer to adopt their own format and sequence of ideas. Personal expression is considered important, as it allows natural language use in writing, which can reveal the writer's deep emotions and attitudes (Slatcher and Pennebaker 2006). By being self-directed, unstructured writing allows freedom in style and content, and therefore, the attitude and tone that the writer adopts may vary, allowing the writer to write potentially in a self-accepting or self-critical way throughout the activity. Ongoing self-criticism has been considered as one of the most pervasive features of psychopathology (Gilbert et al. 2012), and body image difficulties frequently encompass self-criticism as a central feature (Veale and Gilbert 2014; Wasylkiw et al. 2012). Furthermore, individuals high in self-criticism can find it particularly difficult to access a self-supportive narrative or create affiliate feelings toward themselves (Leaviss and Uttley 2015).

Hence, assisting a writer to adopt a self-compassionate attitude, and using additional prompts to structure the difficult event in a self-compassionate way, may assist the individual to experience less distress while maintaining exposure to a painful event. There is some evidence that self-compassionate writing may assist in limiting activation of the psychophysiological threat system, and in this way, may help to minimize distress and avoidance in processing of difficult events (Johnson and O'Brien 2013). Although single session writing activities have been shown to be a feasible intervention for breast cancer survivors (Henry et al. 2010), no evidence could be located that self-compassion-focused structured writing for body image changes, such as this, has been attempted in oncology settings.

This investigation aimed to evaluate the impact of a self-compassion-focused writing exercise for breast cancer survivors regarding body image changes on emotional and cognitive outcomes. Specifically, the effects of self-compassionate prompts in writing about difficult post-treatment body image experiences on negative affect and self-compassionate attitude were examined in a two-group experimental design (self-compassionate writing with prompts vs. control, writing with no prompts). It was hypothesized that women assigned to self-compassionate writing would report less negative affect after the writing activity and recollection of difficult experiences related to their body, and greater self-compassionate attitude, compared with control group participants. It was further predicted that this effect would be greatest among women with low pre-existing levels of self-compassion.

Method

Participants

All participants were members of the Breast Cancer Network of Australia (BCNA), which is a community-based breast cancer consumer organization, who were invited to participate in the study through an emailed advertisement distributed by this organization. The participants were recruited between August 2012 and July 2013. The online study enrolment link was accessed and consented to by 152 women who met the following study eligibility criteria: over 18 years of age; previously diagnosed with breast cancer; completed any prescribed active breast cancer treatment (i.e., any of surgery, chemotherapy, radiation); and willing to undertake a writing exercise in English.

Procedure

A trained consumer representative from the Breast Cancer Network of Australia advised the researchers on the conduct of this study, providing advice concerning recruitment methods and study protocols. This research was approved by the Macquarie University Human Research Ethics Committee.

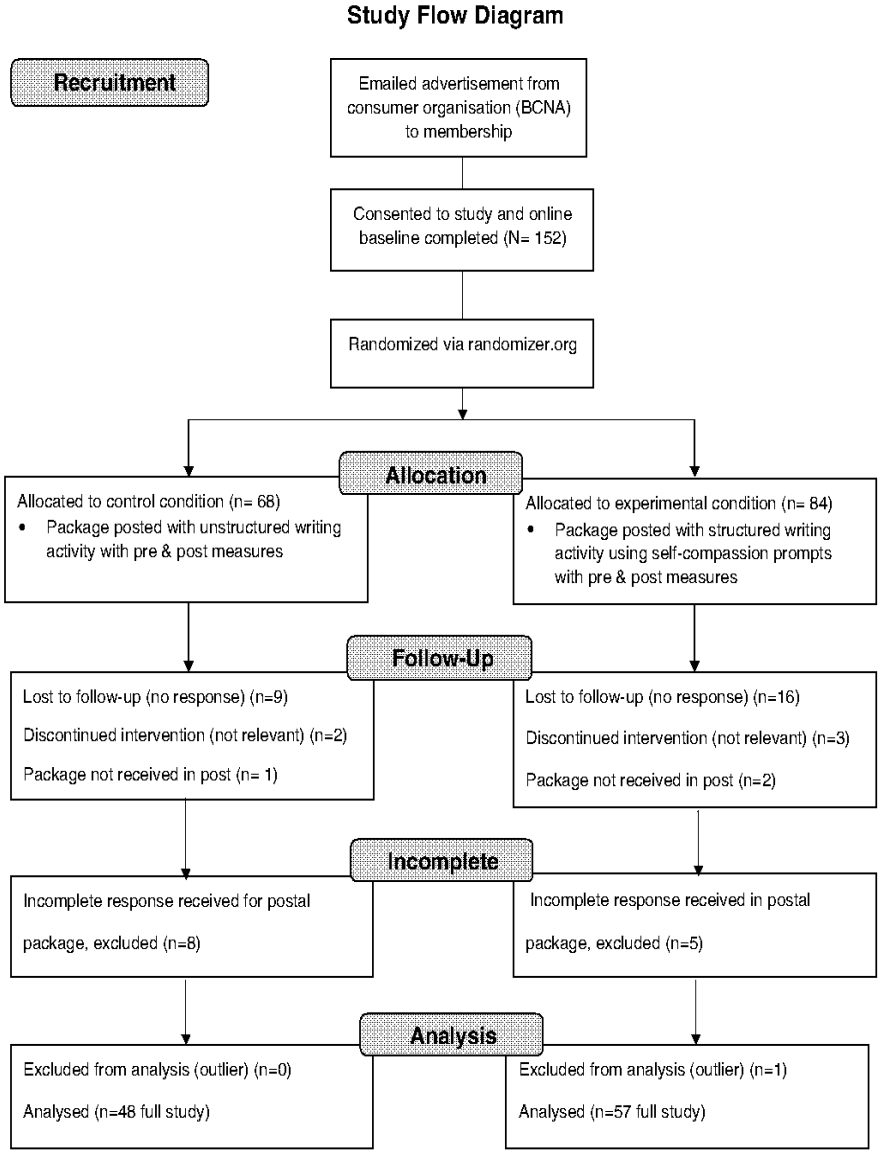
The study consisted of two parts: online background pre-randomization questionnaire (part 1) and a written activity with paper-based pre- and post-intervention measures (part 2). After registering their consent at the study website, the participants completed part 1, which is an online demographic and medical characteristics questionnaire, including an assessment of psychological distress, body image disturbance, body appreciation, and self-compassion levels. Following completion of part 1, the researchers randomly allocated participants to either the control or self-compassionate writing conditions using a computer generated randomizing sequence (randomizer.org). A study package, containing separately sealed pre- and post-writing questionnaires and the respective writing exercise instructions for each study condition, as well as a stamped addressed return envelope was posted to all participants. Participants first completed the pre-questionnaire and then opened the sealed envelope containing the writing instructions for their specific study condition. After completing the writing exercises, participants then completed the post-questionnaire. Upon completion of both questionnaires, participants posted these back to the researchers. On the basis of a medium effect size for affective responses (Cohen's $d = 0.58$) estimated from similar research (Leary et al. 2007), a total sample size of 100 was regarded as adequate to achieve at least 80 % power in the present study, with critical $p = 0.05$ to detect group differences of this magnitude. With a probable expected attrition rate of approximately 25 % when compared with a similar writing-based study (Odou and Brinker 2014), we estimated a requirement of a minimum of 133 women to be recruited into the study to ensure at least a final analyzable sample of 100 participants.

The CONSORT diagram indicating the flow of participants is provided in Fig. 1. The final sample included in the analyses was 105. *T* tests indicated that women who completed the full study were older on average ($M = 55.42$ years, $SD = 9.75$) than women who only completed background measures ($M = 51.45$, $SD = 9.44$), $t(140) = -2.02$, $p = 0.046$. This may have been due to the second part of the study being conducted by post rather than online, and therefore, perhaps, less appealing to younger participants. No other between-group differences were evident.

Study Conditions

Both conditions required the participants to write (approximately four pages) about an event that they had experienced in relation to post-treatment bodily changes, which had adversely impacted on how they perceived their own bodies (i.e., body image). The participants were blind to their

Fig. 1 Study flow diagram



allocated study condition as they undertook the activity alone in the privacy of their own home. Each section of the study was separately sealed and numbered according to opening order, to reduce demand characteristics upon participants. After receiving responses by return post, the lead researcher visually examined the written narratives for completeness as a fidelity check.

Control Condition: Writing with no Prompts

Using a uniform structure of introduction, detailed elaboration, and conclusion, the participants were instructed to describe the event including: what led up to the event; who was present at the event; precisely what happened; and how they felt and behaved at the time. No further writing prompts were provided in this condition, and writing was concluded at the end of the four pages of writing paper provided.

Self-Compassionate Writing Condition: Writing Following Self-Compassionate Prompts

The self-compassionate writing condition also involved writing about a negative event, which was introduced in the same manner as the control condition but further contained self-compassion prompts designed to induce a personal self-compassionate perspective (Leary et al. 2007; Neff 2003a). Leary et al.'s (2007) self-compassion writing task has been adapted and replicated in a number of contexts for various purposes (e.g., Johnson and O'Brien 2013; Odou and Brinker 2014; Zabelina and Robinson 2010). In this study, the writing prompts were redesigned for post-treatment body image difficulties. As in the control condition, the participants were initially asked to introduce their event on the first page. The first self-compassionate prompt requested that women consider the changes their body had undergone through the

experience of treatment, and write whether they had treated themselves and their body with kindness. Next, the participants wrote a paragraph showing understanding and kindness for themselves adopting a style they would use if they were to address a friend who had undergone a similar experience. These prompts were used to focus participants on the self-kindness component of self-compassion. The participants were then asked to look at their feelings using a bigger perspective, while trying to put some space between the event and their reactions, therefore, adopting a mindfully aware perspective of the situation. The final prompts were designed to assist the participants to focus on aspects of common humanity, by asking them to write about how other survivors, and indeed women in general, may experience events where they feel uncomfortable about their bodies, and then conclude by writing a self-compassionate letter to themselves. Writing was concluded at the end of the four pages of writing paper provided.

Measures

Demographics Information was gathered at the pre-randomization assessment on participants' age, country of birth, marital status, education level, type of breast cancer treatment, use of reconstructive techniques, and time since treatment completion.

Psychological distress The 21-item short form of the valid and reliable Depression, Anxiety and Stress Scale (DASS21) assessed psychological distress (Lovibond and Lovibond 1995). The DASS21 comprises three subscales measuring depression, anxiety, and stress (i.e., nervous tension and irritability, factorially distinct from depression and anxiety). The participants rated questions such as, "I felt that I wasn't worth much as a person" (0 "did not apply to me at all" to 3 "applied to me very much or most of the time"). The Cronbach's α in this study were 0.90 (depression subscale), 0.81 (anxiety subscale), and 0.83 (stress subscale). A total score out of 21 was calculated for each subscale and then multiplied by two to be comparable with full-scale DASS (42-item) scores. These pre-randomization levels of psychological distress were assessed as potential covariates.

Body image disturbance Levels of body image disturbance were measured by the 10-item Body Image Scale (BIS; Hopwood et al. 2001). Each item is scored on a four-point scale (0 "not at all" to 3 "very much") and summed to make a total score. This is a specific measure for body image concerns in cancer patients, and higher scores indicate greater body image disturbance. Cut-off scores that indicate clinical levels of disturbance for body image problems have not been defined for the BIS (Hopwood et al. 2001), however, it has been suggested that a score of 10 might serve as a threshold indicating dissatisfaction with body image (Hopwood et al. 2000). The Cronbach's α for the BIS in this study was 0.92. The pre-randomization level of body image disturbance was assessed as a potential covariate.

Body appreciation Pre-existing levels of body appreciation were measured by the 13-item Body Appreciation Scale (BAS; Avalos et al. 2005). Items are rated on a five-point scale (1 "never" to 5 "always") and are averaged to produce a total score (higher scores indicate greater body appreciation). This scale shows a unidimensional structure, with good construct, discriminant, and incremental validities (Avalos et al. 2005). The Cronbach's α for the BAS in this study was 0.92. The pre-randomization level of body appreciation was assessed as a potential covariate.

Self-compassion Pre-randomization levels of self-compassion were assessed with the 26-item Self-Compassion Scale (SCS; Neff 2003b) in which participants rated (1 "almost never" to 5 "almost always") the extent to which they treat themselves with self-compassion during times of difficulty (e.g., "I'm disapproving and judgmental about my own flaws and inadequacies"). Total mean scores (range 1–5) were calculated with higher scores indicating greater self-compassion (Cronbach's $\alpha = 0.92$ in the current study). There is adequate evidence that this scale is valid and reliable (Neff 2003b). Pre-randomization self-compassion was assessed as a potential covariate.

Pre- and Post-Writing Questionnaires

Prior to undertaking the writing task, and immediately following completion of the writing task, all participants completed measures of affect and self-compassionate attitude to assess short-term responsivity to the writing manipulations.

Affective and Cognitive Responses Participants' affect levels and the tendency to have a self-compassionate attitude regarding one's difficult post-treatment bodily changes and experiences, were measured by 22 Likert-type items. Affect items were based on Leary et al.'s (2007) rating scale, as used by similar studies (e.g., Johnson and O'Brien 2013; Odou and Brinker 2014; Zabelina and Robinson 2010), and a scale created by the researchers to rate self-compassionate attitude. Following the procedure set by Leary et al. (2007), the participants rated their feelings on 16 items representing sadness (e.g., "down"), anger (e.g., "irritated"), anxiety (e.g., "tense") and happiness (e.g., "happy") on a seven-point Likert-type scale (1 = not at all to 7 = extremely). These items were summed to provide subscales of sadness ($\alpha = 0.92$), anger ($\alpha = 0.90$), anxiety ($\alpha = 0.93$), and happiness ($\alpha = 0.93$) (with the four happiness items reverse scored). A principal-axis factor analysis indicated that the four affect scores formed a

single factor, which is similar to Leary et al.'s (2007) negative affect. Self-compassionate attitude (SCA) was assessed with six items reflecting the definition of self-compassion with inclusion of the body (Berry et al. 2010; Neff 2003b): bodily self-acceptance (i.e., "accepting of my body"), mindful awareness of self (i.e., "in touch with my own needs," "connected with my emotions," "calm"), kindness (i.e., "kind"), and common humanity (i.e., "connected with others"). The participants rated each attitude item on the same seven-point Likert-type scale used for the negative affect items, which was summed to yield a total attitude score (α = 0.85). Principal component factor analysis indicated that a single factor accounted for 58 % of the variance of the items. The eigenvalue for the first component was 3.5, and the remaining components were all less than one. So, these six items were summed to provide a SCA score.

Data Analyses

All data were analyzed using the SPSS statistical package (version 21). Baseline depression, anxiety, and stress scores were log transformed due to their skewed distribution prior to bivariate and multivariate analyses. Background demographic data and questionnaires were examined via *t* tests and chi-square analysis to investigate any pre-existing differences between control and self-compassionate writing groups. Pearson's correlations were calculated between continuous variables to examine associations between negative affect and attitude scores. Multivariate analyses of covariance were conducted to examine the effect of writing condition upon these negative affect and self-compassionate attitude outcomes, and to assess the possible moderating effect of baseline self-compassion, controlling for relevant covariates. Critical alpha for all analyses was 0.05.

Results

Demographic and medical characteristics of the sample are given in Table 1. The overall average age of participants was 54.55 years (SD 9.79), with a range from 25 to 81 years. Chi-square analyses revealed significant differences between the control and experimental groups in education levels (control group was more educated), radiation treatment (control group was less likely to have had radiation treatment), and a non-significant trend for hormone treatment (control group was less likely to be using hormonal medication). Regarding psychological variables, there were no differences between groups pre-writing in terms of self-compassion, body image, or body appreciation. Overall, the women had a moderate level of self-compassion prior to undertaking the writing task (SCS moderate range 2.5–3.5). While there is no clinical cut-off on the BIS for body image disturbance, the average score in this study was above 10 (which is a probable indicator of body image dissatisfaction; Hopwood et al. 2000). Furthermore, 28.3 % of women scored within the clinical range for depression, 18.9 % for anxiety, and 21.6 % for stress (Lovibond and Lovibond 1995). Further, the *t* tests indicated a marginal between-group difference in baseline depression levels, with the intervention group displaying higher overall scores. Consequently, education, radiation treatment, hormonal treatment, and depression were entered as covariates in multivariate analyses.

Pearson's correlations between pre-writing psychological distress, age, negative affect, and self-compassionate attitude variables were all in the expected direction (see Table 2). In particular, negative affect was positively correlated with psychological distress and body image disturbance, as well as negatively correlated with age and self-compassion, self-compassionate attitude, and body appreciation. Self-compassionate attitude was positively correlated with self-compassion, body appreciation, and age, as well as negatively correlated with psychological distress and body image disturbance.

Multivariate analysis of covariance (MANCOVA) with negative affect and self-compassionate attitude as outcomes, controlling for pre-writing levels of these variables, and the identified covariates (education, radiotherapy, current hormone use, and baseline depression) revealed an overall main effect for condition, Wilks' $\lambda = 092$, $F(2, 104) = 4.70$, $p = 0.01$, and $\eta_p^2 = 0.08$. Univariate tests revealed significant effects in the predicted direction for negative affect, $F(1,105) = 8.50$, $p = 0.01$, and $\eta_p^2 = 0.08$, with the control group experiencing significantly more negative affect post-writing than individuals in the experimental group, when accounting for pre-writing levels of negative affect (see Table 3). Likewise, univariate tests revealed an effect in the predicted direction for self-compassionate attitude, $F(1, 105) = 4.87$, $p = 0.03$, and $\eta_p^2 = 0.05$, with post-writing scores significantly greater in the experimental group (whose participants experienced an increase in self-compassionate attitude) following writing, than the control group (see Table 3). Estimated treatment effect sizes (Cohen's *d* based on the adjusted means and their standard errors) for negative affect was 0.38 (medium effect size), and self-compassionate attitude was 0.26 (small effect size). No significant interaction effect was evident for baseline levels of self-compassion on the treatment condition, Wilks' $\lambda = 0.99$, $F(2, 108) = 0.28$, and $p = 0.76$.

Discussion

This study is the first of its kind to evaluate the effects of self-compassionate writing for women who have experienced bodily alteration due to breast cancer treatment. When exposed to a memory of a distressing event related to body image, women

Table 1 Demographic, medical history, and baseline psychological characteristics of the sample by condition

Variable	Total group (N = 142–152)[a]	Experimental (n = 78–84)[a]	Control (n = 64–68)[a]	p value
Age mean—years (SD)	54.55 (9.79)	54.93 (9.85)	54.09 (9.78)	0.615
Marital status n (%)				0.739
Single/divorced/widowed	37 (24.5 %)	21 (20.5 %)	16 (18.7 %)	
Married	114 (75.5 %)	62 (79.5 %)	52 (81.3 %)	
Country of birth n (%)				0.306
Australia	121 (80.1 %)	67 (80.7 %)	54 (79.4 %)	
UK/Europe	20 (13.3 %)	12 (14.5 %)	8 (11.7 %)	
Other	10 (6.6 %)	4 (4.8 %)	6 (8.9 %)	
Education n (%)				0.024*
High school or less	35 (23.3 %)	26 (31.3 %)	9 (13.4 %)	
Vocational	24 (16.0 %)	11 (13.3 %)	13 (19.4 %)	
Some tertiary	20 (13.3 %)	10 (12.0 %)	10 (14.9 %)	
Tertiary or above	71 (47.4 %)	36 (43.4 %)	35 (52.3 %)	
Treatment n (%)				
Surgery	151 (100 %)	83 (100 %)	68 (100 %)	1.000
Chemotherapy	107 (71.3 %)	59 (75.6 %)	48 (75.0 %)	0.854
Radiation	101 (66.9 %)	61 (78.2 %)	40 (62.5 %)	0.043*
Hormone	102 (67.5 %)	54 (69.2 %)	48 (75.0 %)	0.474
Reconstruction	27 (27.3 %)	17 (21.8 %)	10 (15.6 %)	0.452
Not using hormones currently	81 (54.0 %)	50 (64.1 %)	31 (48.4 %)	0.089
Time since treatment completion n (%)				0.645
Less than 1 year	17 (11.5 %)	9 (11.5 %)	8 (12.5 %)	
1–2 years	19 (12.8 %)	8 (10.3 %)	11 (17.2 %)	
2–3 years	21 (14.2 %)	10 (12.8 %)	11 (17.2 %)	
3–4 years	43 (29.1 %)	26 (33.3 %)	17 (26.6 %)	
5 or more years	48 (32.4 %)	28 (35.9 %)	20 (31.3 %)	
Psychological baseline variables (n)				
Depression	0.5 (151)	0.5 (83)	0.4 (68)	0.067
Anxiety	0.3 (151)	0.3 (83)	0.2 (68)	0.109
Stress	0.7 (151)	0.7 (83)	0.7 (68)	0.587
Self-compassion	3.3 (148)	3.3 (82)	3.4 (66)	0.744
Body image	10.3 (151)	10.5 (83)	10.2 (68)	0.809
Body appreciation	3.7 (151)	3.7 (83)	3.7 (68)	0.747

*$p < 0.05$

[a] The sample size varied because data completeness differed for variables

who were given self-compassion-focused writing prompts displayed less negative affect and greater self-compassionate attitude, when compared with post-writing responses of women who were undertaking the non-structured writing task that was not focused specifically on self-compassion.

These results indicate that the self-compassionate writing task has had a protective effect regarding negative affect for the women assigned to the experimental study condition. In comparison, for women in the control condition, the experience of recalling and writing about a difficult body image-related memory in an unstructured way has led to them experiencing increased negative affect. The protective effect of the self-compassionate writing intervention regarding negative affect is consistent with prior non-oncology based research (Leary et al. 2007) using a self-compassion induction approach, and also with self-compassion theory in general (Gilbert 2009; Neff 2003a, b). Unsurprisingly, women in the control condition (unstructured writing) experienced an immediate increase in negative affect compared to baseline scores, and this is an expected after-effect associated with writing about distressing events (Pennebaker and Beall 1986; Smyth 1998). However, negative affect was essentially stable in women who wrote using self-compassionate prompts, and significantly lower than the levels of negative affect experienced by those who wrote

Table 2 Pearson's correlations between baseline characteristics and pre-intervention cognitive and affective responses

	1	2	3	4	5	6	7	8	9
1. Age	1	−0.121	−0.091	−0.092	−0.353**	0.436**	0.332**	−0.183	0.266**
2. Depression		1	0.611**	0.674**	0.385**	−0.434**	−0.613**	0.603**	−0.524**
3. Anxiety			1	0.625**	0.281**	−0.262**	−0.408**	0.423**	−0.285**
4. Stress				1	0.349**	−0.316**	−0.526**	0.461**	−0.420**
5. Body image disturbance					1	−0.542**	−0.449**	0.331**	−0.433**
6. Body appreciation						1	0.592**	−0.551**	0.566**
7. Self-compassion							1	−0.512**	0.638**
8. Negative affect								1	−0.655**
9. Self-compassionate attitude									1

*$p < 0.05$, **$p < 0.01$ (two-tailed)

without such prompts. It is also consistent with previous research which found that self-compassionate writing was associated with less negative affect than unstructured expressive writing, both immediately and after a 2-week follow-up period (Johnson and O'Brien 2013). In that study, less intense negative affect was not associated with any decrease in effectiveness, with compassionate writing participants exhibiting significantly reduced depressive symptoms and shame proneness than comparison groups (Johnson and O'Brien 2013). Such results provide further evidence that self-compassion may assist in regulation of negative affect when dealing with various difficult situations, such as medical problems (Terry and Leary 2011; Terry et al. 2013). Of note is the stability of negative affect in the self-compassionate writing group reported immediately after exposure to a distressing memory, in contrast to the control group's negative affect, which increased substantially. This occurred without the use of additional relaxation techniques, body image patient resource information, or any explicit teaching of coping skill approaches, which are typically offered in cancer survivor support programs to address body image concerns (Fingeret et al. 2014). As such, a self-compassion-based writing activity may have the potential to strengthen psychological well-being by limiting the tendency of negative events to activate one's threat system (Johnson and O'Brien 2013).

As predicted, women in the self-compassionate writing condition reported increased thoughts and perspectives associated with a self-compassionate outlook, compared with those who used unstructured writing. A self-compassionate attitude appears to have been activated by writing about one's experiences according to related prompts. In contrast, the control group participants experienced a small decrease in self-compassionate outlook after writing about their difficult body image experience. Although this result was statistically significant, its clinical significance is unknown at this stage. The present study only provides a glimpse of the potential role of this attitude change in the short term, but needs to be considered with other research, in which self-compassion-based interventions appear to change not only women's attitudes but also, potentially, the foundations upon which their attitudes rest (Albertson et al. 2014). Attitudes and mindsets can be seen as cognitive operations that are used by humans to interpret information, and thus influence subsequent affect and behavior (Freitas et al. 2004; Gollwitzer et al. 1990). Furthermore, congruent attitudes and mindsets are being viewed as the underlying processes which need to be activated, in order to help support the utilization of any related self-help

Table 3 Intervention effects of condition upon two outcome factors

	Pre-intervention *M* (SD)	Post-intervention *M* (SD) (adjusted)	*F*(1, 105)	Mean square	95 % CI	*p* value	*d*[a]
Negative affect							
Experimental	37.42 (14.87)	36.80 (17.47)	8.471	1473.93	33.73–40.23	0.004	0.38
Control	35.66 (13.79)	44.28 (21.23)			40.62–47.94		
SC attitude[b]							
Experimental	29.34 (5.73)	30.69 (6.51)	4.896	65.38	29.74–31.63	0.029	0.26
Control	29.57 (5.17)	29.11 (5.78)			28.10–30.12		

[a] Cohen's *d*, based on the Time 2 means, adjusted for the Time 1 measures and other covariates (education, radiotherapy, current hormone use, baseline depression)

[b] Self-compassionate attitude (SC attitude)

skills which have been externally taught (Yeager and Dweck 2012). It is possible that an increased self-compassionate attitude could be used to enhance a self-compassionate coping style (Johnson and O'Brien 2013), with adoption of a self-compassionate personal narrative to one's situation, but this requires further research. Common problematic coping strategies found in breast cancer patients may include avoidance, disengagement, and self-blame (Malik and Kiran 2013), with related cognitions contributing to an individual's distress. Such a cycle might be broken by directly practicing self-compassion through activities such as meditation, or by holding more self-compassionate background attitudes (Johnson and O'Brien 2013). So, adoption and enhancement of a self-compassionate outlook may assist in the reduction of ineffective approaches in relation to the many difficulties faced by survivors, including body image disturbance. It is a noteworthy issue as appearance-related self-compassion has been associated with healthier body related affect, cognitions, and behaviors among undergraduate populations (Breines et al. 2014), hence, justifying further investigation into potential benefits for cancer survivors.

Unexpectedly, we found no significant moderating effect of baseline levels of self-compassion on the effect of the intervention, with all women, irrespective of their pre-intervention levels of self-compassion, benefitting equally from exposure to the self-compassionate intervention. Prior work (Leary et al. 2007) has found that self-compassion induction may assist in perceptions of similarity to others for those who are initially low in self-compassion, by enhancing these individuals' level of "common humanity." A key feature of "common humanity" is the understanding that one is not alone in the experience of difficulty, and that all people experience painful circumstances or suffering at some time during their life (Neff 2003a, b). However, breast cancer survivors may be more aware of a common experience leading from diagnosis, treatment, and bodily loss than the general population, particularly in light of the extensive network of community support services available to these women. Therefore, membership of a consumer organization, in itself, may have the potential for a moderating effect on the common humanity aspect of the self-compassionate intervention. A different result may have been obtained if the participants were not already pre-existing members of a support network, but this requires further investigation.

Given the relatively brief nature of the intervention and the multifaceted nature of body image distress, the exact mechanism of change cannot be clearly established by this study. There are suggestions that self-compassion may mediate reactions to stressful situations by deactivating the biological "threat system" and activating the biological "self-soothing system" (Gilbert 2005, 2009; Gilbert and Irons 2005). Preliminary evidence suggests that self-compassion-based mediation may be present in this process with cancer survivors (Przezdziecki et al. 2013) and in medically well populations (Wasylkiw et al. 2012); however, longitudinal data are needed to verify this proposed mechanism. The findings of this study, along with the confirmed link between self-compassion and psychopathology (MacBeth and Gumley 2012), suggest that self-compassionate approaches show potential as a possible self-soothing mechanism when faced with difficult personal circumstances or recollections, and furthermore, could also act as an ongoing enhancer of personal coping in any planned exposure-based therapies for cancer survivors or non-oncology populations. This may be particularly helpful for individuals who find the "observation" skill of mindfulness problematic due to habitual misjudgment or hypervigilance (Prowse et al. 2013). Other research suggests that developing mindfulness and self-compassion appears more promising than developing mindfulness alone (Mantzios and Wilson 2015), and therefore, a self-compassionate writing intervention may be a useful adjunct to existing mindfulness programs.

Furthermore, this self-compassion-based writing intervention shows elements that are in common with Acceptance and Commitment Therapy (ACT). ACT applies mindfulness and acceptance processes, as well as commitment and behavior change processes in the creation of psychological flexibility (Hayes et al. 2006). The ACT model of therapeutic change, also known as the Hexaflex, is based upon the following six interactive processes: present moment "here and now," personal values, action, self-as-context, defusion, and acceptance-openness (Levin and Hayes 2009; Hayes et al. 2012). These processes lead to a core of psychological flexibility, by which ACT aims to assist the individual to live a rich and meaningful life amidst the suffering which comes to all humans (Wilson and Murrell 2004). The Hexaflex has been described as inherently embodying compassion through elements which enhance the willingness to experience difficult emotions, to mindfully observe distressing self-evaluative thoughts without dominating one's state of mind, to engage more fully in life's pursuits with self-kindness, and to flexibly shift one's perspective to a broader sense of self (Hayes et al., 2006; Dahl et al. 2009; Neff and Tirch 2013). Hence, ACT practitioners may be able to broaden their therapeutic repertoire by targeting the process of self-compassion more directly (Neff and Tirch 2013) through this self-compassion writing intervention.

In considering the findings of this study, potential limitations also need to be considered. Induction of a self-compassionate attitude appears to have an immediate effect when faced with a distressing or difficult personal situation; however, whether the participant's actual level of self-compassion was changed is unable to be ascertained. Given the exploratory nature of this study, longer-term follow-up was not conducted after the participants had completed their immediate post-writing activity questionnaire, so it is not

possible to establish the duration of the observed affective and attitude changes. Furthermore, use of a larger sample would allow greater understanding of other potential contributing key features such as time since treatment, type of surgery used, presence of a partner, and partner's attitude toward the participant's body. An exploration of different positive features and attitudes, such as body appreciation, could also contribute further knowledge regarding well-being in terms of body image. These would be worthwhile future endeavors using methodologies with greater reach, and ease of use, such as online applications. Other existing evidence suggests that the benefits of self-compassion may arise quite rapidly after even brief intervention (Adams and Leary 2007) or from self-guided home study (Albertson et al. 2014). Furthermore, such effects appear to be maintained over time (Albertson et al. 2014; Neff and Germer 2013) and may be cumulative depending on an individual's practice (Neff and Germer 2013). Hence, the activity is likely to be most beneficial when placed within a context of regular practice or skill building, and this would also be an area for future investigation. The participants in this study were self-selected members of an Australian breast cancer consumer organization, who were all English speaking and computer literate. These women were mostly Australian born, partnered, and had some tertiary education; therefore, results may not be generalizable to other survivor populations. The question of generalizability can be further examined by replication of the study among other groups, and is a potential area for future research.

In conclusion, these findings provide preliminary evidence to support the use of self-compassionate-focused writing as a means to assist women in managing breast cancer-related body image changes. As this type of self-compassionate writing intervention is self-administered and brief, it has the potential for wide reach due to the simplicity of the approach, and would readily translate to clinical applications, helping to meet the acknowledged prevention and treatment goal of minimizing body image disturbance in women with breast cancer (Eccles 2013; Harrison et al. 2009; Moorey 2013). This type of writing approach could also be used to complement existing information and skill-based cancer survivor programs. As reminders of bodily changes following breast cancer can readily occur, such as through routine physical examination of the body, medical follow-up appointments, questions from others, or by recollected difficult memories, an accessible and easy-to-use intervention, such as self-compassionate writing, may provide an ongoing resource to which women can turn to address these concerns. This study provides preliminary support for the viability and efficacy of a focused writing activity using self-compassionate prompts that produces immediate results for survivors faced with post-treatment body image difficulties. Furthermore, the self-compassion-focused writing activity could be a useful adjunct to existing mindfulness and ACT interventions to assist with the management of body image disturbance due to medical treatment. In addition, this model could be easily modified for potential application in other health care contexts, educational settings, exercise programs, or counseling services, where difficulties related to body image may arise.

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Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institution: Macquarie University Human Research Ethics Committee (Medical Sciences), Reference No. 5201200298, title "Short Term Self-Compassion Exercise for Body Image in Breast Cancer Survivors."

Informed Consent Informed consent was obtained from all individual participants included in the study.

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5.2. Addendum to Empirical Study II

A particular finding of interest in Study II was the effect of different writing conditions used for participants, especially the increase in negative affect obtained for participants in the expressive writing condition. It had been decided to compare self-compassion based writing against what may be considered the usual written intervention used in psychology, which is expressive writing as developed by Pennebaker (Pennebaker, 1997). This approach was taken in research conducted by Leary and colleagues, who also used expressive writing as a control condition (Leary, et al., 2007), and upon which the current study was based. Furthermore, Leary found that participants (college students) who had undertaken a self-compassionate perspective to their writing experienced significantly less negative affect than participants who undertook expressive writing. However, in Study II of this thesis, different results were observed to that of Leary. It was found that participants who undertook self-compassion based writing experienced a stability of their negative affect, compared with those who undertook expressive writing who experienced an increase of negative affect immediately after writing. The reason for this effect is not clear, but may be due to different populations being studied (i.e. college students vs. breast cancer survivors), and the nature of the writing (i.e. generalised distressing events vs. a specific distressing topic – bodily alteration). As such, the obtained results were difficult to anticipate, as no prior studies could be located that investigated the effects self-compassion based writing about bodily changes in cancer survivor populations.

Therefore, exploration of different writing conditions is a fruitful area for future research, possibly investigating a broader range of comparison conditions such as: wait list, neutral topics (i.e. non-cancer writing), factual writing (writing about the facts of one's cancer experience rather than emotions), positive reframing, and use of different induction conditions (e.g. self-esteem vs. self-compassion). This would allow a greater understanding of the effects of self-compassionate writing as compared with other approaches.

A major limitation of Study II, was the extremely brief time-frame used to record affective responses (i.e. participants were asked to rate their emotional responses *immediately* after writing), with no further follow up of possible changes to affective states. It is quite possible that any negative affective changes were extremely brief, and that participants' emotional states returned to baseline (pre-writing levels) very quickly. The short time-frame of Study II was acknowledged as a limitation in the subsequent publication, and therefore the following studies (Study III and Study IV) incorporated a different time-frame which would be more conducive to obtaining detailed results.

6. Chapter Six: Empirical Study III

6.1. Empirical Study III

Title: My Changed Body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer

This chapter reports on the translation from a proof-of-concept trial of the paper-based self-compassionate writing activity to a more sustainable and user friendly online format. Backed by self-compassion theory, and results from the earlier studies showing both a role for self-compassion in body image disturbance with breast cancer survivors, and evidence of a beneficial short term effect upon affect and attitude, it was decided to translate this approach to a more convenient online format that would be acceptable to consumers. An advantage of an online format is the ability to confirm the presumed mechanism, i.e. that through being self-compassionate in writing subsequent intervention effects may ensue. A further benefit of translation of this activity would be to obtain health professional feedback as to the appropriateness of the activity for their clientele.

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Short communication

My Changed Body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer

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ABSTRACT

Objective: To assess consumer and health professional user acceptability of a web-based self-compassion writing activity to minimize psychological distress related to the negative impact of breast cancer on body image.
Methods: "My Changed Body" is a web-based writing activity that combines expressive writing with a self-compassionate approach that focuses on cancer-related adverse body image alterations. Breast cancer survivors ($n = 15$) and health professionals ($n = 20$) provided feedback via a survey regarding the appearance, organization and content of the website and writing activity.
Results: Both breast cancer survivors and health professionals rated the website highly in terms of design, layout and content. Participants commented positively on the website's clear wording, appealing design and ease of navigation. Suggestions for improving the website included simplifying the instructions for the writing activity and allowing participants' writing to be saved.
Conclusion: Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings for the overall impression of the website.
Practice implications: Self-compassion based writing interventions can be translated to a web-based self-administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers and health professionals.

1. Introduction

Breast cancer treatment can bring negative body changes, poor adjustment and ongoing psychological distress [1,2]. Central to this is the reality of change and loss regarding certain aspects of a woman's appearance and function. In addition, some women develop lymphedema as a consequence of their treatment, characterized by severe swelling of the affected area, resulting in the need to wear visible compression garments [3], and consequently, further challenging the woman's body image [4–6]. The Cash theoretical model suggests that adverse appearance changes will increase the discrepancy between an individual's ideal and perceived body image, making her more likely to experience body image-related distress [7]. Unfortunately, body image problems are not always adequately recognized or addressed, with evidence of unmet needs [1,2,7–9].

Many existing interventions designed to address body image difficulties after breast cancer treatment focus on couple or group formats within clinic settings [7], and have limited effectiveness for younger women [10]. Such approaches can be limited by demand for staff, cost, and the need to attend in-person, potentially resulting in poor accessibility [11]. There is a need for more interventions addressing body image distress that employ novel approaches, such as writing activities [7], that can be delivered in an individual, accessible format [12,13] which may especially benefit those with an increased reliance on online materials [14].

Expressive, unstructured writing has been used in the field of psychology [15] and oncology [16] to assist individuals who are experiencing distress. Writing interventions are a simple and inexpensive way to provide support, with evidence of physical and psychological benefits [15–17]. To date, unstructured writing has not been used to address cancer-related body image disturbances,

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Fig. 1. Screenshot of the My Changed Body website 'Welcome' page.

possibly as despite its many strengths, limited effectiveness in addressing body image concerns has been demonstrated by unstructured expressive writing in a variety of contexts [18–22]. Alternatively, self-compassion based approaches may be uniquely placed to address the difficulties associated with body image disturbance [23]. Thus, a need to investigate this possibility in the cancer context is indicated.

Self-compassion is a promising approach to assist with difficult life experiences, and has been linked to lower psychopathology [24]. It relates to a woman's ability to approach herself with kindness, a sense of mindful awareness about her circumstances, within a context of common humanity (i.e., knowing difficulties and loss are normal part of human life) [25]. A woman who is higher in self-compassion is likely to display less self-criticism, a more accurate appraisal of her losses, as well as the ability to place her problems within the broader context of life [25,26]. Furthermore, there is evidence that self-compassion is associated with decreased body image disturbance and psychological distress in breast cancer survivors [2], therefore making it a potentially valuable aspect to address.

In sum, combining unstructured writing with self-compassion-based prompts may provide dual benefits of decreasing distress and body image disturbance related to breast cancer treatment and its outcomes in a single intervention.

2. Methods

2.1. My Changed Body intervention development

2.1.1. Website and content development

My Changed Body is a web-based writing intervention designed to address body image concerns arising from breast cancer and lymphedema. It entails a self-paced writing activity that is estimated to take approximately 30 min to complete. The website provides "Welcome" page user instructions (Fig. 1) followed by information about the developers of the website. The remaining section comprises the intervention writing activity instructions, prompts and writing text boxes (Fig. 2). Six writing prompts are provided: (1) an introductory unstructured writing section where individuals write about a negative body image experience according to a modified Pennebaker [15] writing prompt; (2) treatment of one's body with kindness; (3) kind advice to oneself; (4) connection with others who experience difficulties with body image; (5) awareness of one's circumstances and reactions in a broader context; and, (6) a self-compassionate letter to the writer that acts as a summary of the most salient points of self-compassion as applied to one's own situation. Thus, the intervention user addresses self-kindness, common humanity and mindful awareness, as outlined by self-compassion research [25].

2.1.2. Consultation with consumers and health care professionals and assessment of user acceptability

Following website development, consumers (breast cancer survivors) and health professionals experienced in breast cancer were given access to the website and provided feedback via an online survey regarding their perceptions of the website. Consumers and health professionals were recruited to ensure that we gathered perspectives from the population of women who would be using the intervention, as well as from health professionals who would be referring women to the intervention. Health professionals were recruited from the researchers' networks via an online advertisement. Consumers were recruited via the consumer-based breast cancer organization, the Breast Cancer Network Australia.

Participants were sent a link to the study website and asked to interact with all web pages before completing the online user

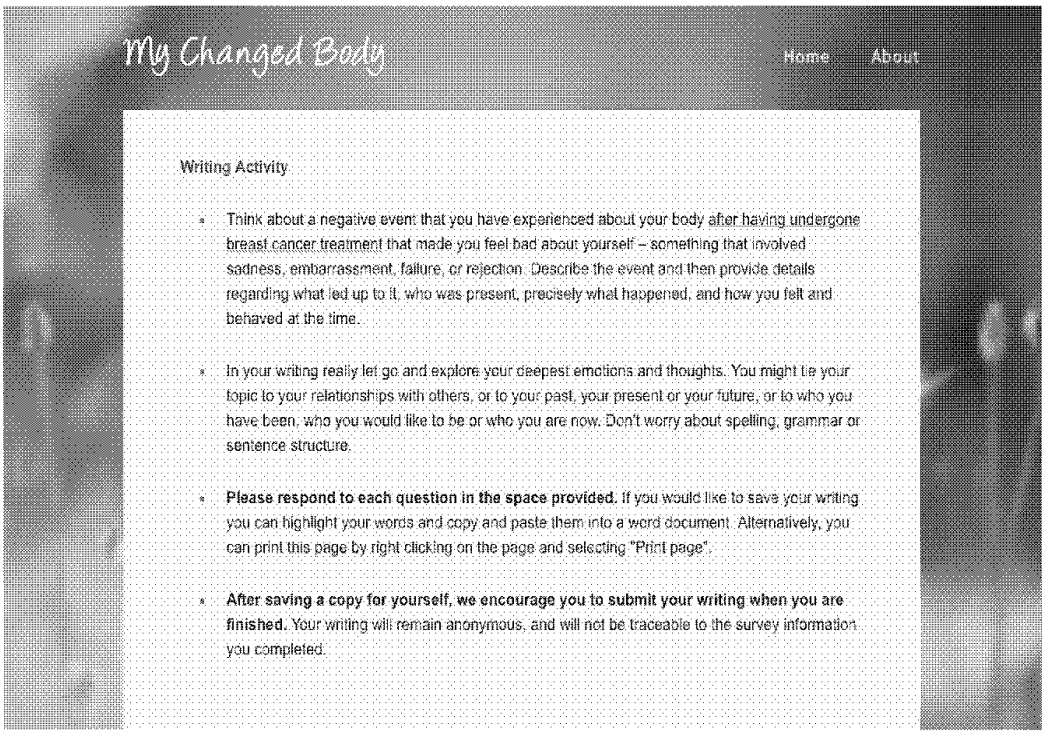

Fig. 2. Screenshot of the My Changed Body website writing activity page.

acceptability survey (both activities were estimated to take 20 min to complete). Feedback was provided for 18 statements regarding the overall impression of the website (e.g., "The website appeals to me"), website layout and design (e.g., "The website is easy to navigate") and website information and content (e.g., "The information contained in the website is clear") on a 5-point Likert-type scale (1 "strongly disagree" to 5 "strongly agree"). Demographic information and self-rated experience with websites was also collected, as well as providing free text sections for qualitative comments. In addition, the health professional survey collected the area of professional expertise, while the consumer survey collected information on the participants' breast cancer diagnosis, treatment and diagnosis of lymphedema.

3. Results

A total of 20 consumers and 15 health professionals participated in this study. Participant characteristics are displayed in Table 1. The mean rating for the overall impression of the website (5 items; $\alpha = 0.81$) was 3.97 (SD = 0.78) for consumers and 3.96 (SD = 0.69) for health professionals. The mean rating for the website layout and design (7 items; $\alpha = 0.95$) was 4.05 (SD = 0.69) for consumers and 3.98 (SD = 0.57) for health professionals. The mean rating for the website information and content (6 items; $\alpha = 0.89$) was 3.96 (SD = 0.81) for consumers and 3.86 (SD = 0.56) for health professionals. A series of *t*-tests indicated that there were no significant differences between consumers' and health professionals' ratings of the website user acceptability ($p = 0.100–0.900$).

Thematic analysis was used to analyze the qualitative feedback provided by participants (Table 2). To achieve inter-rater agreement two researchers first independently coded participants' responses, and then together discussed and refined identified themes.

Table 1
Participant characteristics.

Consumers ($n = 20$)	*M* (SD) or %
Age	58.22 (9.01)
Breast cancer diagnosis	
Early breast cancer	65%
Secondary breast cancer	0%
Ductal carcinoma in situ (DCIS)	30%
Lobular carcinoma in situ (LCIS)	5%
Breast cancer treatment	
Surgery	96%
Chemotherapy	57%
Radiation therapy	78%
Hormonal treatments	91%
Breast reconstruction surgery	30%
Lymphoedema diagnosis	22%
Level of experience using online activities provided through a website	
None or very low level of experience	0%
Low level of experience	9%
Neutral – neither high nor low level of experience	65%
High level of experience	26%
Very high level of experience	0%
Health Professionals ($n = 15$)	
Age	47.07 (8.63)
Number of years working in oncology	12.93 (8.06)
Occupation	
Nursing	27%
Physiotherapy	20%
Occupational therapy	20%
Psychology	7%
Other	26%
Level of experience using online activities provided through a website	
None or very low level of experience	7%
Low level of experience	0%
Neutral – Neither high nor low level of experience	33%
High level of experience	53%
Very high level of experience	7%

Table 2
User acceptability themes and supporting quotations from thematic analysis of qualitative feedback.

Theme	Supporting quotations from health professionals (HP) and consumers (C)	Response to feedback
Comments on what participants liked about the website.		
Clear wording	HP The text was clear. C Straightforward explanations.	No changes.
Appealing design	HP I really liked the color scheme and design – felt really warm and inviting. C Appealing, user friendly and a useful platform to express ideas, thoughts, emotions encountered on the BC journey.	No changes.
Easy to navigate	HP The website is easy to navigate and not too cluttered or busy looking. C I liked that the website was simple and easy to navigate.	No changes.
Participants' suggestions for improvements to the website.		
Allow writing to be saved.	HP: It would be so great if after the women completed the sections of the writing task, 'print' button would be available, so they can print/save their answers for later use. C: Also I was confused by the message that the text written wouldn't be saved . . . However, it does seem somewhat pointless for people to write/type/spend time on that for the words not to be considered important.	Option provided to participants to print their writing and/or save it to their desktop computer.
Simplify the instructions	HP: I found the instructions somewhat wordy and confusing. C: The instructions are a bit wordy.	Instructions simplified and bullet points were used to break up the text to make it easier to read.
Negative focus	HP: I found it confronting being asked to write about negative experiences upfront for both the non-lymphedema and lymphedema clients. C: I found the early and repeated emphasis on negative feelings really off putting.	Invitations to participate in the pilot evaluation study will specify that the writing intervention includes discussing "negative events" to ensure that women have accurate expectations of what participation will involve.

4. Discussion and conclusion

4.1. Discussion

My Changed Body is a theoretically-based [7,15,16] web-based writing intervention developed to assist breast cancer survivors with body image disturbance resulting from cancer treatment. Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings. Participants reported favorably on the website's clear wording, appealing design and ease of navigation. Suggestions were made by study participants for improving the website, including simplifying the instructions and allowing participants to save or print their writing.

4.2. Limitations

These findings provide preliminary support for the use of this body image-focused intervention. However, a few limitations should be noted. Two participants expressed concerns about the principally negative focus of the writing activity. It is possible that they were expecting positively-focused cognitive-behavioral self-esteem enhancing activities [7]. To ensure that participants have accurate expectations of the My Changed Body intervention, information about the activity has been revised to include the discussion of negative events and body image concerns. Body image disturbance, self-compassion and distress were not measured in this study, so it is not possible to determine if these factors influenced participants' feedback. Finally, consumers were recruited from an online organization; therefore, women in this study may be more experienced with websites and more motivated to participate in research compared with the general breast cancer population.

4.3. Conclusion

Results suggest a moderate to high level of user acceptability for the overall impression of the website as well as layout, design and content. A randomized controlled evaluation study is now underway to assess the impact of the intervention on self-compassion and body image disturbance in breast cancer survivors.

4.4. Practice implications

Self-compassion based writing interventions can be translated to a web-based, self administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers. This approach may also be considered for other situations where psychological distress, particularly for body image, is problematic and a self-paced, non-therapist delivered intervention is indicated.

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Conflict of interest statement

All authors declare no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institution: Macquarie University Human Research Ethics Committee (Medical Sciences), Reference No. 5201401083, Title "Online Self-Compassion Activity for Body Image in Breast Cancer Survivors".

Informed consent: Informed consent was obtained from all individual participants included in the study.

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7. Chapter Seven: Empirical Study IV

7.1. Empirical Study IV

This chapter reports on the findings of Study IV which aimed to evaluate the impact of the online version of the My Changed Body intervention on breast cancer survivor affect and self-compassion.

Given the earlier results of Study II, where control (expressive writing) participants appeared to display no benefit from their intervention, and, the feedback received from Study III where the intervention was found to have too much of negative focus and confusing instructions, it was decided to make further refinements to Study IV to eliminate these problems.

Refinements were undertaken in three main areas. Firstly, better targeting of participants was undertaken by improved invitations and wording, as to the structure and purpose of the study. This was done to avoid recruitment of participants for whom the study may not have been relevant. Secondly, a standardized measure of negative affect (PANAS) was utilised for improved accuracy in Study IV, rather than the brief, simple measure of affect used in Study II. Lastly, it was decided to use a longer study time-frame to allow more comprehensive participant follow up, thus to establish a truer picture of the intervention's impact upon affect over time. At the conclusion of this study, it appeared that these improvements enhanced the accuracy of the findings obtained, with results indicating neither intervention nor control groups experienced any increase in negative affect (as would be expected according to theoretical understanding and research evidence, please see Hypotheses section in Study IV for further detail).

This investigation was undertaken to explore whether levels of negative affect would change over a short to medium time period following an online intervention. A longer time frame and more detailed analysis would allow greater exploration on variables of interest than had occurred in earlier studies. A new focus of Study IV was to explore whether self-compassion levels would change over a short to medium time period following an online intervention. Thus both negative affect and trait self-compassion were measured at baseline, and then at 1-week, 1-month and 3-months post intervention. The potential moderating effect of specific body image variables (such as self-evaluative salience) on the effect of the writing intervention was also explored.

Title: My Changed Body: An investigation of the effect of a brief online self-compassion writing activity on negative affect and self-compassion, for breast cancer survivors.

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Abstract

Introduction: Body image-related concerns of breast cancer survivors following treatment are not always adequately addressed. Self-compassion has been linked to decreased psychological distress. This randomised controlled trial evaluated the impact of a brief online self-compassionate writing activity regarding adverse bodily changes upon negative affect, and self-compassion. The potential moderating effect of age and self-evaluative salience was also investigated.

Methods: Female breast cancer survivors (N=206) completed self-report baseline measures (including PANAS, Self-Compassion Scale). Participants were then randomly allocated to either writing with self-compassionate prompts (Intervention) or unstructured writing (Control) regarding their experiences of body image difficulties after cancer. Affect and self-compassion were reassessed 1-week, 1-month and 3-months later.

Results: Linear mixed model analyses indicated significant effects for negative affect and self-compassion. A time x condition x age interaction indicated that negative affect decreased from baseline over time for Intervention, but not Control participants. Younger women demonstrated this effect from 1-week onwards, whereas for older women this was evident from 1-month. For self-compassion levels, older Intervention participants experienced a significant increase, whereas younger women experienced no change.

Conclusions: These findings demonstrate that an online structured writing intervention entailing self-compassion based prompts can provide benefit to breast cancer survivors who have experienced body image-related difficulties. A single administration of the intervention resulted in decreased negative affect, which was sustained at 3-months. These findings support the use of this brief, inexpensive writing intervention to address negative affect related to body image in breast cancer survivors, and may be a useful adjunct in the provision of survivorship care.

Keywords: Breast cancer, body image, self-compassion, writing, intervention, online

Background

Breast cancer is the most common malignancy in women worldwide, with an estimated 1.7 million new cases in 2012 (25% of all cancers in women) (Ferlay et al. 2012). With continuing improvements in detection, refinement of existing treatments and gains from new therapies, the numbers of breast cancer survivors are increasing (Ganz & Hahn, 2008; IMS Institute Report 2015). Physical side-effects from breast cancer treatment are complex, and may arise from a number of treatment modalities (i.e., surgery, chemotherapy, radiation therapy, hormonal therapies) (Ganz & Hahn, 2008). Visible side-effects may include loss of part, whole or both breasts and scarring, as well as upper extremity dysfunction, hair loss, and skin discolouration. Furthermore, treatments may trigger early onset menopause with hot flushes, weight gain and changes to body composition (Binkley et al., 2012; Ganz & Hahn, 2008; Kadela-Collins, et al., 2011). Women report being uninformed about the occurrence of some side-effects, such as physical impairment, and experience surprise that such difficulties could remain as part of their lives (Binkley et al., 2012). Given the various adverse effects upon the body, a subset of survivors may experience body image disturbance after breast cancer treatment. Disturbance of body image is a subjective process in which negative feelings, thoughts and behaviours regarding one's body are present, and result in dissatisfaction with oneself (Fingeret, Teo & Epner, 2014; Stokes & Frederick-Rescasino, 2003). Body image difficulties have even been reported for women who undertake risk reducing mastectomies for whom the side-effects of adjuvant treatments are typically absent, as surgery alone is the predominant intervention recommended for this population (Brandberg et al., 2008). In addition, women who choose to undergo breast reconstruction may find themselves facing an extended period of appearance altering procedures, and may discover that even at completion of this surgery that body image difficulties still persist (Chua et al., 2015; Sackey et al. 2010). The impact of these body image changes can also be

more diffuse in their nature, with individuals seeing their own body as a threat to their health and a source of ongoing future discomfort (Lehmann et al., 2015).

Body image concerns appear to be relatively common amongst breast cancer survivors, with up to 50% reporting some degree of body image problems after treatment completion, indicating that a substantial subset of women are likely to be affected (Figueiredo et al., 2004; Fingeret et al., 2014; Fobair et al., 2006). A review by Fingeret and colleagues suggests that body image disturbance is more likely for younger women, and those with higher body mass index (Fingeret et al., 2014). Furthermore, body image disturbance is more common for those women experiencing a greater number of post-treatment complications, and certain types of interventions, for example, greater distress has been found with mastectomy when compared to breast conserving surgeries (Fingeret et al., 2014). Consistent evidence points to a link between body image concerns and higher levels of anxiety, depression, poorer quality of life, and ongoing problems with sexual functioning in breast cancer patients (Bartula & Sherman, 2015; Figueiredo et al., 2004; Fingeret et al., 2014; Paterson et al., 2015). Some researchers conceptualise the experience of post-breast cancer body change as a reaction with pervasive traumatic stress-like symptoms (Frierson et al., 2006), indicating a need for early identification and effective interventions.

A woman's body image, and specifically her personal investment in appearance, is likely to be an important factor underlying psychological distress in these women. Body image generally is a complex, multifaceted construct and reflects many dimensions (Thompson, 2004), including personal perception of one's appearance, bodily function and the specific importance of these facets to the individual. Evidence suggests that female body dissatisfaction may occur throughout adult life as women gradually move away from the societal young, thin ideal as they age (Frederick et al., 2006; Tiggemann, 2004); however, a chronic focus on one's appearance as a discrepancy from an ideal body can bring negative

psychological consequences to women regardless of their age (Engeln & Salk, 2016). Body image dissatisfaction is further explained by Cash's (2011) body image theory which discusses two subcomponents - appearance evaluation (indicating level of satisfaction with one's appearance), and appearance investment (indicating the importance placed upon physical appearance attributes). These subcomponents are regarded as being independent, and highlight the importance of distinguishing satisfaction with appearance from an investment or concern with one's appearance (Thompson, 2004). The diagnosis and treatment of breast cancer can abruptly magnify discrepancies between a woman's body image ideals and her current state, particularly for those who have high levels of appearance investment prior to cancer diagnosis, leading to increased distress (Fingeret et al., 2014). Furthermore, women may minimize expression of body image distress due to shame, embarrassment or guilt (Fingeret et al., 2014), as speaking about one's body can be an intensely personal experience, and so may not be readily brought to the attention of health professionals. Issues such as a need for privacy, adequate time and sensitivity towards the topic have also been reported as factors affecting women's disclosure of body image concerns (National Breast Cancer Centre, 2004). As such, intervention approaches for body image difficulties that do not require direct face to face contact, such as expressive writing interventions, may be an attractive option for this population.

Expressive Writing

Unstructured expressive writing has been used since the 1980's in the general population to assist in coping with difficult events (Baike & Wilhelm, 2005; Smyth, 1998), and more recently, for people undergoing cancer treatment (Merz et al., 2014). Historically, this approach uses quite general writing instructions that ask the individual to choose a traumatic or upsetting experience, and to write freely about their deepest thoughts and

feelings (Pennebaker & Beall, 1986). Such writing is typically unstructured and self-directed, with no further prompting provided. In oncology-specific studies, writing instructions related to cancer have been typically employed (Merz et al., 2014). Although cancer can be considered more of a chronic disease rather than a one-off traumatic experience, unstructured writing interventions about cancer-related thoughts and feelings, similar to the method developed by Pennebaker (Pennebaker & Beall, 1986; Pennebaker & Chung, 2011), have also led to improvements in participant sleep and reported pain, as well as in overall physical and psychological symptoms (Merz et al., 2014). Within a breast cancer-specific population, evidence suggests that a single session of unstructured writing in the home environment can provide benefits in terms of improved mood and reduced depressive symptoms for three months in breast cancer survivors (Henry et al., 2010), with good participant retention and feedback. As such, unstructured expressive writing appears to provide benefit for breast cancer survivors; however, its specific application to address body image disturbance amongst breast cancer survivors has not yet been explored.

Historically, writing about body image difficulties appears to present a more complex picture, compared with writing about more general difficult personal experiences. There have been fewer studies conducted in this area overall, and therefore, less is known about the effectiveness of expressive writing-type intervention approaches. The available evidence regarding interventions entailing writing specifically about body image concerns in the general population is equivocal, with unstructured expressive writing studies mostly reporting no additional benefits from expressive writing compared with that of control conditions (e.g. Earnhardt et al., 2002; Grasso, 2007; Johnston et al., 2010; Stice et al. 2006; Truxillo, 2001), or displaying mixed results (Lafont & Oberle, 2014). It remains unclear as to why individuals with body image disturbance have not experienced greater benefits from unstructured expressive writing, such as that obtained by individuals who write about more general

distressing events (Baike & Wilhelm, 2005). Given the lack of specificity in this regard, a closer examination of possible barriers that may impact self-administered body image-based therapeutic writing interventions is required.

In general, body image disturbance may be particularly difficult to treat given the context of broader social pressures on women regarding their appearance (Choma et al., 2009; Pearson et al. 2012; Rumsey & Harcourt, 2004). Cognitive behavioural therapy (CBT) interventions have a substantive history of being therapeutically administered for body image difficulties, using therapist contact or group formats (Grant & Cash, 1995). However, when CBT skills are adapted as self-administered written activities for body image, these interventions have displayed high rates of attrition and little differentiation in outcome between study conditions (Strachan & Cash, 2002). It has been suggested that interventions, such as disputation of dysfunctional cognitions, may be insufficiently implemented in an independent self-help modality without therapist assistance (Strachan & Cash, 2002). Other research suggests that the task of independently correcting one's negative thoughts or self-beliefs, such as used by CBT, may not be a pleasant experience for the individual, which may then lead to disengagement and high attrition (Geraghty et al., 2010). Self-administered body image interventions may require content that is particularly reinforcing and supportive, which also simultaneously helps users to reduce their distress (Geraghty et al., 2010). Furthermore, the breast cancer survivor, who has experienced additional bodily losses compared to women without a diagnosis, may need to receive even greater support and assistance in independently approaching a body image focussed writing task for an optimal outcome.

In general, unstructured expressive writing may be able to help an individual to construct a narrative for an event that has no existing or coherent organisation, or personal interpretation of impact. It is possible that with a sensitive and deeply personal topic, such as one's own appearance and body, a cohesive narrative may be difficult to construct by oneself.

Or if a narrative does exist, it may not be a particularly helpful one, and additional support to assist with "story-prompting", in which individuals are guided towards new ways of understanding themselves and their situation, may be especially useful (Wilson, 2013), and this may be particularly true for individuals with cancer-related body image difficulties.

Self-compassion

Self-compassion is a relatively new focus of psychological intervention, which has displayed recognised benefits in enhancing psychological wellbeing, reducing negative affect and providing assistance with body image difficulties (Albertson et al., 2014; Leary et al., 2007; Neff, 2003a; Neff, 2003b). Self-compassion has been defined as the ability to be open to one's difficulties with an attitude of warmth and caring, (Neff, 2003a; Neff, 2003b), which inherently involves a sensitivity to one's suffering and a desire to alleviate it (Gilbert, 2010). Neff's conceptualisation of self-compassion involves three distinct yet essential elements; kindness towards the self, *and* mindful awareness of one's painful feelings, *and* a perspective of seeing one's painful experience as part of life's challenges that all people face (Neff, 2003a; Neff, 2003b). Emotion regulation is regarded as a defining characteristic of self-compassion (Neff, Hsieh & Dejitthirat, 2005), and, therefore, would be of particular use in matters related to management of negative affect.

Enhancement of self-compassion may even have greater relevance amongst specific subgroups who face adversity. Aging has been considered to be inherently challenging, and self-compassion may become increasingly important with social losses over time (such as deaths), as well as difficult overall declines in mental and physical health experienced by people as they get older (Allen & Leary, 2014; Phillips & Ferguson, 2013). Specifically, with older adults, self-compassion is associated with increased well-being in later life, and interventions to specifically enhance self-compassion may also improve quality of life in this

age group (Allen et al., 2012). Therefore, self-compassion focused interventions may also be applicable to the specific concerns faced by older adults, such as physical decline, cumulative health problems, bodily aging and changes to appearance (Allen & Leary, 2014; Phillips & Ferguson, 2013; Rakhkovskaya & Holland, 2015).

Evidence is emerging that self-compassion provides benefits for body image and appearance. With general and university student populations, self-compassion has been associated with less appearance contingent self-esteem and body comparison (Homan & Tylka, 2015; Neff & Vonk, 2009). Appearance contingent self-esteem is the tendency to base one's self-worth upon certain standards of appearance being met, whereas body comparison represents a tendency to use others' appearance as a source of self-evaluation regarding one's own appearance (Patrick et al., 2004). Both of these domains reflect evaluative processes, and are factors that have been linked with negative feelings about the body (Homan & Tylka, 2015). Women who highly value their appearance as a source of personal self-worth tend to show lower levels of body appreciation (Homan & Tylka, 2015), an outlook with wider consideration of the body's features, functionality and health, which does not solely focus on one's appearance as a source of worth (Tylka & Wood-Barcalow, 2015). The negative associations between body comparison and body appreciation and appearance contingent self-worth tend to diminish for individuals with relatively high levels of self-compassion, suggesting that self-compassion has a protective effect on a woman's body appreciation (Homan & Tylka, 2015). As such, self-compassion may function as moderator of women's self-evaluative processes regarding body image (Homan & Tylka, 2015). More specifically, self-compassion has demonstrated a moderating effect against psychological distress related to body concerns in women who have experienced actual bodily alteration through breast surgery (Sherman et al., 2016). Therefore, enhancement of self-compassion may have clinical

importance and be a target for psychological intervention (Andrew et al., 2013; Sherman et al., 2016).

Some attempts have been made to increase self-compassion through non-therapist administered psychological interventions. Albertson, et al. (2014) have developed and tested an online self-administered approach to enhancing self-compassion. This was undertaken via a randomised controlled trial (RCT) using a three-week online self-compassion training program. Participants were provided with links to 20 minute meditations via podcasts. The intervention involved daily personal practice of self-compassion meditations, and outcomes were compared to a waitlist control condition. With a multi-generational sample of female participants recruited through internet advertisements and social media, the use of self-compassion meditations raised self-compassion levels and improved a variety of aspects including body image and body related distress compared with the controls, with these effects maintained at three month follow up. Medium to large effect sizes were obtained in this study suggesting that self-compassion may have an important influence on aspects of self-criticism associated with body image distress, and that even brief exposure may be sufficient to impact on behaviour (Albertson et al., 2014). A similar approach has been used with self-generated visualisation to increase self-compassion by McEwan and Gilbert (2016). They used a non-clinical student population to independently engage in online self-compassion imagery exercises over a two week period. The intervention required personal practice of generating images of a compassionate "other" and an ideal compassionate "self". Significant improvements in self-compassion and self-reassurance were obtained at the conclusion of the study which were maintained at six months follow-up (McEwan & Gilbert, 2016). Another approach has been demonstrated by Falconer and colleagues (2014) who used a virtual reality environment, in which female undergraduate participants practiced both giving a compassionate response to another, and experiencing the receipt of a compassionate response

delivered by an avatar. The rehearsal, delivery and receipt of self-compassionate thoughts, feelings and behaviours was shown to specifically reduce self-criticism, improve self-compassion and increase feelings of safety (Falconer, et al., 2014). Such studies demonstrate that the opportunity to compose, elaborate, and apply compassion to one's self, in the absence of direct assistance from a clinically-trained professional, is an effective method in enhancing self-compassion. As with the online and virtual reality approaches, writing is another type of activity or intervention that is typically undertaken independently without therapist input. Given that writing activities have shown some benefit in cancer settings (Merz, 2014), and existing self-compassion activities have shown benefit regarding body image difficulties in other populations (e.g. Albertson et al., 2014), it is possible that an intervention combining both approaches may be particularly beneficial. Both expressive writing and self-compassion activities have produced results when administered without direct therapist input, and therefore, it is possible that a self-administered writing task using a structured self-compassionate perspective may more effectively assist the unique needs of breast cancer survivors with regard to their body image.

Use of self-compassion based writing for body image in cancer survivors

The My Changed Body (MCB) intervention is a self-directed writing activity that employs structured prompts to focus the writer on each aspect of self-compassion: self-kindness, mindful awareness and common humanity (Neff 2003a; Neff 2003b). The approach entails gradual exposure to the concept of self-compassion in the context of body image difficulties, culminating in the user writing a self-compassion based letter to herself (Przezdziecki et al., 2016). Initially devised as a paper-based activity (Przezdziecki & Sherman, 2016), MCB has now been developed in an online format, providing ease of access and diminishing barriers to accessing this intervention (Przezdziecki et al., 2016). A proof of

concept pilot trial conducted with the initial paper-based version of this intervention demonstrated immediate benefits for women receiving the MCB intervention in terms of significantly lower negative affect and higher self-compassionate attitude, compared with those assigned to the expressive writing control condition (Przezdziecki & Sherman, 2016). These data indicate the potential for the MCB self-compassion focused writing approach to provide benefit to breast cancer survivors in the context of body image difficulties.

Hypotheses

The aim of this study was to assess the impact of the online version of the My Changed Body (MCB) intervention on negative affect, body image and self-compassion over a three month period through a randomised controlled trial. That is, a comparison was made between the structured self-compassion focussed MCB writing activity and an active control condition (unstructured expressive writing).

Specifically, it was predicted that negative affect and body image disturbance would decrease for both groups of women undertaking writing activities, consistent with general findings that emotional expression is inversely related to body dissatisfaction (Hayaki et al., 2002), but that the decrease in negative affect and body image disturbance would occur at a faster rate and to a greater extent over time for women allocated to the My Changed Body (MCB) intervention, compared with Control group participants. Since expressive writing generally does not specifically focus on self-compassion, it was further predicted that post-randomisation, women in the MCB self-compassion based intervention group would have significantly higher self-compassion than those allocated to the Control group.

Research has indicated that age is a relevant factor in regard to both body image and self-compassion in breast cancer survivors (Przezdziecki et al., 2013), and therefore is likely to influence outcomes associated with a self-compassion based writing activity focussed on

difficult body image experiences. Age has a negative relationship with body image, and a positive relationship with self-compassion (Przezdziecki et al., 2013, Przezdziecki & Sherman, 2016). Therefore, the relative age group of the breast cancer survivor may also influence specific responses to self-compassion based interventions.

Younger women are likely to be closer to society's body image ideal (Chrisler & Ghiz, 1993), and therefore may experience greater negative affect and distress due to sudden body alteration from breast cancer treatment (Paterson et al., 2015). Furthermore, a younger woman may be unprepared some effects of breast cancer treatment, such as loss of fertility and menopause, and such experiences may not be the norm amongst her age group. Self-compassion has been recognised in the literature as alleviating negative affect and distress (Neff, 2003a; Leary et al., 2007), and therefore a self-compassion focussed activity may have particularly beneficial effects upon negative affect in younger women due to the adverse impact of their sudden bodily changes.

In contrast, older women may have greater cumulative bodily losses, apart from breast cancer, during their lives (Chrisler & Ghiz, 1993). Negative bodily changes due to treatment, are in *addition* to ongoing aging processes, and these outcomes may a have broader impact upon an older woman's sexuality, self-esteem and general self-concept. Having such widespread ongoing physical losses can contribute to difficulties in being able to adopt a positive outlook (Chrisler & Ghiz, 1993) not only in relation to her body, but also to life in general. Self-compassion has been recognised as having a beneficial effect in coping with many kinds of losses (Neff, 2003b), and therefore may be a particularly important resource for the older woman as she continues to encounter losses from different sources (Allen & Leary, 2014; Phillips & Ferguson, 2013).

Moderating effects

Given the evidence that both age and appearance investment (self-evaluative salience) influence the extent of body image disturbance and overall distress, (Cash, Melnyk & Hrabosky, 2004; Clarke & Griffin, 2008; Moreira, Silva & Canavarro, 2010; Homan & Tylka, 2015; Rakhkovskaya & Holland, 2015), it was predicted that these variables would moderate the effect of the MCB intervention.

Specifically, it was expected that older women would be more likely to derive benefit from the MCB intervention in terms of self-compassion enhancement, compared with younger women. Although body image studies in older women are relatively rare, research in other areas suggests that older women have a heightened awareness of advancing age and perceptions of body failure (Clarke & Griffin, 2008). Given an older woman's likely experience of various health difficulties and associated broader experience of physical limitations, a writing intervention that entails kindness and acceptance is likely to be readily applicable for the needs of this population. Therefore, it is possible that older women may have a greater need for self-compassion. Since older women are more likely to have other health difficulties, apart from those associated with breast cancer, they may find self-compassion suitable to a broader range of their experiences than younger women. As such, it is possible that the experience of aging is more conducive to adoption of a self-compassionate outlook.

It was also expected that women with higher levels of appearance investment would be more likely to derive benefit from the MCB intervention through reduction of negative affect. Specifically, it was expected that the MCB intervention would have most impact on negative affect in women who had higher baseline levels of self-evaluative salience (Moreira, Silva & Canavaro, 2010; White, 2000). This hypothesis is based upon theoretical literature

(White, 2000), which argues that cancer patients with high levels of personal investment in physical attributes, should experience more negative psychological consequences if these attributes are adversely affected by treatment. Empirical evidence amongst breast cancer patients has also shown that those who place greater importance on their appearance are more vulnerable to poor adjustment when facing appearance changes (Moreira & Canavarro, 2010; Sherman et al., 2016). Conversely, self-compassion takes the entire self-evaluation process out of the picture, and thus reduces focus on self-judgement and conditional acceptance of self (Neff, 2003b). Therefore, a self-compassion enhancing intervention is likely to have most impact on those women who strongly focus on appearance as the indicator of their personal self-worth.

Secondary hypothesis

Given evidence that self-compassion is associated with improved body image and emotional regulation, and diminished psychological distress in non-oncology populations (Duarte et al., 2015), the effect of the MCB intervention upon psychological distress in the breast cancer population was explored as a secondary hypothesis. Self-compassion has not been directly addressed in clinical work with psychological distress (Dundas et al., 2016), hence less is known about the possible benefits of such interventions. Greater levels of self-compassion have been found to consistently predict lower levels of depression, anxiety, stress, and generalised distress amongst individuals (Dundas, et al., 2016; Neff, 2012; Neff & Germer, 2012), and may provide an additional avenue of psychological assistance. Previous research has identified the inverse relationship between self-compassion and psychological distress in breast cancer survivors (Przezdziecki et al., 2013). A self-compassionate outlook may influence whether unhelpful personal responses associated with distress proliferate and prevail (Dundas et al., 2016), and therefore, an intervention that enhances self-compassion levels may provide further psychological benefit. Specifically, it was predicted that women

receiving the MCB intervention would report significantly lower general psychological distress (depression, anxiety, stress) and cancer related distress symptoms (hyperarousal, intrusion, avoidance), compared with those in the Control condition.

Method

Participants

Individuals eligible for study participation were: (1) female; (2) over 18 years of age; (3) previously diagnosed with breast cancer and/or ductal carcinoma in-situ (DCIS) and/or lobular carcinoma in-situ (LCIS); (4) completed active breast cancer treatment (i.e., any combination of surgery, chemotherapy, radiation); (5) not diagnosed with cancer-related lymphoedema; and, (6) able to undertake an online writing activity in English. Information about the research was disseminated to women who were members of Australian breast cancer consumer organisations (Breast Cancer Network of Australia – BCNA, and, Breast Cancer Care Western Australia). Participants were invited to join the study through distribution of advertisements about the research via email by contact persons within these organisations. It is estimated that approximately 2,000 invitational emails were distributed to members of these consumer organisations. Unfortunately, it is not possible to accurately calculate a response rate to these invitations, as first, it is not known whether the invitations had been received by all emailed recipients, and second, it is not possible to accurately determine the proportion of invitees who met eligibility criteria. Generally within Australia, 86% of the population are known to have household access to the internet (Australian Bureau of Statistics, 2014-2015). As a conservative estimate, 80% of invitees were likely to have received the invitation, when taking into account factors such as internet accessibility, and absence from home for any number of reasons (travel, personal commitments). As such, it is likely that 1,600 women received an invitation for the current study. Moreover, surveys of

BCNA members indicate approximately 45% have completed their active treatment (Ussher et al., 2011). Therefore, we anticipate that approximately 55% of emailed members may not have been eligible to enter this study, thus leaving 720 potential recruits. Research indicates that up to 50% of breast cancer survivors may experience body image difficulties (Fobair et al., 2006), and therefore, 360 women may have found the study relevant to their experience. On these grounds, we estimate that the 206 women who consented for the MCB study represent approximately 57% of all eligible women who were invited.

Power calculation and recruitment

A two group, randomised, control design, with an Intervention (MCB structured self-compassionate writing) and active Control (unstructured expressive writing) conditions was employed for this research. Ethics approval was granted by the Macquarie University Human Research Ethics Committee.

In estimating the required sample size the likely attrition from this longitudinal study needed to be taken into account. Multi-part writing-based activities can have variable attrition rates, ranging from approximately 25% when administered at a campus location (Odou & Brinker, 2014), to higher levels such as 62% (Geraghty et al., 2010) when entirely self-administered via the internet. In considering estimated sample size for this study, we anticipated a medium effect size for affective responses (Cohen's d=0.58) that was obtained from earlier research using a self-compassion based writing activity (Leary et al., 2007), and which was subsequently confirmed in breast cancer populations (Przezdziecki & Sherman, 2016). On this basis, and conservatively anticipating up to a 50% attrition rate, we estimated requiring an initial sample of 200 to be recruited in order to have a final analysable sample of at least 100, so as to achieve at least 80% power, critical p=0.05 to detect group differences of

this magnitude. Recruitment was closed when the required total sample size of 200, (100 participants per study condition) was obtained.

It was the responsibility of the consumer group members to determine their eligibility for the study, and the enrolment link was accessed and consented to by 206 women. All parts of the study were conducted online. All participants received access to an online writing intervention for breast cancer survivors, and were randomised by Qualtrics (online survey software) to either the MCB intervention or the Control condition.

Procedure

The study involved completion of a self-compassion focussed writing activity (MCB) vs. unstructured writing (Control) for body image difficulties associated with cancer treatment. Both groups completed baseline, one-week post-randomisation, one-month post-randomisation, and, three-months post-randomisation questionnaires. It was expected that each occasion of questionnaire completion would take less than 30 minutes.

An initial email was sent notifying participants that completion of a follow-up questionnaire was due at each follow-up time point. If the follow-up questionnaire link was not accessed, additional action was taken with up to two reminder emails being sent to the participant. If there was still no completion of follow up questionnaires, the participant received a follow up text message or phone call from the researchers.

A criterion of 80% participant retention during the study was considered an appropriate measure of feasibility in this study, in accordance with previous longitudinal research involving a self-compassion based intervention (Bluth et al., 2015).

Intervention and Control Conditions

Intervention: The MCB intervention group was provided with a link to an online writing activity that used a modified expressive writing prompt (Pennebaker, 1997; Pennebaker & Beall, 1986) as the initial writing starting point. The modified expressive writing prompt invited participants to think about a distressing event related to their body after having completed breast cancer treatment, and to write freely to introduce the event. MCB intervention participants were then asked to continue writing about their body image after cancer treatment with the use of five self-compassionate prompts to structure their writing. Each self-compassionate prompt used a separate text box to assist participants in organising their writing. Participants were asked to write in each text box while being guided by the relevant writing prompt. This online intervention using self-compassionate writing prompts had been previously assessed for acceptability by health care professionals and breast cancer survivors during its development (Przezdziecki et al. 2016, see Chapter Six for more detail), and was based on the initial paper-based version of this self-compassion focused writing activity (Przezdziecki & Sherman, 2016, see Chapter Five).

Control: The Control participants received access to a comparable plain version website that also invited unstructured writing about a negative body image event, with use of the same initial modified expressive writing prompt (Pennebaker, 1997; Pennebaker & Beall, 1986), but without any self-compassionate writing prompts. Therefore, the Control condition participants were asked to only undertake a Pennebaker-type writing task regarding a negative event related to their body. This unstructured writing was also conducted in a five section format (comparable to the MCB Intervention group), with participants instructed to continue writing with only general instructions ("Please continue writing about the event"), but without the use of specific prompts, until all writing sections were completed. This ensured that both groups wrote to a similar length and for a similar duration across the two

conditions. The Control group writing activity was expected to take no more than 30 minutes in total.

A single dose of the intervention was employed on this occasion to enhance acceptability of the writing activity, reduce time burden, and thus to maximise the user-friendly aspects of the activity. There are precedents in the research literature for using a single session dose in both expressive writing with oncology patients (Henry, Schlegel, Talley, Molix, & Bettencourt, 2010), and prompted self-compassion based writing amongst undergraduate students (Leary, et al., 2007). Hence a single episode of writing was used in this investigation, as part of a step towards development of a larger future intervention, which could investigate a possible optimum dose.

Demographic Information

Demographic data collected at baseline included marital status, country of birth, level of education, type of treatment received, and time since diagnosis to allow greater understanding of participant characteristics.

Measures

The following measures were used at baseline, and at 1-week, 1-month and 3-months follow-up, to assess participant negative affect, body image disturbance, self-compassion, and general and cancer-specific psychological distress.

Affect

Positive and Negative Affect Scale (PANAS)

The Positive and Negative Affect Schedule (PANAS) was developed as a brief instrument to assess levels of positive and negative affect (Watson et al., 1988). Participants

are required to respond to the 20-item measure, comprising 10 negative affect (NA) items, and 10 positive affect (PA) items, using a 5-point scale (1 "very slightly or not at all" to 5 "extremely"). A variety of timeframes can be used for the PANAS in terms of rating affect ("right now" to "during the past year"). The present moment "right now" was selected in this study as it best reflects participant state, and therefore, any changes in affect (Watson, et al., 1988).

Due to the nature of the writing activity (i.e. difficult, negative experiences related to one's body image), no enhancements of positive affect were expected in participants. Therefore, only the NA subscale of the PANAS was considered to be of primary interest and importance. NA scores in the PANAS are summed within a range of 10-50, with higher scores indicating a higher level of affect. The PANAS has strong reported validity with such measures as general distress, depression and state anxiety (Crawford & Henry, 2004). Cronbach's α in this study was .89 for NA.

Body Image Disturbance

Body Image Scale (BIS)

The Body Image Scale (BIS) was developed by Hopwood, Fletcher, Lee & Ghazal (2001) for use with oncology populations. It consists of 10 items to measure body image distress, including aspects of affect, behaviour and cognition. Each item is scored on a 4-point scale (0 "not at all" to 3 "very much") and summed to make a total score. This is a specific measure for body image concerns in breast cancer patients, and higher scores indicate greater body image disturbance (possible range: 0 to 30). Cut-off scores to indicate clinical levels of disturbance for body image problems have not been defined for the BIS (Hopwood et al. 2001), however, it has been suggested that a score of 10 might serve as a

threshold indicating dissatisfaction with body image (Hopwood et al., 2000). The Cronbach's α for the BIS in this study was .95.

Self-Compassion

Self-Compassion Scale (SCS)

The Self-Compassion Scale (SCS) measures compassion towards the self, as rated by the participant using 26 items (Neff, 2003b). Respondents rate (1 "almost never" to 5 "almost always") the extent to which they treat themselves with self-compassion during times of difficulty (e.g., "I'm disapproving and judgemental about my own flaws and inadequacies"). Total mean scores (range 1-5) are calculated with higher scores indicating greater self compassion (Cronbach's α = .93 in the current study). There is adequate evidence that this scale is valid and reliable (Neff, 2003b, Neff, 2016). The Self-Compassion Scale was developed as a trait measure, however it has also been used to measure shifts in self-compassion levels following intervention programs (Neff & Germer, 2013).

Generalised Psychological Distress

Depression, Anxiety and Stress Scale (DASS 21)

The Depression, Anxiety and Stress Scale (DASS 21) is a short version of the full 42 item DASS scale developed by Lovibond & Lovibond (1995). The valid and reliable DASS21 was used to assess psychological distress (Lovibond & Lovibond, 1995) in the study participants. The DASS21 comprises three subscales measuring depression, anxiety and stress (i.e., nervous tension and irritability, factorially distinct from depression and anxiety), representing generalised psychological distress. Participants rated questions such as, "I felt that I wasn't worth much as a person" (0 "did not apply to me at all" to 3 "applied to me very much, or most of the time"). The Cronbach's α in this study were .94 (Depression subscale),

.82 (Anxiety subscale) and .89 (Stress subscale). A total score out of 21 was calculated for each subscale and then multiplied by two, to be comparable with full scale DASS (42-item) scores.

Cancer-specific Psychological Distress

Impact of Event Scale – Revised (IES-R)

The Impact of Event Scale - Revised (IES-R) is a 22 item instrument widely employed to measure post-trauma phenomena, and has been frequently used to assess cancer-specific psychological distress (e.g. Lindberg & Wellisch, 2004; Mehnert & Koch, 2007; Stanton et al., 2005). The IES-R in this study was used to focus on responses of avoidance (8 items), intrusion (8 items) and hyperarousal (6 items), (Weiss & Marmar, 1997) in relation to one's breast cancer diagnosis. While related, the subscales measure different dimensions of the stress response. Items such as "Any reminder brought back feelings about it" are rated on a Likert scale (0 "not at all" to 4 "extremely") with respect to how distressing each item has been during the past week. The questionnaire instructions in this study asked individuals to specifically indicate how distressing each item had been during the past seven days with respect to their breast cancer diagnosis and treatment. Mean scores are calculated with higher scores indicating greater distress across each subscale. A total IES-R score was used in this study. There is evidence for good test-retest reliability (Weiss & Marmar, 1997), and validity of this measure (Creamer et al., 2003). A universal clinical cut-off score has not been established, although a range between 22-44 has been used in the literature previously (Morina et al., 2013). Suggestions have been made that total scores of 33 and above are likely to indicate a clinically diagnosable condition (Creamer et al., 2003). Cronbach's α in this study was .93. Pre-randomisation levels of cancer specific distress were assessed as potential covariates.

Potential Moderators

Age

Participant age was collected as part of baseline demographic information. Participants entered their age in years.

Self-Evaluative Salience

Appearance Schema Inventory Revised (ASI-R short form)

The Appearance Schema Inventory Revised (ASI-R short form) measures appearance investment, that is, the importance or cognitive-behavioural salience of one's appearance (Cash et al., 2004). The ASI-R has 20 items with two subscales; Self-Evaluative Salience (12 items) and Motivational Salience (8 items). Self-Evaluative Salience reflects the extent to which individuals measure their self-worth by their appearance, and Motivational Salience reflects the extent to which individuals involve themselves in appearance management behaviours. The items are scored on a 5-point scale (1 "strongly disagree" to 5 "strongly agree") with a mean of all 20 items used to form a composite score of appearance investment (ranging from 1 to 5). The two subscales can also be used separately to form self-evaluation and motivational scores, and it has been recognised that self-evaluative salience levels are particularly being reflective of dysfunctional investment in one's appearance (Cash et al., 2004). Therefore, the Self-Evaluative Salience subscale score was considered to be of primary importance and was investigated as a potential moderating variable. Cronbach's α in this study for the Self-Evaluative Salience subscale was .86.

Statistical Analysis

All data were analyzed using SPSS statistical package (version 21; IBM Corp., 2012). Data were initally analysed for normality of distributions. Analysis showed that variables

were normally distributed apart from the Negative Affect subscale of the PANAS, Body Image Scale, and the DASS21 which were positively skewed. Data collected by these instruments (PANAS, Body Image Scale, DASS21), which typically test for clinical disorders such as depression, anxiety and body image disturbance, are recognised to have a positive skew when administered to non-clinical (i.e., psychologically clinical) populations (e.g. Crawford & Henry, 2003; Crawford & Henry, 2004; Fingeret et al., 2010), as was the case for this study. The value of transforming such data is doubtful, as it would involve changing the natural shape of distributions, and may even introduce new problems into analysis (Feng et al., 2014). Nevertheless, an exploration of the consequences of applying log transformation was undertaken for these variables (Negative Affect, Body Image Scale, DASS21). However, the transformation of the skewed distributions (Negative Affect, Body Image Scale, DASS21) had no effect on the outcome of these analyses. Therefore, the data reported in the following sections have not been transformed.

Background demographic data and baseline questionnaires were examined via *t*-tests and chi-square analysis to investigate any pre-existing differences between the experimental and control group. Furthermore, Pearson's correlations were calculated between variables for bivariate associations between the demographic, predictor and outcome variables.

Given multiple cases of data for each participant, mixed methods modelling was used to measure effects of the intervention upon negative affect, body image disturbance and self-compassion over time. A mixed model is a statistical model that takes into account both fixed effects and random effects, and allows investigation of significant main effects or interaction effects. Mixed models employ maximum likelihood estimation which assumes that data are missing at random (Han & Guo, 2014), and is considered to be a more accurate method of dealing with missing data than other methods (Von Hippel, 2007). The dataset featured four stacked time points (baseline, 1- week, 1-month, 3-months) for each participant. Mixed

model analyses were conducted assessing potential main effects of Condition, Time, Condition x Time (change in effect over time), and the interaction of Time x Condition with age and self-evaluative salience, respectively, while controlling for identified covariates (radiation, reconstruction status), and are described in more detail in the sections below.

Results

From the 206 women who consented to the study and undertook the writing activity, 190 remained in the study at 3 month follow up (92.2%). (See Fig. 1 below, Study flow diagram). Overall, dropout rates were low across both groups.

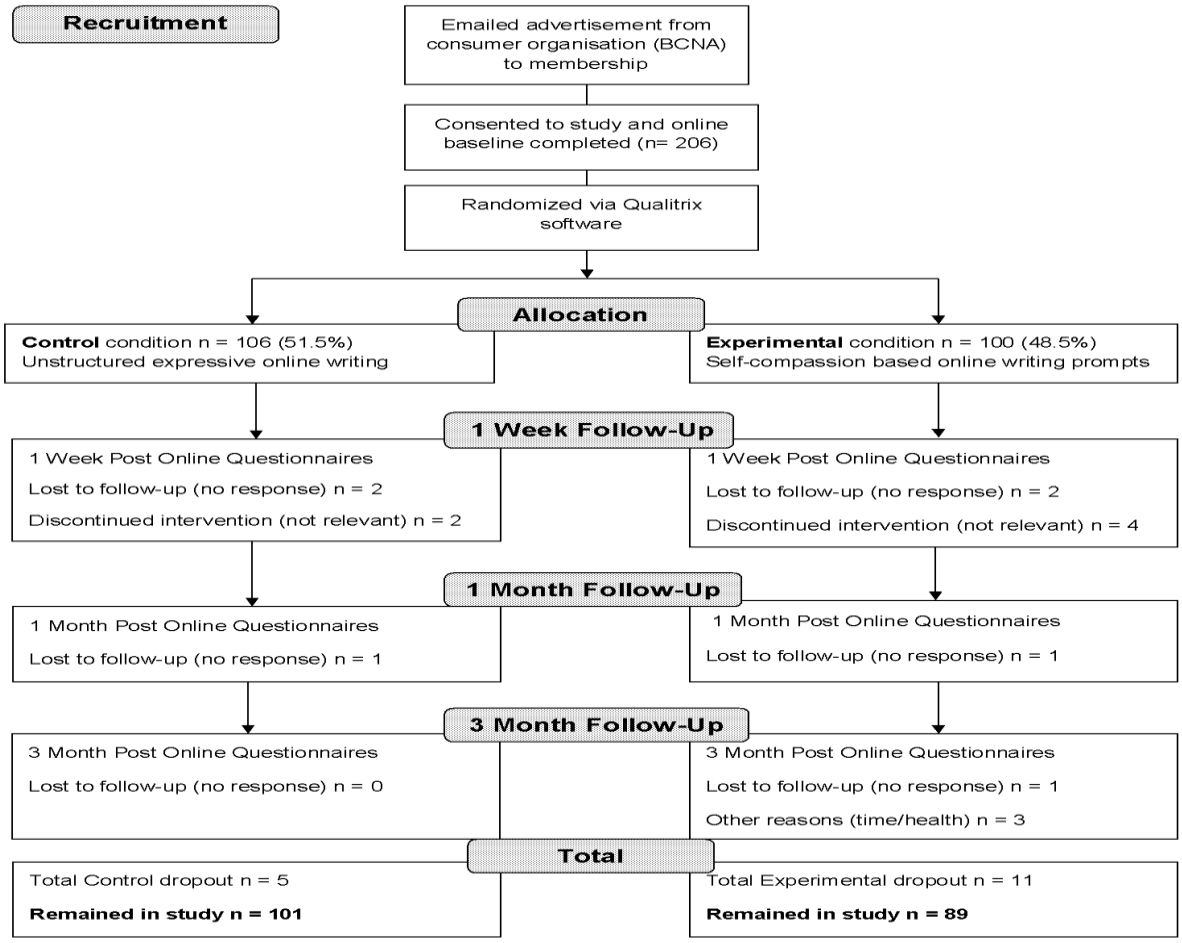

Figure 1: Study flow diagram

An overall comparison of baseline characteristics between women who remained and those who left the study indicated that non-completers had lower baseline levels of self-compassion (mean SCS 2.93) than those who remained in the study (mean SCS 3.25) $t(195)=2.004$, $p=0.046$. The reason for this is not clear. It is possible that women who had low pre-existing levels of self-compassion may have found the writing activity, especially unstructured writing, particularly difficult. Alternatively, it is possible that an associated construct "fear of compassion" may be an important factor for some individuals' lack of participation (Gilbert et al., 2011; Gilbert et al., 2012). Individuals who are high in fear of compassion may actively resist engaging in compassionate experiences, and this can have important implications for therapeutic interventions (Gilbert et al., 2011). Despite this possibility, overall numbers of non-completion were considered to be low, and thus likely to indicate high levels of user acceptability.

Demographic and medical characteristics of the sample are given in Table 1 below. The average age of the recruited participants was 56.43 years (SD 9.73), with a range from 29 to 80 years.

Chi- square tests were conducted on participant categorical variables (marital status, country of birth, education, treatment type) and *t*-tests were performed on all other variables to assess whether the randomised groups differed systematically at baseline. Chi-square analyses revealed a significant difference between the Intervention and Control groups in regard to radiation treatment (Intervention group were less likely to have had radiation), and a non-significant trend for reconstruction (the Intervention group were more likely to have had breast reconstruction, see Table 1). Consequently, radiation treatment and reconstruction status were entered as covariates in subsequent analyses.

Regarding psychological variables, there were no differences between groups pre-randomisation in terms of negative affect, body image disturbance, self-compassion, and generalised or cancer-specific psychological distress (See Table 1 below). Overall mean negative affect was on the 63rd percentile of population averages using normative data provided by Crawford and Henry (2004).

Table 1: Sample characteristics at baseline by study condition

Variable	Total Group (n=184-206) [a]	Experimental (n=88-100) [a]	Control (n=96-106) [a]	Significance X^2 or T Test
Age mean – years (SD)	56.43 (9.73)	56.60 (10.42)	56.28 (9.09)	$t(182)=-0.22$, $p=0.82$
Marital status n (%)				$X^2=0.88$, $p=0.35$
Single/Divorced/Widowed	44 (21.7%)	24 (11.8%)	20 (9.9%)	
Partnered	159 (78.3%)	74 (36.5%)	85 (41.9%)	
Country of Birth n (%)				$X^2=4.27$, $p=0.75$
Australia	163 (79.9%)	79 (38.7%)	84 (41.2%)	
New Zealand	8 (3.9%)	4 (2.0%)	4 (2.0%)	
UK	23 (11.3%)	9 (4.4%)	14 (6.9%)	
Europe	1 (0.5%)	1 (0.5%)	0 (0.0%)	
Asia & Pacific	2 (1.0%)	2 (1.0%)	0 (0.0%)	
America	3 (1.5%)	1 (0.5%)	2 (1.0%)	
Other	4 (2.0%)	2 (1.0%)	2 (1.0%)	
Education n (%)				$X^2=2.21$, $p=0.53$
Less than high school	21 (10.4%)	9 (4.5%)	12 (6.0%)	
High school	21 (10.4%)	13 (6.5%)	8 (4.0%)	
Some tertiary	76 (37.8%)	36 (17.9%)	40 (19.9%)	
Tertiary or more	83 (41.3%)	37 (18.4%)	46 (22.9%)	
Treatment n (%)				
Had breast surgery	202 (99.0%)	98 (48.0%)	104 (51.0%)	$t(202)=0.99$, $p=0.32$
Had chemotherapy	130 (63.7%)	59 (28.9%)	71 (34.8%)	$t(202)=1.11$, $p=0.26$
Had radiation	138 (67.6%)	59 (28.9%)	79 (38.7%)	$t(202)=2.20$, $p=0.03$*
Had/having hormone	151 (74.0%)	73 (35.8%)	78 (38.2%)	$t(202)=1.02$, $p=0.31$
Had targeted	27 (13.2%)	11 (5.4%)	16 (7.8%)	$t(202)=0.09$. $p=0.92$
Had reconstruction	57 (29.9%)	34 (16.7%)	23 (11.3%)	$t(202)=-2.04$, $p=0.08$
Time since diagnosis - Months (SD)	67.18 (63.96)	70.38 (66.65)	64.23 (61.57)	$t(192)=.67$, $p=0.51$
Outcome variables (n)				
Primary				
Negative Affect	16.37 (199)	16.08 (96)	16.63 (103)	$t(197)=0.59$, $p=0.56$
Body Image	11.52 (200)	11.37 (98)	11.66 (102)	$t(198)=0.22$, $p=0.82$
Self-Compassion	3.23 (197)	3.25 (97)	3.20 (100)	$t(195)=-0.66$, $p=0.51$
Secondary				
Depression	7.69 (202)	7.59 (98)	7.79 (104)	$t(200)=0.15$, $p=0.88$
Anxiety	5.41 (202)	5.45 (98)	5.37 (104)	$t(200)=-0.09$, $p=0.93$
Stress	11.30 (202)	10.63 (98)	11.92 (104)	$t(200)=1.07$, $p=0.29$
Impact of Event (total)	15.55 (201)	14.49 (98)	16.55 (103)	$t(199)=1.00$, $p=0.32$
Moderating variable (n)				
Self-evaluative salience	2.89 (200)	2.88(98)	2.90(102)	$t(198)=-0.19$, $p=0.73$

[a] The sample size varied because data completeness differed for variables
* $p<0.05$

On average, the women had a moderate level of self-compassion at baseline, in line with previous studies conducted with breast cancer survivors (Przezdziecki et al., 2013; Przezdziecki & Sherman, 2016). While there is no clinical cut off on the BIS for body image disturbance, the average score in this study was above 10 which is a probable indicator of body image dissatisfaction (Hopwood et al. 2000). Although mean scores for depression, anxiety and stress (DASS) (Lovibond & Lovibond, 1995) were within normal levels, 28.64% of women scored within the clinical range of depression, 24.27% for anxiety, and 22.33% for stress.

All correlations were in the expected directions. Negative affect was positively correlated with body image disturbance, generalised and cancer specific psychological distress, and self-evaluative salience. Negative affect was negatively correlated with age and self-compassion. As expected, self-compassion was positively correlated with age and negatively correlated with negative affect, body image disturbance, generalised and cancer specific psychological distress, and self-evaluative salience (See Table 2).

Table 2. Pearson's correlations between selected variables of interest

	1	2	3	4	5	6	7	8	9
1. Age	1								
2. Negative Affect	-.40**	1							
3. Body Image Disturbance	-.38**	.54**	1						
4. Self-compassion	.26**	-.60**	-.55**	1					
5. Depression	-.10	.56**	.48**	-.58**	1				
6. Anxiety	-.11	.55**	.33**	- .52**	.73**	1			
7. Stress	-.25**	.63**	.42**	-.63**	.68**	.70**	1		
8. Impact of Event (total)	-.22**	.55**	.64**	-.55**	.60**	.54**	.48**	1	
9. Self-Evaluative Salience	-.30**	.45**	.56**	-.65**	.40**	.32**	.40**	.46**	1

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).
N = 178-202

Mixed Model Analysis

Overview of primary outcomes

Linear mixed model analysis with negative affect, self-compassion and body image disturbance as outcomes, controlling for radiation, reconstruction and age revealed significant effects for negative affect and self-compassion, but not for body image disturbance $F(6,499)=1.06$, $p>.05$. The two primary outcomes with significant effects are discussed separately in more detail below using data focused on ±1SD participant subgroups.

Negative Affect

Although the main effect for Condition was non-significant $F(1,187)=0.63$, $p=0.801$, a significant main effect for Time was obtained $F(3,501)=9.49$, $p=.000$, however, the Condition x Time interaction was non-significant $F(3,501)=0.85$, $p=0.468$. Importantly, the three-way interaction of Time x Condition x Age was significant for Negative Affect $F(6,502)=3.82$, $p=.001$, as was the interaction with self-evaluative salience, Time x Condition x Self-Evaluative Salience $F(6,498)=3.60$, $p=.002$. Therefore, simple slopes analyses were performed to more fully understand the nature of these interactions, with data from women at three age points (-1SD, mean age, +1SD) compared in relation to negative affect over time (See Figure 2), and three different levels of self-evaluative (SE) salience (-1SD SE, mean SE, +1SD) with regard to negative affect over time (Figure 3). The following time-points were used: baseline (T1), one week (T2), one month (T3) and three months (T4).

Age: Given that a significant interaction was evident for Time x Condition x Age with regard to Negative Affect $F(6,502)=3.82$, $p=.001$, it was decided to perform simple slopes analyses that compared three age groups of women (-1SD, Mean, +1SD) and their levels of negative affect over time. Mean negative affect scores of younger (-1SD) were 21.96 (*SD* 3.25) at T1, 20.28 (*SD* 3.26) at T2, 18.98 (*SD* 3.27) at T3, and 19.16 (*SD* 3.27) at

T4. In comparison, mean negative affect scores of younger (-1SD) Intervention participants continued to drop over the entire follow-up period 21.92 (*SD* 3.49) at T1, 19.34 (*SD* 3.51) at T2, 17.76 (*SD* 3.51) at T3, and 17.60 (*SD* 3.54) at T4. This is shown in the first box of Figure 2. A similar procedure was adopted to compare negative affect scores amongst women of mean age over time. Scores of mean age Control participants were 19.49 (*SD* 2.99) at T1, 18.85 (*SD* 3.00) at T2, 17.52 (*SD* 3.00) at T3, and 17.66 (*SD* 3.00) at T4. Meanwhile, negative affect scores of mean age Intervention participants were 18.83 (*SD* 3.07) at T1, 17.83 (*SD* 3.07) at T2, 16.51 (*SD* 3.76) at T3, and 16.72 (*SD* 3.08) at T4. These means are shown graphically in the second box in Figure 2. The same analysis was also performed on negative affect scores of older women (+1SD), with Control participants recording scores of 17.69 (*SD* 3.17) at T1, 17.81 (*SD* 3.18) at T2, 16.46 (*SD* 3.16) at T3, and 16.56 (*SD* 3.18) at T4. Scores of older Intervention women (+1SD) were not significantly different from Control participants at any timepoint, with means of 16.59 (*SD* 3.16) at T1, 16.73 (*SD* 3.17) at T2, 15.60 (*SD* 3.18) at T3, and 16.07 (*SD* 3.17) at T4. Scores of older women (+1SD) are represented graphically in the last box of Figure 2.

Considering the above, overall the moderating effect of age on negative affect, in the Intervention condition, younger women (-1SD) demonstrated a significant decrease in negative affect from baseline to 1-week follow-up, whereas for comparatively older women (mean age) this significant decrease in negative affect was delayed until after the 1-month follow-up. The women in the Control group also displayed decreased negative affect over time, but these decreases did not reach statistical significance. Women who were older than the mean age (+1SD) did not show a significant reduction of negative affect from baseline over time in either Control or Intervention conditions.

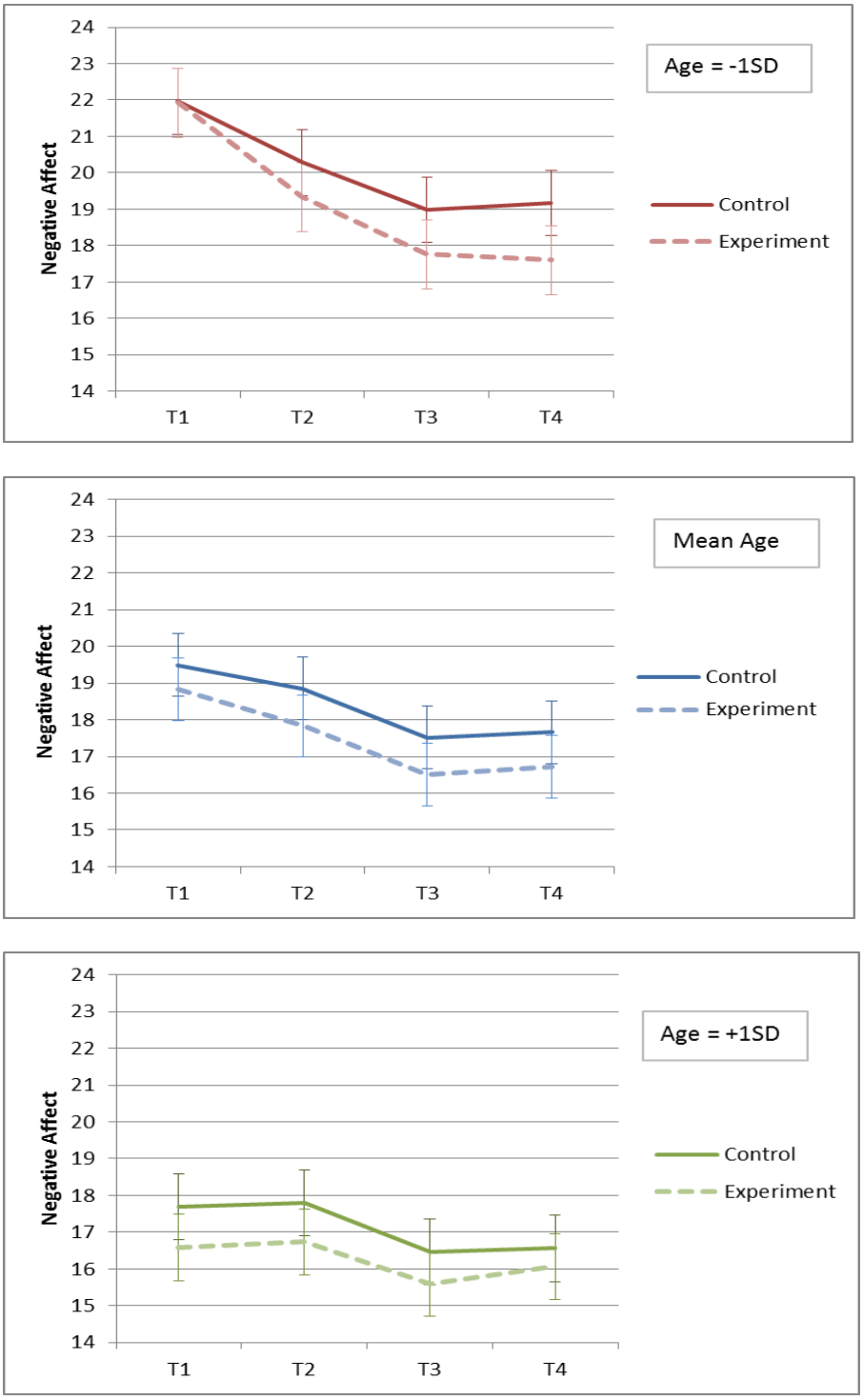

Figure 2. Negative Affect over Time by Condition for 3 age groups

Self-Evaluative Salience: Given that a significant interaction was evident for Time x Condition x Self-Evaluative Salience $F(6,498)=3.60$, $p=.002$, it was decided to perform simple slopes analyses that compared the negative affect levels of women with three levels of

self-evaluative salience (-1SD, Mean, +1SD) over time. Negative affect scores of Control women with higher self-evaluative salience (+1SD) were 21.71 (*SD* 3.78) at T1, 21.88 (*SD* 3.82) at T2, 20.21 (*SD* 3.88) at T3, and 19.92 (*SD* 3.85) at T4. Meanwhile, negative affect scores of Intervention women with high self-evaluative salience (+1SD) were 22.69 (*SD* 3.89) at T1, 20.70 (*SD* 3.89) at T2, 18.63 (*SD* 3.93) and 18.82 (*SD* 3.97) at T4. This information is represented graphically in the first box of Figure 3. In a similar way, women with mean levels of self-evaluative salience were compared across time with regard to negative affect levels. Women with mean self-evaluative salience in the Control condition obtained negative affect scores of 20.35 (*SD* 3.63) at T1, 19.97 (*SD* 3.63) at T2, 18.83 (*SD* 3.66) at T3, and 18.54 (*SD* 3.64) at T4. In comparison, women with mean self-evaluative salience in the Intervention condition obtained scores of 19.76 (*SD* 3.70) at T1, 18.90 (*SD* 3.72) at T2, 17.64 (*SD* 3.72) at T3, and 17.88 (*SD* 3.73) at T4. These are displayed in the second box of Figure 3. Likewise, women with low levels of self-evaluative salience were compared according to negative affect scores over time, with Control participants obtaining means of 18.98 (*SD* 3.80) at T1, 18.07 (*SD* 3.75) at T2, 17.45 (*SD* 3.76) at T3, and 17.15 (*SD* 3.73) at T4, while Intervention participants obtained means of 16.83 (*SD* 3.82) at T1, 17.09 (*SD* 3.82) at T2, 16.64 (*SD* 3.80) at T3, and 16.94 (*SD* 3.79) at T4. This information is shown in the last box of Figure 3.

Considering the above, the moderating effect of self-evaluative salience, women with higher levels of self-evaluative salience (+1SD) in the Intervention group demonstrated a significant decrease in negative affect from baseline to 1-week post intervention, and also demonstrated a further significant decrease in negative affect from 1-week to 1-month. This decrease in negative affect was maintained at 3-month follow up. However, women in the Control condition with higher self-evaluative salience (+1SD) did not display a significant decrease in negative affect at any time point. For women with mean levels of self-evaluation

in the Intervention, this significant decrease in negative affect was evident slightly later from 1-month post intervention, and also maintained at 3-month follow up. Although women in the Control group with mean levels of Self-Evaluative Salience also displayed lowering of Negative Affect over time, these decreases did not reach statistical significance. Women who were low on Self-Evaluation Salience (-1SD) did not show a significant reduction of negative affect from baseline over time in either Control or MCB intervention conditions. This is shown in Figure 3 below.

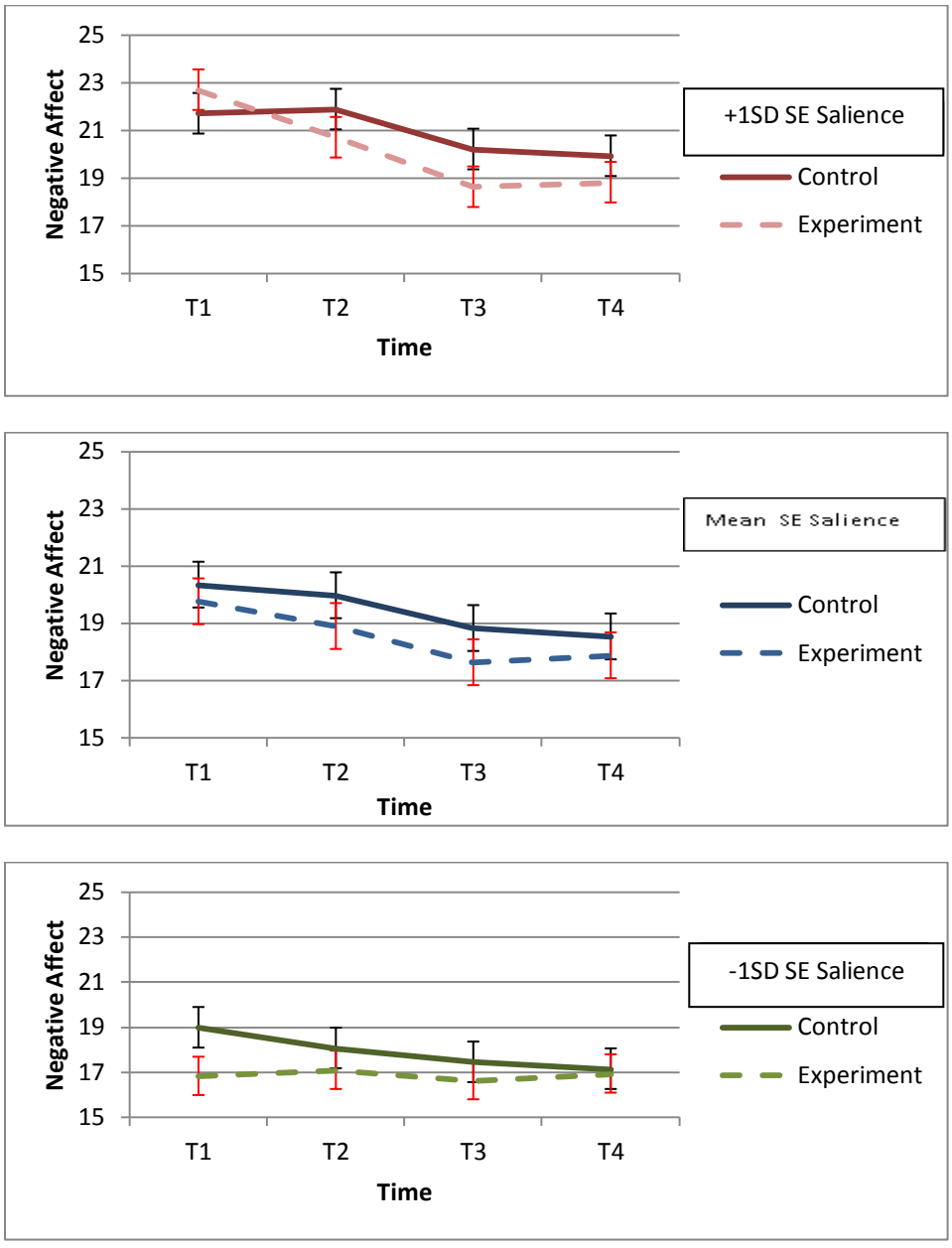

Figure 3. Negative Affect by Condition, Time and Self-Evaluative Salience levels

Self-Compassion

For self-compassion, a significant main effect for Condition was observed $F(1,188)=4.68$, $p=.03$, but the main effect of Time was non-significant $F(3,491)=.215$, $p=.88$. No significant interaction effect was found for Time x Condition $F(3,491)=.927$, $p=.43$.

However, a significant interaction was evident for Condition x Age, $F(1,188)=5.69$, $p=.02$. To more fully understand the nature of this interaction, a simple slopes analysis was performed that compared self-compassion scores of Control participants from three age groups: younger women -1SD (*M* 2.94, *SD* .72), mean age (*M* 3.02, *SD*. 69), and older women +1SD (*M* 3.08, *SD* .72), with scores obtained by three age groups of Intervention participants: younger women -1SD (*M* 2.80, *SD* .74), mean age (*M* 3.10, *SD* .71) and older women +1SD (*M* 3.33, *SD* .72) (See Figure 4 below). Analysis indicated older women (+1SD) in the Intervention displayed significantly greater levels of self-compassion levels at all timepoints, than women in the Control condition.

The investigation of interaction for Time x Condition x Age was non-significant $F(6,491)=.65$, $p=.69$.

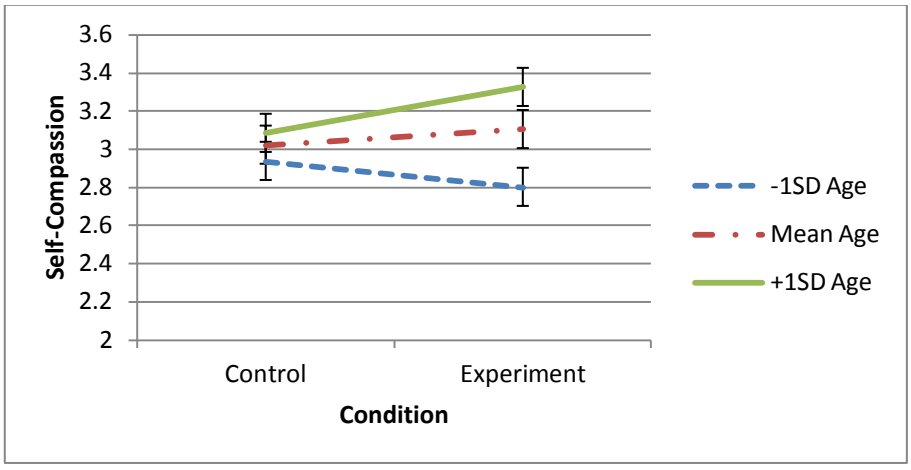

Figure 4. Self-Compassion by Condition and Age

Body Image Disturbance

No significant effects of the intervention over time according to age were found for Body Image Disturbance $F(6,499)=1.06$, $p>.05$. Other results were also non-significant Condition $F(1,194)=.43$, $p>.05$, Time $F(3,499)=.82$, $p>.05$, Time x Condition $F(3,499)=.86$, $p>.05$, therefore no further analysis was performed on this variable.

Secondary hypotheses

No significant effects of the intervention were found on either generalised or cancer specific psychological distress, thus the secondary hypotheses of the study were not supported. Specifically, no significant effects of the intervention over time according to age were found for Depression $F(6,500)=.90$, $p>.05$. Other results for Depression were also non-significant Condition $F(1,189)=.16$, $p>.05$, Time $F(3,500)=1.12$, $p>.05$, Time x Condition $F(3,500)=.14$, $p>.05$.

No significant effects of the intervention over time according to age were found for Anxiety $F(6,505)=.94$, $p>.05$. Other results for Anxiety were also non-significant Condition $F(1,191)=.03$, $p>.05$, Time $F(3,505)=.18$, $p>.05$, Time x Condition $F(1,191)=.03$, $p>.05$.

No significant effects of the intervention over time according to age were found for Stress $F(6,502)=.51$, $p>.05$. Other results for Stress were also non-significant, Condition $F(1,186)=.24$, $p>.05$, Time $F(3,502)=.60$, $p>.05$, Time x Condition $F(3,502)=1.06$, $p>.05$.

No significant effect of the intervention over time according to age was found upon Impact of Event scores $F(6,497)=.42$, $p>.05$. Other results for Impact of Event were also non-significant, Condition $F(1,187)=.01$, $p>.05$, Time $F(3, 497)=.22$, $p>.05$, Time x Condition $F(3,497)=.66$, $p>.05$.

Discussion

This is the first study to investigate the difference between unstructured expressive and structured self-compassion based writing beyond the immediate short term, with women who have specific difficulties regarding post-treatment body image. Overall, this initial investigation has provided ambiguous support for the MCB intervention if only a broad range of outcomes is considered. However, in specific areas, results obtained indicate that a self-compassion based intervention which is targeted and structured, may prove more beneficial than expressive writing alone, which by its nature is unstructured and self-directed. In contrast to other research which has demonstrated no main effects from home-based unstructured expressive writing for cancer-related psychological difficulties (Jensen-Johansen et al., 2013), the current study has shown benefit from both structured and unstructured writing undertaken independently without clinician support. Results in this study have demonstrated that structured self-compassionate writing helps to decrease negative affect over time for younger women specifically, but less so for older women, and to enhance levels of self-compassion for older women. Moreover, those women with the highest baseline self-evaluative salience, which is a recognised vulnerability factor (Moreira & Canavarro, 2010), experienced the greatest reduction in negative affect from the MCB intervention. In accordance with the study's hypotheses, unstructured writing also produced some benefit for women in terms of negative affect, but these reductions were at lower levels than those derived from the MCB intervention. Specific areas of significance regarding negative affect and self-compassion are discussed below, and the broader context of ambiguity from non-significant outcomes is discussed in following sections.

Self-compassion and negative affect are recognised as being inversely correlated (Neff, Kirkpatrick, & Rude 2007), and in this study the effects of the MCB intervention on these outcomes are unique. Negative affect as measured by the PANAS represents a state

dimension, with this measure being particularly sensitive to change from interventions (Watson et al. 1988). Body image disturbance is a complex post-treatment concern for breast cancer survivors, particularly younger women (Paterson et al. 2015), and hence may explain higher levels of baseline negative affect for this group. Negative affect, as a state, has already been shown to be responsive to self-compassion based interventions as demonstrated by other studies (e.g. Leary et al., 2007, Przezdziecki & Sherman., 2016). Likewise, in the current study, younger women, who displayed higher baseline negative affect, experienced most improvement if they were in the MCB intervention. In general, higher negative affect is considered to be a general dimension of subjective distress with aversive mood states which helps to promote vigilant apprehensiveness (Crawford & Henry, 2004), and is related to self-reported stress, poor coping and health complaints (Watson et al., 1988). In non-oncology research, negative affect has been found to predict body dissatisfaction in girls, adolescents and adult women (McCabe & Ricciardelli, 2003), and is seen as an important risk factor for the onset and maintenance of eating disorders (Atkinson & Wade, 2012). Furthermore, individuals who have difficulty in 'bouncing back' from negative affect and experience prolonged negative affective reactions, are likely to be less responsive to other interventions, such as cognitive therapy (Cohen et al. 2008). With regard to oncology-related literature, negative affect constitutes a considerable burden for patients in its own right, and therefore, has been recommended as the aim of therapeutic intervention in follow up for cancer survivors (Koller et al., 1996). It is likely that higher levels of negative affect indicate activation of the threat system (Phillips & Ferguson, 2013), and hence, these individuals were particularly responsive to the self-compassionate focused intervention. In contrast, low negative affect is considered to be a state of calmness and serenity (Watson et al. 1988), which would be consistent with the self-soothing intent of self-compassion (Gilbert, 1989; Gilbert & Irons, 2005) and the broader outcome of the MCB intervention.

The MCB writing activity enhanced older women's level of self-compassion generally across the duration of the study, compared with younger women. The presence of self-compassion does not merely represent a lack of negative affect (Neff, Kirkpatrick & Rude 2007), and has been generally associated with indices of psychological well-being (Allen & Leary, 2010). Given that unstructured expressive writing itself does not target self-compassion directly, or attempt to induce a self-compassionate state, the women in the control condition were unlikely to experience the same benefit in this regard. Self-compassion has been shown to be reliably primed by writing in other studies (Leary et al., 2007; Rowe et al., 2016; Zabelina & Robinson, 2010), as occurred in this study with the effect of the online MCB writing intervention for older, but not younger, women. Since aging is inherently challenging, self-compassion may become increasingly important as people become older, given broader associated undesirable declines in mental and physical health (Allen & Leary, 2014; Phillips & Ferguson, 2013). Therefore individuals with health difficulties due to cancer, as well as ongoing age-related bodily challenges over time, may have a higher need and motivation for adopting a self-compassionate stance, and a single occasion of self-compassionate induction may have been adequate to achieve this in older women. In other words, older women who were induced to think more self-compassionately potentially may have been better able to assimilate an ongoing self-compassionate stance because of their life circumstances. As such, there may be more enduring change to self-compassion as a trait, however this would need further investigation. It has been suggested that use of self-compassionate thinking may be the mechanism that underlies the extent to which individuals' attitudes help them cope with aging (Allen & Leary, 2014). The lack of change in self-compassion for younger women may have possibly arisen from a shorter overall personal history of negative bodily alterations. For some younger women, diagnosis and treatment of breast cancer may have been their first experience of significant bodily loss.

Therefore, women of different ages may have varying levels of familiarity with physical loss and differing levels of self-compassion applicability to their lives. It has also been suggested that individuals with generally poorer health may need more self-compassion to cope with their circumstances, with evidence of negative correlation between self-compassion and physical health (Raque-Bogdan et al. 2011). However, evidence also suggests self-compassion can be increased with repetition and training, thus allowing an individual to become more self-compassionate in their day to day life (Allen & Leary, 2014) regardless of their age. This avenue would need to be investigated more thoroughly in the future with breast cancer survivors of various ages and differing exposure to self-compassion induction activities. Although statistically significant, the associated clinical effects of the MCB intervention are unknown as all age groups still remained in the moderate range for self-compassion, but the results may indicate increased responsivity to self-compassionate induction in older women.

In addition to age being a relevant factor with regard to the impact of the MCB intervention, pre-existing levels of self-evaluative salience were found to moderate women's levels of negative affect following the writing intervention. Women with the greatest tendency to self-evaluate responded most rapidly with a significant decrease in negative affect following the MCB writing intervention, whereas women with slightly less self-evaluative tendencies experienced a reduction in negative affect, but with a somewhat delayed response. Women with the lowest levels of self-evaluative salience did not experience any significant changes to their levels of negative affect. Women with the lowest levels of self-evaluative salience may also have had the lowest self-critical orientation towards their bodies. Given that self-compassion works to decrease conditional self-acceptance (Neff, 2003b), a floor-effect for the MCB intervention may have been experienced in those women with low pre-existing self-evaluative salience. With breast

cancer patients, levels of appearance investment generally predict body image disturbance after treatment (Moreira & Canavarro, 2010, Sherman, Woon, French & Elder, 2016), with higher initial levels of self-evaluative salience associated with poorer adjustment (Moreira et al. 2010). As such, self-evaluative salience has been described as a "vulnerability factor" for subsequent emotional distress, fear of negative evaluation, and body shame (Moreira & Canavarro, 2010, Moeira et al. 2010). Furthermore, appearance changes are likely to become more salient in the survivorship period, as the individual's focus changes from disease survival to longer term quality of life, (Moreira & Canavarro, 2010). Self-compassion specifically targets self-kindness and may assist in countering a woman's self-criticism of her physical shortcomings (Albertson et al., 2014), and therefore would be especially useful for women with negative alteration as they face adjustment during survivorship. This could be particularly relevant for women who have been previously heavily invested in their appearance as a source of self-acceptance or self-worth (Carver et al., 1998; Teo et al,. 2015). Use of structured self-compassion based writing appears to be particularly effective in women with high pre-existing levels of self-evaluative salience, and is worth further investigation in terms of clinical applications.

Unexpectedly, the MCB intervention did not produce significant changes in body image disturbance, or general and cancer related psychological distress and this has indicated unclear support for the intervention with respect to its ability to foster broader changes. Although there is evidence that self-compassion enhancement activities may improve body image in general populations (e.g. Albertson, et al. 2014), the context may be more complex for women who have experienced medically-induced negative bodily alteration, as is the case for women following a diagnosis of breast cancer. It is possible that the effects of MCB may be affected by "dose" or frequency of practice, as body image generally is difficult to modify (Altabe & Thompson, 1996). It is possible that a single session of self-compassionate

structured writing may not have been sufficient to address a woman's underlying body image disturbance, especially if it has been of long duration, and if her body image disturbance existed prior to breast cancer treatment. Furthermore, length and frequency of writing may also be relevant factors with regard to distress symptomatology, but this too would need to be explored in future research.

In interpreting these findings, several limitations of the study should be considered. The sample comprised predominantly Australian-born, English speaking women who were computer literate and therefore, these findings may not be applicable to other populations. However, such participant groups are comparable with other studies which have used similar populations (e.g. Bartula & Sherman, 2015, Sheehan et al., 2007, Sherman et al., 2016, Yu & Sherman, 2015). Furthermore, all women who undertook the study were part of consumer breast cancer survivor organisations, and as a consequence these women may be different in some ways from women who do not join such groups. The study relied on self-report measures for all data, however, given the subjective nature of cancer-related body image disturbance, self-evaluative salience and self-compassion, alternative methods of measurement would be difficult to implement. No qualitative data were collected in this research, and this avenue could prove to be a source of valuable additional information to better understand the way in which the women responded to the MCB writing intervention. Future studies may wish to recruit a wider subset of women of different ages who are outside consumer organisations, and collect qualitative data to gain a broader understanding of this area. Furthermore, effects of structured writing on more than one occasion could be investigated in future studies, as possible effects of repeated self-compassionate priming have been raised as an avenue for future research (Rowe et al., 2016).

Overall despite ambiguity for MCB as a broad-reaching intervention, this research has explored a novel approach with promising results to specifically addressing negative affect

and self-compassion in breast cancer survivors using a quick and simple, low-cost, self-administered intervention. Evidence suggests that self-compassion interventions are generally not particularly difficult to implement (Adams & Leary, 2007), and may be effective within a short period of time (Albertson et al. 2014), and can produce benefits even when largely self-administered in the absence of a formal therapeutic relationship (Johnson & O'Brien, 2013, Liss & Erchull, 2015, Przezdziecki & Sherman, 2016). One occasion of structured self-compassionate online writing provided benefits to younger women in particular, who experienced reductions in negative affect over time. Furthermore, engaging in the self-compassion based writing activity improved older women's level of self-compassion, generally. The intervention was particularly effective in reducing the negative affect of women with high levels of self-evaluative salience in terms of appearance investment. Self-evaluative salience has been recognised as a vulnerability factor in body image adjustment, and a self-compassion based intervention may be particularly helpful for targeting women who are potentially at risk of developing body image-related difficulties. Furthermore, reduction of negative affect is likely assist women with broader medical issues and treatment adherence. High levels of negative affect can reduce effective decision making, drain self-regulatory resources, and promote unhealthy behaviours (Terry & Leary, 2011). Therefore, any factor that lowers harmful negative affect should promote more judicious health-related decisions, (Terry & Leary, 2011). An activity such as MCB could potentially be applied at various time-points for women diagnosed with breast cancer including as a preventative approach before breast surgery, early intervention for women after surgery, or as part of a therapeutic program for women experiencing difficulties in adjustment during survivorship. A brief, structured self-compassionate intervention approach, such as the MCB activity, is likely to be an attractive option for the time pressured health professional, and addresses

these women's preference for sensitive, non-face to face assistance with regard to managing body image difficulties during survivorship.

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8. Chapter Eight: Overview and closing comments

This thesis addresses gaps in current knowledge relating to the relevance and usefulness of self-compassion to assist female survivors of breast cancer with body image concerns. Specifically, the role of self-compassion was examined through a series of empirical studies to first to ascertain the relevance of self-compassion in relation to post-breast cancer body image disturbance, develop a self-compassion focused writing intervention, and then to investigate the effectiveness of this intervention. These investigations were undertaken in the larger context of exploring the possible roles of self-compassion as a state/trait, and, mediator/moderator amongst the breast cancer survivor population.

This section will summarise key findings from each empirical study, placing these in the context of previous research. The limitations of the thesis will be discussed along with implications for future research and clinical practice.

8.1. Relevance of self-compassion in body image disturbance and distress

Given that body image disturbance after breast cancer is a significant source of distress for some women (Fobair & Spiegel, 2009; Jorgensen, Garne, Sogaard, & Laursen, 2015), relevant factors that may assist with its alleviation are worthy sources of investigation to assist in improving these women's quality of life. The benefits of self-compassion have been evident in research related to general psychological wellbeing (Zessin, et al., 2015), health behaviours (Terry, Leary, Mehta, & Henderson, 2013), and body image (Wasylkiw, et al., 2012), amongst others. However, the concept of self-compassion had not been investigated previously in relation to body image concerns in cancer populations, so its potential roles and usefulness was unknown. To answer this question, a cross-sectional study (Study I, Chapter 4) was undertaken to investigate the relevance and possible role of self-compassion to assist with body image disturbance in the breast cancer survivor population. This study was informed by Self-Discrepancy Theory (Higgins, 1987), and Cash's Body Image Theory (Cash & Pruzinsky,

2002), which predict that breast cancer treatment may increase the discrepancy between one's ideal and actual body image resulting in body image disturbance (White, 2000). Furthermore, given the nature of cancer treatment, Baumeister's theory predicts that some individuals may be in a depleted state (Baumeister, Muraven, & Tice, 2000) regarding their personal resources to cope with adverse changes. Body image disturbance has been acknowledged as a predictor of psychological distress in cancer patients (Sharpe, Patel, & Clarke, 2011). Self-compassion theory predicts that those higher in self-compassion are better able to manage adverse life events (Neff, 2003a; Neff, 2003b) with less psychological distress.

Results obtained (Chapter 4) indicated that trait self-compassion is not only a significant, factor regarding body image related concerns, but also has a possible mediating role in the relationship between body image disturbance and psychological distress. Although cross-sectional investigation cannot provide conclusive evidence regarding causal mechanisms, preliminary evidence was obtained to support this study hypothesis. Furthermore, the results were consistent with evidence from studies in other areas which indicate the mediating role of self-compassion (Chapter 2, Section 2.1.5). The results obtained are also consistent within the broader theoretical nature of self-compassion as a personal resource that assists with psychological wellbeing (Neff, 2003a; Neff, 2003b).

Given the promising results regarding the relevance and possible role of self-compassion as resource for breast cancer survivors, subsequent studies focussed on investigating the usefulness of a novel self-compassion focussed writing based intervention by inducing a self-compassionate state. The following three studies (Chapter 5, Chapter 6 and Chapter 7) were devised to pilot, translate and measure the effectiveness of a self-compassion based writing intervention.

8.2. Impact of self-compassion based writing to assist affect and outlook

The findings from Study I (Chapter 4) indicated the relevance and possible role of self-compassion with regard to breast cancer survivor body image difficulties, however, no studies had investigated the potential for a writing intervention using self-compassionate prompts to modify an individual's affect or outlook in these circumstances. Therefore, a proof-of-concept, pilot study (Study II, Chapter 5) was devised to test whether self-compassion based writing was able to provide any short term benefits, when compared to other existing approaches such as unstructured expressive writing. In addition to Baumeister's Ego Depletion Theory, Higgins Self-Discrepancy Theory and Cash's Body Image Theory as mentioned above, Study II was also informed by Baumeister's Escape Theory which predicts that individuals are likely to escape unpleasant awareness (Baumeister, 1997), and this may be particularly true in situations where a woman has actual new bodily deficits, and may be facing greater self-discrepancies regarding her body image post treatment. Awareness of her bodily losses, unpleasant memories, and related negative affect may be especially difficult to tolerate, and could be distressing or even traumatising to the individual (Frierson, Thiel, & Anderson, 2006). Given this context, Study II was also informed by other research on the theoretical nature of self-compassion (Neff, 2003a), and the likely effects of inducing a self-compassionate attitude (Leary, et al., 2007). Self-compassion does not encourage the individual to suppress their uncomfortable thoughts, emotions, experiences or memories, but instead assists the person to hold these with an attitude of kindness, warmth and acceptance (Neff, 2003a; Neff, 2003b). Self-compassionate individuals, therefore, are not encouraged to engage in behaviours recognised to be resource depleting such as control, suppression or regulation of unpleasant emotions or thoughts (Baumeister, Muraven, & Tice, 2000). Disengagement and avoidance have been recognised as common unhelpful coping strategies used by breast cancer survivors (Malik & Kiran, 2013). As well as being resource depleting, such activities may also enable ongoing longer term avoidance of negative cancer treatment-

related memories, and escape from the awareness of the individual's actual circumstances, and thus delay emotional adjustment to actual bodily changes. As such, it was predicted that an activity which directly targets self-compassion, such as self-compassion based writing, would produce a beneficial effect upon an individual's negative affect and self-compassion state in a context of difficult body image memories, compared with an alternate activity such as expressive writing. Furthermore, given the results of research in other areas (Leary, Tate, Adams, Allen, & Hancock, 2007), it was hypothesized that this effect would be the greatest in women with pre-existing low levels of trait self-compassion.

As predicted, self-compassion based writing made an immediate impact upon a breast cancer survivor's negative affect and self-compassionate outlook (Chapter 5, Study II). The self-compassion based writing appeared to have a stabilising effect on negative affect. Experimental participants experienced no significant changes to their negative affect after writing about difficult body changes, however, negative affect levels rose in women who undertook unstructured expressive writing. One may speculate that increased negative affect might also make avoidance or escape strategies more likely. However, structured writing according to self-compassionate prompts appears to have triggered a self-compassionate state in these women, compared with those in the control condition. It is possible that inducing a self-compassionate state may have assisted women to face memories of their adverse bodily changes and associated negative events. As such, they did not experience a significant increase in negative affect even when their awareness was focussed on writing about painful recollections. It is possible that as one experiences less negative affect towards one's painful circumstances and losses, then one would be less inclined to undertake avoidance, suppression or escape strategies, as predicted by Baumeister's Escape Theory (Baumeister, 1997). An ability to be exposed to one's challenging realities is the foundation of interventions such as exposure, habituation and meaning-making (Stanton, et al., 2000). Therefore, through the pilot investigation (Chapter 5, Study II), proof-of-concept was demonstrated that a self-

compassionate state could be induced through a structured writing activity, with beneficial effects in participants. It also addressed a question raised in related literature regarding whether modified writing activities may provide any additional benefit over and above those obtained by standard Pennebaker-type expressive writing (Boals, Murrell, Berntsen, & Southard-Dobbs, 2015). Study II indicated that structured self-compassion based writing may be a superior approach to unstructured expressive writing in this population, but this possibility required greater exploration.

The second hypothesis of Study II predicted that most benefit would be experienced by those participants with a lower initial baseline of trait self-compassion; this prediction was not supported. Women in the experimental condition experienced benefit from the structured writing activity regardless of their pre-existing level of self-compassion. This indicated a possible broad application of such an intervention. Therefore, further investigation was undertaken regarding the duration and extent of benefits that could be obtained by self-compassion based writing.

Study III took the concepts and methodologies of Study II, and aimed to translate these to an online intervention which would be acceptable to both consumers and associated health professionals. Both breast cancer survivors and health professionals were asked to interact with a draft online version of the My Changed Body (MCB) structured self-compassion based writing activity. Qualitative and quantitative feedback was sought regarding the context, organisation, clarity, presentation and ease of use of the MCB intervention. Results obtained in Study III (Chapter 6) indicated a moderate to high acceptability of the draft intervention. Hence, the aim of demonstrating intervention acceptability to the target group and related health workers was supported. Action was taken to incorporate feedback regarding the wording, presentation and organisation of the draft to further improve acceptability of the final version of the My Changed Body intervention.

The concluding study (Study IV) in this thesis was implementation of the online My Changed Body structured writing intervention as part of a randomised controlled trial using 206 breast cancer survivors (Chapter 7). The overall aim of the study was to demonstrate that self-compassion levels can be improved in the short to medium term (3 months), by an online structured writing activity regarding post treatment body image delivered online. Associated aims were to demonstrate that the My Changed Body intervention would also decrease negative affect and body image disturbance over the short to medium term. Furthermore, any benefits observed would be greater in the experimental (MCB) group, compared with the control condition (unstructured expressive writing). Given that unstructured self-expressive writing as investigated by Pennebaker and others (Pennebaker & Beall, 1986; Pennebaker, Kiecolt-Glaser, & Glaser, 1988), has a long tradition of providing beneficial effects, improvements in control participants were expected to some extent from facilitation of self-expression. However, unstructured expressive writing does not in itself target self-compassion, hence no significant improvement in self-compassion levels were expected from the control group.

Evidence of a potential moderating factor was also hypothesised in Study IV. It was expected that a component of appearance investment, (i.e. baseline Self-Evaluative Salience - SES) would interact with the self-compassion based intervention, and thus showing an effect upon negative affect. Theoretically, it is thought that self-compassion works against conditional self-evaluation, and instead promotes unconditional self-acceptance (Neff, 2003a). Therefore, induction of a self-compassionate state was likely to minimise any existing body based conditional self-evaluation, and thus decrease body related negative affect. It was expected that the higher one's pre-existing self-evaluative salience, the greater potential reduction of conditional self-evaluation experienced, and therefore, the bigger possible reduction of negative affect in this regard. As such, it was expected that self-evaluative salience (SES) would function as a moderator and that women high in pre-existing self-

evaluative salience (SES) would be particularly affected by a self-compassionate writing activity.

The online self-compassion based writing intervention (Study IV) demonstrated an effect upon self-compassion levels and survivor negative affect, but also indicated that this relationship was not straightforward. With regard to self-compassion, a significant interaction was found between experimental condition and age. More specifically, older women who undertook self-compassionate writing displayed higher personal self-compassion levels regardless of time. With regard to negative affect, a significant interaction was found between experimental condition, time and age. Self-compassion based writing about one's difficult body image experiences was associated with decreased negative affect over time for certain age groups. More specifically, self-compassionate writing helped to decrease negative affect over time for younger women, hence it was this group who obtained greatest benefit. Levels of pre-existing appearance investment (self-evaluative salience) moderated the effects of the self-compassion intervention. Those women with the higher levels of pre-existing self-evaluative salience had the greatest reduction in negative affect from the self-compassion writing intervention. This is particularly noteworthy, as self-evaluative salience is recognised as a vulnerability factor in the development of body image disturbance in breast cancer patients (Moreira & Canavarro, 2010; Moreira, Silva, & Canavarro, 2010). Such results indicate that a structured self-compassion based writing activity such as My Changed Body has an effect beyond that of the immediate act of writing, and is more effective than expressive writing alone. The MCB intervention also demonstrated that self-compassion and negative affect regarding one's body can be manipulated in breast cancer survivors, albeit with different age groups receiving benefit in distinct ways.

However, no significant main effects were found with regard to body image disturbance from the MCB self-compassion based structured writing. Body image disturbances

have been acknowledged to be widespread, difficult to treat and to be resistant to a number of interventions (Pearson et al., 2012). Although there is evidence that enhancement of self-compassion may improve body image in general populations (e.g. Albertson, et al. 2014), the context may be more complex for women who have experienced medically-induced negative bodily alteration. Evidence obtained as part of this thesis (Study I) indicates self-compassion is involved in the body image disturbance – psychological distress relationship in female survivors of breast cancer (Przezdziecki et al., 2013); however, perhaps length, frequency and intensity of writing may also be relevant factors but this would need to be explored in future research.

Taken together, the findings from the empirical studies in this thesis suggest that self-compassion is a relevant factor in relation to body image difficulties in breast cancer patients during survivorship. A self-compassionate attitude towards one's body image difficulties can be manipulated, and a single administration of My Changed Body was able to lead to a shift in compassion and negative affect. Furthermore, study of moderators in My Changed Body helped with understanding the responses of specific subgroups. Induction of a self-compassionate state through the structured MCB written activity is associated with a beneficial impact upon negative affect for some women. The effects of structured self-compassion based writing are also moderated by a woman's pre-existing level of self-evaluative salience. The activity appears to have a larger impact on women with high levels of self-evaluative salience, and reduce negative affect more readily in these women, compared with those who have average or low levels of self-evaluative salience. However, it must be kept in mind that these relationships are not straightforward, and are likely to be affected by a woman's age. Although negative affect was reduced by the intervention in younger women, their levels of self-compassion did not change as readily. There may be a need for booster interventions or work of a greater intensity for these women.

8.3. Possible areas for future research

The question of who is most suited to receive benefit from a structured self-compassionate writing intervention is still left unanswered by the exploratory research contained in this thesis. Greater study of this question is likely to lead to treatments which are targeted to groups who may be at risk of developing body image disturbance. It could also potentially lead to the development of preventative interventions that could be implemented before treatment commences.

Some subgroups of women who may particularly benefit from self-compassionate activities have already been identified in other literature, and promising further avenues have been generated by research in this thesis (Study IV). A possible answer may lie in further exploring effects of the intervention for women who have high levels of appearance investment, particularly self-evaluative salience. Evidence exists which suggests that adjustment to visible differences is enhanced by placing less significance on one's appearance, and instead placing a greater value on one's other characteristics and qualities (Egan, Harcourt, & Rumsey, 2011). Self-compassion is recognised to work against conditional self-acceptance (Neff, 2003a), and hence may be most therapeutic for this subgroup. At the same time, impact of the intervention upon various age groups needs to be considered. Younger women may be less prepared for bodily losses related to their diagnosis, whereas older women may be struggling with an accumulation of losses from various aspects (social, cognitive, physical abilities). Although all women studied in this thesis were breast cancer survivors, their experience of losses were also different in some respects. As such, both these age groups may react differently from a self-compassion based intervention regarding their body image after breast cancer treatment.

In addition, other relevant factors are emerging in relation to self-compassion that may have had an impact upon effects of a self-compassion based intervention. Fear of self-

compassion has been recognised as an important factor influencing engagement in self-compassion based interventions, and individuals who exhibit high levels of fear may actively resist such experiences (Gilbert, McEwan, Matos, & Rivis, 2011). These individuals may find compassionate experiences uncomfortable due to many possible reasons such unfamiliarity with compassion, feeling undeserving of compassion, seeing self-compassion as a weakness, or compassionate feelings triggering difficult childhood experiences when compassion was needed from others but not received (Hermanto, et al., 2016). It would be of interest to investigate whether fear of self-compassion might also be a relevant factor in post-breast cancer body image disturbance. The effects of a structured self-compassion writing activity measuring subsequent levels of fear of compassion would shed further light on the effects of such an intervention.

Furthermore, the literature suggests that distress related to post-cancer body image alteration may be influenced more by individual features (such as relationships with early caregivers) than by characteristics of the disease, type of treatment received, or perceived social support. (Favez, et al., 2015). Hence, a broader number of personal characteristics may need investigation. Attachment theory may have a significant part to play in survivor distress. It has been generally acknowledged that various stressors can activate the attachment system and threat related schema (Ein-Dor & Hirschberger, 2016). Research has found that individuals with avoidant or anxious attachment styles display increased negative outcomes specifically regarding post-breast cancer body image distress (Favez, et al., 2015). In fact, body image may be the outcome of most concern amongst women with attachment difficulties, as their body betrays the fact to others that they have had to face a disease (Favez, et al., 2015). Favez and colleagues suggest that women with avoidant or anxious attachment styles should receive greater support in the post-breast cancer treatment period with regard to coping with body image alterations. Given that associations already exist between attachment experiences and self-compassion (Wei, Liao, Ku, & Shaffer, 2011), further investigation of attachment

style, body image disturbance and self-compassion based intervention amongst breast cancer survivors are indicated.

Other future directions may also involve closer investigation of the methodology of MCB administration. The possibility that repeated administration of self-compassion based writing may produce a stronger beneficial effect upon distress is a worthy area of future exploration. Other evidence suggests that the effects of self-compassion practices may be cumulative with practice (Albertson, et al., 2014), and therefore, booster sessions may be particularly beneficial for the individual. Furthermore, the effect of repeated practice may also help to extend the duration of effects for longer than a three-month period. This would need further exploration with longitudinal research to provide evidence of benefit and connection to various wellbeing outcomes.

It may also be helpful to explore the possible effects of tailoring instructions, content and frequency of MCB for future participants. This could be based on a woman's pre-existing level of trait self-compassion, by taking into account her background skills in this area. For example, some women may have a greater familiarity with self-compassionate approaches (such as these skills being modelled by family members), while for other women self-compassion may be an entirely new concept. Women with lower self-compassionate skills may benefit from greater psycho-educational content, simpler instructions and increased practice sessions (dose), and these possible enhanced outcomes could be ascertained by further research studies.

Other future directions may include investigation of qualitative information and analysis of writing content from MCB. This could be conducted in a number of ways, including use of the Linguistic Inquiry and Word Count (LIWC) specialised analysis program developed by Pennebaker (Pennebaker, Booth, Boyd, & Francis, 2017). Alternately, for women who find written activities challenging, qualitative information may be collected by audio or video recording as they speak about their thoughts.

8.4. Limitations

Various limitations need to be kept in mind when considering the results of this thesis. The first limitation is related to the scope of outcome measures used. Due to the nature of the study, all instruments were self-administered. These measures were also entirely based on participant self-report and no objective measures were employed. Due to the subjective nature of distress, body image disturbance and self-compassion, it is difficult to use objective outcomes for purposes of evaluation. In regard to self-compassion, very few alternate measures are available for this construct, and hence the majority of research in the field is reliant upon this single instrument (Lopez, et al., 2015). Future studies may be able to incorporate a broader range of measures including reports from participants' partners or family, access to medical records regarding issues of treatment / cosmesis, use of physiological information such as heart rate to indicate levels of distress, or even functional MRI to provide complementary neuropsychological data. This could assist in corroborating self-report data with information from other sources to build a more comprehensive picture of intervention impact.

The participant sample used for the studies in this thesis could also be considered to be a limitation. Data were collected from women who were members of breast cancer consumer organisations, English speaking, computer literate and mostly Australian-born. Therefore, women who were non-members of consumer organisations, non-English speaking and computer illiterate were excluded from contributing to the data collected. Consequently, the results obtained may not be representative of all breast cancer survivors. Women who are members of breast cancer consumer organisations may be particularly well informed and motivated with regard to their self-improvement during survivorship. As pointed out previously (Study II, Chapter 5), membership of a consumer organisation may impact upon a woman's sense of "common humanity", as she may have well-developed connections with other breast cancer survivors through their communication regarding a common experience of

cancer treatment. Conversely, women who are not members of breast cancer consumer organisations may have a greater sense of isolation regarding their experience, and have more difficulties experiencing common humanity. This of course may have important implications for successful research translation of the online self-compassion focused intervention. Future research could specifically target women who are not part of formal cancer organisations to explore their experience with the MCB intervention. It would be worthwhile to perform similar investigations amongst women who are computer illiterate and non-English speaking. Such research would evaluate the generalisability of findings in order to assist greater numbers of women in the future.

8.5. Conclusion

The findings from this thesis have important implications for women diagnosed with breast cancer and the health professionals who work with them. Given that a sub-set of breast cancer survivors are expected to experience body image disturbance and associated negative affect (Kornblith & Ligibel, 2003), it is important that women are assisted with evidence based interventions. Furthermore given that body image difficulties typically require cost, labour and resource intensive interventions (Lewis-Smith, et al., 2015), an alternative that is both resource effective and makes low demands on a woman for face to face attendance during treatment or survivorship, may be an attractive alternative to offer by the time pressured clinician.

This thesis has examined self-compassion both as a state and as a trait, and that a self-compassionate state can be induced in breast cancer survivors with regard to their body image changes. There is suggestion from other non-oncology areas (e.g. Albertson et al., 2014, Germer & Neff, 2013, Neff & Germer, 2013) that training to enhance self-compassionate states can influence self-compassion as a trait in the medium to longer term. This thesis has also investigated the varied roles of self-compassion as a mediator and moderator of breast

cancer related distress and negative affect, and therefore, has potentially introduced a novel avenue for both researchers and clinicians in this area.

Self-compassion enhancement is novel intervention for breast cancer survivors, and related outcomes have also been examined in this thesis. Self-compassion was found to be inversely related to body image disturbance and psychological distress in breast cancer survivors. Therefore, it is a logical point of potential intervention by the health professionals. Importantly through this research, it was ascertained that is not just the experience of negative bodily events alone that impacts a woman's affect and psychological distress, but also the influence of low levels of self-compassion. Self-compassion is an important influence on emotional regulation that may ameliorate the link between adverse experiences, bodily changes, negative affect and distress (Duarte, Ferreira, Trindade, & Pinto-Gouveia, 2015). This thesis has examined application of self-compassion theory to the needs of breast cancer survivors; and has also provided health professionals with a cost-effective, brief, self-administered writing activity to offer their clients.

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Appendices

Appendix A – Empirical Study I questionnaires

Appendix B – Empirical Study II questionnaires

Appendix C – Empirical Study III questionnaires

Appendix D – Empirical Study IV questionnaires

Appendix E – Ethical approval of studies

Appendix F – Awards and grants during candidature

Appendix G – Accepted conference presentations

Appendix H – Invited seminars

Appendix I – Overview of theoretical framework (summary sheet)

1. Appendix A – Empirical Study I

1.1. Participant information and consent – Study I

Welcome

You are invited to take part in a study of feelings towards eating, wellness and your body after treatment for breast or gynaecological cancer.

Purpose of the study

By completing this questionnaire, you will be helping to provide valuable information to help the research team understand the experiences and needs of women who have completed treatment for breast and gynaecological cancers.

This survey may also help increase the information communicated when you are seeking the assistance of a health professional.

Who is conducting the study?

The study is being conducted by Astrid Przezdziecki, Clinical Psychologist, who can be contacted on (02) 9828 5180, or via email astrid.przezdziecki@students.mq.edu.au.

This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of Dr Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Psychology Department Macquarie University.

What does the study involve?

If you decide to participate you will be asked to use an anonymous online questionnaire. You will be asked about some background information about yourself. You will also be asked about your opinions and experiences during treatment for your cancer. There are questions about your eating behaviours and your feelings towards your body.

It is expected that you will need no more than about 20-25 minutes to complete this questionnaire. If you wish to discuss any of the matters raised in the questionnaires please speak to the primary investigator (contact details listed below).

By filling out the survey, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the online questionnaire.

Your decision to participate in this survey is completely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions.

Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly

involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline (phone number 131120) or Lifeline Counselling Services (phone number 13 11 14) can provide more help. These services are provided free of charge.

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, Clinical Psychologist can be contacted by phone on (02) 9828 5180, or via email astrid.przezdziecki@students.mq.edu.au.

The ethical aspects of this study have been approved by the Macquarie University Ethics Review Committee (Human Research). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, fax [02] 9850 8799, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome

PARTICIPANT CONSENT

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study and commence the questionnaire

❍ YES

1.2. Questionnaire package – Empirical Study I

How old are you? Please enter your age in years

Marital Status: What is your marital status? (Please tick one answer)

- ❍ Single, never married
- ❍ Married / Partnership
- ❍ Divorced / Separated
- ❍ Widowed

Country of Birth: What is your country of birth? (Please tick one)

- ❍ Australia
- ❍ New Zealand
- ❍ Britain / Ireland
- ❍ Asia
- ❍ Middle East
- ❍ Western Europe
- ❍ Eastern Europe
- ❍ Pacific Islander
- ❍ Africa
- ❍ South America
- ❍ North America
- ❍ Other _____

Level of Education: What is your highest level of education? (Please tick one)

- ❍ Less than Year 8
- ❍ Year 8 to Year 11 (School Certificate)
- ❍ High School Certificate (HSC)
- ❍ Vocational Education / TAFE
- ❍ Some university study
- ❍ Bachelor's degree
- ❍ Post Graduate degree
- ❍ Doctoral degree

Current occupational status (Please tick one)

- ❍ Employed full-time
- ❍ Employed part-time
- ❍ Unemployed due to illness
- ❍ Unemployed
- ❍ Retired / Homemaker / Student
- ❍ Other (Please specify below) _____

Background Medical History – Breast Cancer

Have you ever been diagnosed with breast cancer?

- ❑ Yes
- ❑ No

If No (please move to next sec... Is Selected, Then Skip To End of Survey

The following question is displayed only if participants select having been diagnosed with breast cancer.

How long ago were you diagnosed with breast cancer? Please tick one.

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

What kinds of treatment did you receive for breast cancer? (Please tick all the treatments you received)

- ❍ Surgery
- ❍ Chemotherapy
- ❍ Radiation
- ❍ Hormonal treatments
- ❍ Other

How long has it been since you completed your active non-hormonal treatment (i.e. surgery, chemotherapy, radiation) for breast cancer? (Please tick one)

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

Are you currently receiving hormonal treatment for breast cancer? (Please tick one)

- ❍ Yes
- ❍ No

Background Medical History – Gynaecological Cancer

Have you ever been diagnosed with gynaecological cancer?

- ❑ Yes
- ❑ No

If No (please move to next sec... Is Selected, Then Skip To End of Survey

The following question is displayed only if participants select having been diagnosed with gynaecological cancer.

How long ago were you diagnosed with gynaecological cancer? Please tick one.

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

What kinds of treatment did you receive for gynaecological cancer? (Please tick all the treatments you received)

- ❍ Surgery
- ❍ Chemotherapy
- ❍ Radiation
- ❍ Hormonal treatments
- ❍ Other

How long has it been since you completed your active non-hormonal treatment (i.e. surgery, chemotherapy, radiation) for gynaecological cancer? (Please tick one)

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

Are you currently receiving hormonal treatment for gynaecological cancer? (Please tick one)

- ❍ Yes
- ❍ No

Experiences with Personal Body Weight

Has your weight changed at all since completing treatment (surgery, chemotherapy, radiation)?

- ❍ Yes
- ❍ No

If changed, did you lose or gain weight? Please tick one answer

- ❍ Lost weight
- ❍ Gained weight
- ❍ Not applicable, my weight did not change

How much did your weight change? Please enter number of kilograms below.

Do you feel comfortable with your present weight? Please tick one answer.

- ❍ Yes
- ❍ No

Do you feel your weight is: (Please tick one answer)

- ❍ Just right
- ❍ Under desired weight
- ❍ Over desired weight

Have you tried any weight reduction measures since completing treatment? Please tick one answer.

- ❍ Yes
- ❍ No
- ❍ Not applicable

What types of weight reduction methods have you used? Please tick one answer

- ❍ Exercise program
- ❍ Dietary program
- ❍ Both dietary and exercise programs

How many different programs have you tried? Please tick one answer

- ❍ 1
- ❍ 2
- ❍ 3-5
- ❍ More than 5 programs

Are you currently receiving weight management advice from another health professional? Please tick one answer.

- ❍ Yes
- ❍ No

Body Image

Do you feel that your current weight has had an impact on how you feel about your body? (Please chose the answer that best describes how you feel now).

- ❍ Feel much worse about myself
- ❍ Feel a bit worse about myself
- ❍ No impact
- ❍ Feel a bit better about myself
- ❍ Feel much better about myself

Have you experienced any pressure from others with regard to your weight?

- ❍ Yes
- ❍ No

If YES, from who? (Tick as many as apply)

- ❍ Yes – from my family
- ❍ Yes – from my friends, acquaintances, or co-workers
- ❍ Yes – from health professionals
- ❍ Yes – from media, advertising

Your Cancer Experience

Do you feel that your experience of cancer treatment has disrupted your usual eating behaviour? (Please choose the option below that best describes how you feel)

- ❍ Many more problems with eating
- ❍ Few more problems with eating
- ❍ No impact
- ❍ Few less problems with eating
- ❍ Much less problems with eating

Do you feel that your experience of cancer has disrupted your usual activity / exercise routines? (Please choose the option below that best describes how you feel)

- ❍ Many more problems with activity
- ❍ Few more problems with activity
- ❍ No impact
- ❍ Few less problems with activity
- ❍ Much less problems with activity

Do you feel that your experience of cancer treatment has impacted upon your usual weight? (Please chose the option below that best describes how you feel)

- ❍ Many more problems with weight
- ❍ Few more problems with weight
- ❍ No impact
- ❍ Few less problems with weight
- ❍ Much less problems with weight

Do you feel that your experience of cancer treatment has impacted upon your feelings about your body? (Please choose the option below that best describes how you feel)

- ❍ Feel much worse about my body
- ❍ Feel a bit worse about my body
- ❍ No impact
- ❍ Feel a bit better about my body
- ❍ Feel much better about my body

Do you worry about your current body weight since finishing treatment? (Please choose the option below that best describes how you feel)

- ❍ Many more worries
- ❍ Few more worries
- ❍ No impact
- ❍ Few less worries
- ❍ Much less worries

Mindful Eating Questionnaire (MEQ)

Please read each statement and consider how much it applies to you. Tick the answer that best describes you.

	Never /Rarely	Sometimes	Often	Usually / Always
I stop eating when I'm full even when eating something I love	❍	❍	❍	❍
When a restaurant portion is too large, I stop eating when I'm full	❍	❍	❍	❍
When I eat at "all you can eat" smorgasbords, I tend to overeat	❍	❍	❍	❍
If there are leftovers that I like, I take a second helping even though I'm full	❍	❍	❍	❍
If there is good food at a party, I'll continue eating even after I'm full	❍	❍	❍	❍
When I'm eating one of my favourite foods, I don't recognise when I've had enough	❍	❍	❍	❍
When I'm at a restaurant, I can tell when the portion I've been served is too large for me	❍	❍	❍	❍
If it doesn't cost much more, I get the larger food or drink regardless of how hungry I feel	❍	❍	❍	❍
I notice when there are subtle flavours in the foods I eat	❍	❍	❍	❍
Before I eat, I take a moment to appreciate the colours and smells of my food	❍	❍	❍	❍
I appreciate the way my food looks on my plate	❍	❍	❍	❍
When eating a pleasant meal, I notice if it makes me feel relaxed	❍	❍	❍	❍
I taste every bite of food that I eat	❍	❍	❍	❍
I notice when the food I eat affects my emotional state	❍	❍	❍	❍
I notice when foods and drinks are too sweet	❍	❍	❍	❍

I recognise when food advertisements make me want to eat	❍	❍	❍	❍
I notice when I'm eating from a bowl of lollies just because its there	❍	❍	❍	❍
I recognise when I'm eating and not hungry	❍	❍	❍	❍
I notice when just going into a movie theatre makes me want to eat lollies or popcorn	❍	❍	❍	❍
When I eat a big meal, I notice if it makes me feel heavy or sluggish	❍	❍	❍	❍

Depression, Anxiety and Stress Scale DASS-21

Please read each statement and chose a response which indicates how much the statement applied to you OVER THE PAST WEEK. There are no right or wrong answers. Do not spend too much time on any statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of the time	Applied to me very much, or most of the time
I find it hard to wind down	❍	❍	❍	❍
I was aware of dryness of my mouth	❍	❍	❍	❍
I couldn't seem to experience any positive feeling at all	❍	❍	❍	❍
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	❍	❍	❍	❍
I found it difficult to work up the initiative to do things	❍	❍	❍	❍
I tended to over-react to situations	❍	❍	❍	❍
I experienced trembling (eg, in the hands)	❍	❍	❍	❍
I felt that I was using a lot of nervous energy	❍	❍	❍	❍
I was worried about situations in which I might panic and make a fool of myself	❍	❍	❍	❍
I felt that I had nothing to look forward to	❍	❍	❍	❍
I found myself getting agitated	❍	❍	❍	❍
I found it difficult to relax	❍	❍	❍	❍
I felt down-hearted and blue	❍	❍	❍	❍
I was intolerant of anything that kept me from getting on with what I was doing	❍	❍	❍	❍
I felt I was close to panic	❍	❍	❍	❍
I was unable to become enthusiastic about anything	❍	❍	❍	❍

I felt that I wasn't worth much as a person	❍	❍	❍	❍
I felt that I was rather touchy	❍	❍	❍	❍
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	❍	❍	❍	❍
I felt scared without any good reason	❍	❍	❍	❍
I felt that life was meaningless	❍	❍	❍	❍

Body Image Scale BIS

In this section you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and choose the reply which comes closest to the way you have been feeling about yourself, DURING THE PAST WEEK.

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	❍	❍	❍	❍
Have you felt less physically attractive as a result or your disease or treatment?	❍	❍	❍	❍
Have you been dissatisfied with your appearance when dressed?	❍	❍	❍	❍
Have you been feeling less feminine as a result of your disease or treatment?	❍	❍	❍	❍
Did you find it difficult to look at yourself naked?	❍	❍	❍	❍
Have you been feeling less sexually attractive as a result of your disease or treatment?	❍	❍	❍	❍
Did you avoid people because of the way you felt about your appearance?	❍	❍	❍	❍
Have you been feeling the treatment has left your body less whole?	❍	❍	❍	❍
Have you felt dissatisfied with your body?	❍	❍	❍	❍
Have you been dissatisfied with the appearance of your scar?	❍	❍	❍	❍

Self-Compassion Scale SCS

Please read each statement carefully before answering. Next to each statement indicate how often you behaved like this towards yourself. Choose an answer based on the scale from "Almost never" to "Almost always"

	Almost never	Rarely	Sometimes	Quite Often	Almost always
I'm disapproving and judgmental about my own flaws and inadequacies	❍	❍	❍	❍	❍
When I'm feeling down I tend to obsess and fixate on everything that's wrong	❍	❍	❍	❍	❍
When things are going badly for me, I see the difficulties as part of life that everyone goes through	❍	❍	❍	❍	❍
When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world	❍	❍	❍	❍	❍
I try to be loving towards myself when I'm feeling emotional pain	❍	❍	❍	❍	❍
When I fail at something important to me I become consumed by feelings of inadequacy	❍	❍	❍	❍	❍
When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am	❍	❍	❍	❍	❍
When times are really difficult, I tend to be tough on myself	❍	❍	❍	❍	❍
When something upsets me, I try to keep my emotions in balance	❍	❍	❍	❍	❍
When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people	❍	❍	❍	❍	❍
I'm intolerant and impatient towards those aspects of my personality I don't like	❍	❍	❍	❍	❍
When I'm going through a very hard time, I give myself the caring and tenderness I need	❍	❍	❍	❍	❍
When I'm feeling down, I tend to feel like most other people are probably happier than I am	❍	❍	❍	❍	❍

When something painful happens I try to take a balanced view of the situation	❍	❍	❍	❍	❍
I try to see my failings as part of the human condition	❍	❍	❍	❍	❍
When I see aspects of myself that I don't like, I get down on myself	❍	❍	❍	❍	❍
When I fail at something important to me I try to keep things in perspective	❍	❍	❍	❍	❍
When I'm really struggling, I tend to feel like other people must be having an easier time of it	❍	❍	❍	❍	❍
I'm kind to myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When something upsets me I get carried away with my feelings	❍	❍	❍	❍	❍
I can be a bit cold-hearted towards myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When I'm feeling down I try to approach my feelings with curiosity and openess	❍	❍	❍	❍	❍
I'm intolerant of my own flaws and inadequacies	❍	❍	❍	❍	❍
When something painful happens I tend to blow the incident out of proportion	❍	❍	❍	❍	❍
When I fail at something that's important to me, I tend to feel alone in my failure	❍	❍	❍	❍	❍
I try to be understanding and patient to those aspects of my personality I don't like	❍	❍	❍	❍	❍

2. Appendix B – Empirical Study II

2.1. Participant information and consent – Study II

Welcome

You are invited to take part in a study of feelings towards your body after treatment for breast cancer

Purpose of the study

By completing this questionnaire, you will be helping to provide valuable information to help the research team understand the experiences and needs of women who have completed treatment for breast cancer.

This survey may also help increase the information communicated when you are seeking the assistance of a health professional.

Who is conducting the study?

The study is being conducted by Astrid Przezdziecki, Clinical Psychologist, who can be contacted on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au

This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of Dr Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Psychology Department Macquarie University.

What does the study involve?

This study has two parts.

The first part is an on-line survey to be filled in upon signing up for the study. You will be asked about some background information and your contact details (postal address, email and telephone number). The contact details will be used to send further information to you. You will be asked about your current feelings and the impact of cancer treatment upon your body. It is expected that you will need no more than 20 minutes to complete this on-line survey.

The second part of the study will be posted to you through the mail. You will be asked to do a short writing exercise and complete some surveys. You will be asked about your feelings and experiences during treatment for your cancer as well as its impact upon your body. You will be able to complete this activity in your own home. It is expected that this part will take no more than 45 minutes of your time. A return postage paid envelope will be provided for the return of surveys. You will be free to decide whether you wish to keep your writing exercise or to send it to the researchers in the postage paid envelope.

By filling out the survey, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the on-line questionnaire.

Your decision to participate in this survey is completely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions.

Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline (phone number 131120) or Lifeline Counseling Services (phone number 13 11 14) can provide more help. These services are provided free of charge.

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, Clinical Psychologist can be contacted by phone on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

PARTICIPANT CONSENT

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study and commence the questionnaire

❍ **YES**

2.2. Participant background questionnaire – Study II

Contact Information

Please entry your full name (first name and surname)

Please tell us your email address so that we can be in touch with you during the study

Please tell us your full postal address so that we can send the second part of the study to you through the mail

Please include your telephone number so that we can get in touch with you during the study (if additional contact is needed)

Background Questionnaire

How old are you? Please enter your age in years

Marital Status: What is your marital status? (Please tick one answer)

- ❍ Single, never married
- ❍ Married / Partnership
- ❍ Divorced / Separated
- ❍ Widowed

Country of Birth: What is your country of birth? (Please tick one)

- ❍ Australia
- ❍ New Zealand
- ❍ Britain / Ireland
- ❍ Asia
- ❍ Middle East
- ❍ Western Europe
- ❍ Eastern Europe
- ❍ Pacific Islander
- ❍ Africa
- ❍ South America
- ❍ North America
- ❍ Other _____

Level of Education: What is your highest level of education? (Please tick one)

- ❍ Less than Year 8
- ❍ Year 8 to Year 11 (School Certificate)
- ❍ High School Certificate (HSC)
- ❍ Vocational Education / TAFE
- ❍ Some university study
- ❍ Bachelor's degree
- ❍ Post Graduate degree
- ❍ Doctoral degree

Current occupational status (Please tick one)

- ❍ Employed full-time
- ❍ Employed part-time
- ❍ Unemployed due to illness
- ❍ Unemployed
- ❍ Retired / Homemaker / Student
- ❍ Other (Please specify below) _____

Background Medical History – Breast Cancer

Have you ever been diagnosed with breast cancer?

- ❑ Yes
- ❑ No

How long ago were you diagnosed with breast cancer? Please tick one.

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

What kinds of treatment did you receive for breast cancer? (Please tick all the treatments you received)

- ❍ Surgery
- ❍ Chemotherapy
- ❍ Radiation
- ❍ Hormonal treatments
- ❍ Other

How long has it been since you completed your active non-hormonal treatment (i.e. surgery, chemotherapy, radiation) for breast cancer? (Please tick one)

- ❍ Less than 1 year ago
- ❍ 1-2 years ago
- ❍ 2-3 years ago
- ❍ 3-4 years ago
- ❍ 5 or more years ago

Are you currently receiving hormonal treatment for breast cancer? (Please tick one)

- ❍ Yes
- ❍ No

Have you had reconstructive breast surgery after your treatment?

- ❍ Yes
- ❍ No

This question is displayed only if participants select having undergone reconstructive breast surgery.

What type of breast reconstruction have you had?

- ❍ Implant (saline or silicone)
- ❍ Nipple sparing mastectomy with implant
- ❍ TRAM Flap (Transverse rectus abdominus myocutaneous)
- ❍ LAT Flap (Latissimus dorsi)
- ❍ DIEP Flap (Deep inferior epigastric artery)
- ❍ SIEA Flap (Superficial inferior epigastric artery)

Body Appreciation Scale BAS

Please indicate by ticking whether the statements below are true about you: never, seldom, sometimes, often or always

	Never	Seldom	Sometimes	Often	Always
I respect my body	❍	❍	❍	❍	❍
I feel good about my body	❍	❍	❍	❍	❍
On the whole, I am satisfied with my body	❍	❍	❍	❍	❍
Despite its flaws, I accept my body for what it is	❍	❍	❍	❍	❍
I feel that my body has least some good qualities	❍	❍	❍	❍	❍
I take a positive attitude towards my body	❍	❍	❍	❍	❍
I am attentive to my body's needs	❍	❍	❍	❍	❍
My self worth is independent of my body shape or weight	❍	❍	❍	❍	❍
I do not focus a lot of energy being concerned with my body shape or weight	❍	❍	❍	❍	❍
My feelings towards my body are positive, for the most part	❍	❍	❍	❍	❍
I engage in healthy behaviours to take care of my body	❍	❍	❍	❍	❍
I do not allow unrealistically thin images of women presented in the media to affect my attitudes toward my body	❍	❍	❍	❍	❍
Despite its imperfections, I still like my body	❍	❍	❍	❍	❍

Depression, Anxiety and Stress Scale DASS-21

Please read each statement and chose a response which indicates how much the statement applied to you OVER THE PAST WEEK. There are no right or wrong answers. Do not spend too much time on any statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of the time	Applied to me very much, or most of the time
I find it hard to wind down	❍	❍	❍	❍
I was aware of dryness of my mouth	❍	❍	❍	❍
I couldn't seem to experience any positive feeling at all	❍	❍	❍	❍
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	❍	❍	❍	❍
I found it difficult to work up the initiative to do things	❍	❍	❍	❍
I tended to over-react to situations	❍	❍	❍	❍
I experienced trembling (eg, in the hands)	❍	❍	❍	❍
I felt that I was using a lot of nervous energy	❍	❍	❍	❍
I was worried about situations in which I might panic and make a fool of myself	❍	❍	❍	❍
I felt that I had nothing to look forward to	❍	❍	❍	❍
I found myself getting agitated	❍	❍	❍	❍
I found it difficult to relax	❍	❍	❍	❍
I felt down-hearted and blue	❍	❍	❍	❍
I was intolerant of anything that kept me from getting on with what I was doing	❍	❍	❍	❍
I felt I was close to panic	❍	❍	❍	❍
I was unable to become enthusiastic about anything	❍	❍	❍	❍

I felt that I wasn't worth much as a person	❍	❍	❍	❍
I felt that I was rather touchy	❍	❍	❍	❍
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	❍	❍	❍	❍
I felt scared without any good reason	❍	❍	❍	❍
I felt that life was meaningless	❍	❍	❍	❍

Body Image Scale BIS

In this section you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and choose the reply which comes closest to the way you have been feeling about yourself, DURING THE PAST WEEK.

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	❍	❍	❍	❍
Have you felt less physically attractive as a result or your disease or treatment?	❍	❍	❍	❍
Have you been dissatisfied with your appearance when dressed?	❍	❍	❍	❍
Have you been feeling less feminine as a result of your disease or treatment?	❍	❍	❍	❍
Did you find it difficult to look at yourself naked?	❍	❍	❍	❍
Have you been feeling less sexually attractive as a result of your disease or treatment?	❍	❍	❍	❍
Did you avoid people because of the way you felt about your appearance?	❍	❍	❍	❍
Have you been feeling the treatment has left your body less whole?	❍	❍	❍	❍
Have you felt dissatisfied with your body?	❍	❍	❍	❍
Have you been dissatisfied with the appearance of your scar?	❍	❍	❍	❍

Self-Compassion Scale SCS

Please read each statement carefully before answering. Next to each statement indicate how often you behaved like this towards yourself. Choose an answer based on the scale from "Almost never" to "Almost always"

	Almost never	Rarely	Sometimes	Quite Often	Almost always
I'm disapproving and judgmental about my own flaws and inadequacies	❍	❍	❍	❍	❍
When I'm feeling down I tend to obsess and fixate on everything that's wrong	❍	❍	❍	❍	❍
When things are going badly for me, I see the difficulties as part of life that everyone goes through	❍	❍	❍	❍	❍
When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world	❍	❍	❍	❍	❍
I try to be loving towards myself when I'm feeling emotional pain	❍	❍	❍	❍	❍
When I fail at something important to me I become consumed by feelings of inadequacy	❍	❍	❍	❍	❍
When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am	❍	❍	❍	❍	❍
When times are really difficult, I tend to be tough on myself	❍	❍	❍	❍	❍
When something upsets me, I try to keep my emotions in balance	❍	❍	❍	❍	❍
When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people	❍	❍	❍	❍	❍
I'm intolerant and impatient towards those aspects of my personality I don't like	❍	❍	❍	❍	❍
When I'm going through a very hard time, I give myself the caring and tenderness I need	❍	❍	❍	❍	❍
When I'm feeling down, I tend to feel like most other people are probably happier than I am	❍	❍	❍	❍	❍

When something painful happens I try to take a balanced view of the situation	❍	❍	❍	❍	❍
I try to see my failings as part of the human condition	❍	❍	❍	❍	❍
When I see aspects of myself that I don't like, I get down on myself	❍	❍	❍	❍	❍
When I fail at something important to me I try to keep things in perspective	❍	❍	❍	❍	❍
When I'm really struggling, I tend to feel like other people must be having an easier time of it	❍	❍	❍	❍	❍
I'm kind to myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When something upsets me I get carried away with my feelings	❍	❍	❍	❍	❍
I can be a bit cold-hearted towards myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When I'm feeling down I try to approach my feelings with curiosity and openess	❍	❍	❍	❍	❍
I'm intolerant of my own flaws and inadequacies	❍	❍	❍	❍	❍
When something painful happens I tend to blow the incident out of proportion	❍	❍	❍	❍	❍
When I fail at something that's important to me, I tend to feel alone in my failure	❍	❍	❍	❍	❍
I try to be understanding and patient to those aspects of my personality I don't like	❍	❍	❍	❍	❍

2.3. Experimental Questionnaires (Pre & Post), Writing Activity – Study II

Body Image after Breast Cancer Treatment

Directions:

Thank you for participating in this study. This activity will take approximately 45 minutes to complete.

Today's activity package is divided into two main parts: a writing exercise and survey. You will receive written directions on how to complete the activity in two envelopes (Part 1 and Part 2). Please open these envelopes in the correct order.

There will be a writing exercise and some questions about your thoughts and feelings before and after the writing exercise.

Please read the directions carefully on each page. You will be asked to complete a survey immediately before the writing exercise and complete another survey immediately after writing. Answer each question on the questionnaires as it applies to you right now. If a question is difficult to answer, please give your best answer based on the information, thoughts and feelings that you have right now, although you may leave questions unanswered if you do not feel comfortable answering the question(s). Each answer that you give is valuable to us and is strictly confidential.

After completing the writing exercise and both surveys, please use the stamped addressed envelope provided. We ask that you return the two questionnaires in these envelopes. You are free to decide whether you prefer to keep your writing exercise or return it in the provided envelope to share with the research team.

Thank you

PART 1: **Before** the writing exercise

Please take a moment to notice how you feel **right now** and rate your emotions on the scales below

Happy

1 Not at all	2	3	4	5	6	7 Extremely

Cheerful

1 Not at all	2	3	4	5	6	7 Extremely

Delighted

1 Not at all	2	3	4	5	6	7 Extremely

Pleased

1 Not at all	2	3	4	5	6	7 Extremely

Down

1 Not at all	2	3	4	5	6	7 Extremely

Depressed

1 Not at all	2	3	4	5	6	7 Extremely

Sad

1 Not at all	2	3	4	5	6	7 Extremely

Dejected

1 Not at all	2	3	4	5	6	7 Extremely

Irritated

1 Not at all	2	3	4	5	6	7 Extremely

Annoyed

1 Not at all	2	3	4	5	6	7 Extremely

Mad

1 Not at all	2	3	4	5	6	7 Extremely

Angry

1 Not at all	2	3	4	5	6	7 Extremely

Anxious

1 Not at all	2	3	4	5	6	7 Extremely

Tense

1 Not at all	2	3	4	5	6	7 Extremely

Uneasy

1 Not at all	2	3	4	5	6	7 Extremely

Nervous

1 Not at all	2	3	4	5	6	7 Extremely

Critical of myself

1 Not at all	2	3	4	5	6	7 Extremely

In touch with my own needs

1 Not at all	2	3	4	5	6	7 Extremely

Accepting of my body

1 Not at all	2	3	4	5	6	7 Extremely

Kind

1 Not at all	2	3	4	5	6	7 Extremely

Calm

1 Not at all	2	3	4	5	6	7 Extremely

Connected with my own emotions

1 Not at all	2	3	4	5	6	7 Extremely

Connected with others

1 Not at all	2	3	4	5	6	7 Extremely

Thank you. Please commence the writing exercise on the next page.

Writing Activity

Think about a negative event that you have experienced *about your body after having undergone breast cancer treatment*. This is an event that made you feel bad about yourself – something that involved failure, humiliation or rejection.

Describe the event and then provide details regarding what led up to it, who was present, precisely what happened, and how you felt and behaved at the time.

Please start writing on the next page using the paper provided. Please write according to the directions provided on each page.

- Please take one page to describe the event. (Introduction: 1 page)

- Think about how your body has changed through your experience with cancer diagnosis and treatment. Please write a paragraph about whether you have treated your body and yourself with kindness during this time.

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- Please write a paragraph showing understanding, kindness and concern for yourself. Write in the same way as you would help a friend who had undergone the experience.

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- Please write a paragraph about ways in which you think other women also experience similar events, (how other women may feel uncomfortable about their appearance or body at some stage of their lives).

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- Please look at your feelings using a bigger perspective of the situation. See if you can put some space between the event and your reactions. Think about all the issues that have contributed to the situation and write about your feelings using this outlook.

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Conclusion (1 page)

Write a self-compassionate letter to yourself, in other words, a letter of kindness to yourself. Perhaps extend this to a letter to all women. Having gone through the process of breast cancer treatment, what are some of the things you've needed to hear about your body? What are you needing to say to yourself? What would you say to all women who are struggling with these issues?

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Please open Envelope 2 <u>now</u> and start the questionnaire

PART 2: Immediately after the writing exercise

Please take a moment to notice how you feel **right now** and rate your emotions on the scales below

Happy

1 Not at all	2	3	4	5	6	7 Extremely

Cheerful

1 Not at all	2	3	4	5	6	7 Extremely

Delighted

1 Not at all	2	3	4	5	6	7 Extremely

Pleased

1 Not at all	2	3	4	5	6	7 Extremely

Down

1 Not at all	2	3	4	5	6	7 Extremely

Depressed

1 Not at all	2	3	4	5	6	7 Extremely

Sad

1 Not at all	2	3	4	5	6	7 Extremely

Dejected

1 Not at all	2	3	4	5	6	7 Extremely

Irritated

1 Not at all	2	3	4	5	6	7 Extremely

Annoyed

1 Not at all	2	3	4	5	6	7 Extremely

Mad

1 Not at all	2	3	4	5	6	7 Extremely

Angry

1 Not at all	2	3	4	5	6	7 Extremely

Anxious

1 Not at all	2	3	4	5	6	7 Extremely

Tense

1 Not at all	2	3	4	5	6	7 Extremely

Uneasy

1 Not at all	2	3	4	5	6	7 Extremely

Nervous

1 Not at all	2	3	4	5	6	7 Extremely

Critical of myself

1 Not at all	2	3	4	5	6	7 Extremely

In touch with my own needs

1 Not at all	2	3	4	5	6	7 Extremely

Accepting of my body

1 Not at all	2	3	4	5	6	7 Extremely

Kind

1 Not at all	2	3	4	5	6	7 Extremely

Calm

1 Not at all	2	3	4	5	6	7 Extremely

Connected with my emotions

1 Not at all	2	3	4	5	6	7 Extremely

Connected with others

1 Not at all	2	3	4	5	6	7 Extremely

Thank you - you have finished the writing exercise and surveys

Please put both surveys in the stamped envelope for return to the research team.

You are free to decide whether you wish to keep your writing exercise or share it with the research team. If you wish to share your writing exercise please also include it in the return envelope.

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline or Lifeline Counselling Services can provide more help. These services are provided free of charge. The contact details of these services are listed below.

NSW Cancer Council Helpline – phone number: 13 11 20

www.cancercouncil.com.au

Lifeline 24 hour Counselling Service – phone number: 13 11 14

www.lifeline.org.au

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, can be contacted on 9828 5180 or via email astrid.przezdziecki@students.mq.edu.au. This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of Dr Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Psychology Department Macquarie University.

2.4. Control Questionnaires (Pre & Post), Writing Activity – Study II

Body Image after Breast Cancer Treatment

Directions:

Thank you for participating in this study. This activity will take approximately 45 minutes to complete.

Today's activity package is divided into two main parts: a writing exercise and survey. You will receive written directions on how to complete the activity in two envelopes (Part 1 and Part 2). Please open these envelopes in the correct order.

There will be a writing exercise and some questions about your thoughts and feelings before and after the writing exercise.

Please read the directions carefully on each page. You will be asked to complete a survey immediately before the writing exercise and complete another survey immediately after writing. Answer each question on the questionnaires as it applies to you right now. If a question is difficult to answer, please give your best answer based on the information, thoughts and feelings that you have right now, although you may leave questions unanswered if you do not feel comfortable answering the question(s). Each answer that you give is valuable to us and is strictly confidential.

After completing the writing exercise and both surveys, please use the stamped addressed envelope provided. We ask that you return the two questionnaires in these envelopes. You are free to decide whether you prefer to keep your writing exercise or return it in the provided envelope to share with the research team.

Thank you

PART 1: **Before** the writing exercise

Please take a moment to notice how you feel **right now** and rate your emotions on the scales below

Happy

1 Not at all	2	3	4	5	6	7 Extremely

Cheerful

1 Not at all	2	3	4	5	6	7 Extremely

Delighted

1 Not at all	2	3	4	5	6	7 Extremely

Pleased

1 Not at all	2	3	4	5	6	7 Extremely

Down

1 Not at all	2	3	4	5	6	7 Extremely

Depressed

1 Not at all	2	3	4	5	6	7 Extremely

Sad

1 Not at all	2	3	4	5	6	7 Extremely

Dejected

1 Not at all	2	3	4	5	6	7 Extremely

Irritated

1 Not at all	2	3	4	5	6	7 Extremely

Annoyed

1 Not at all	2	3	4	5	6	7 Extremely

Mad

1 Not at all	2	3	4	5	6	7 Extremely

Angry

1 Not at all	2	3	4	5	6	7 Extremely

Anxious

1 Not at all	2	3	4	5	6	7 Extremely

Tense

1 Not at all	2	3	4	5	6	7 Extremely

Uneasy

1 Not at all	2	3	4	5	6	7 Extremely

Nervous

1 Not at all	2	3	4	5	6	7 Extremely

Critical of myself

1 Not at all	2	3	4	5	6	7 Extremely

In touch with my own needs

1 Not at all	2	3	4	5	6	7 Extremely

Accepting of my body

1 Not at all	2	3	4	5	6	7 Extremely

Kind

1 Not at all	2	3	4	5	6	7 Extremely

Calm

1 Not at all	2	3	4	5	6	7 Extremely

Connected with my own emotions

1 Not at all	2	3	4	5	6	7 Extremely

Connected with others

1 Not at all	2	3	4	5	6	7 Extremely

Thank you. Please commence the writing exercise on the next page

Writing Activity

Think about a negative event that you have experienced *about your body after having undergone breast cancer treatment*. This is an event that made you feel bad about yourself – something that involved failure, humiliation or rejection.

Describe in writing the event and then provide details regarding what led up to it, who was present, precisely what happened, and how you felt and behaved at the time.

Please start writing on the next page using the paper provided. Please write according to the directions provided on each page.

Introduce the event (1 page)

Describe the event (2 pages)

Describe the event (continued)

Please write a conclusion (1 page)

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Please open Envelope 2 <u>now</u> and start the questionnaire

PART 2: Immediately after the writing exercise

Please take a moment to notice how you feel **right now** and rate your emotions on the scales below

Happy

1 Not at all	2	3	4	5	6	7 Extremely

Cheerful

1 Not at all	2	3	4	5	6	7 Extremely

Delighted

1 Not at all	2	3	4	5	6	7 Extremely

Pleased

1 Not at all	2	3	4	5	6	7 Extremely

Down

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Depressed

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Dejected

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Uneasy

1 Not at all	2	3	4	5	6	7 Extremely

Nervous

1 Not at all	2	3	4	5	6	7 Extremely

Critical of myself

1 Not at all	2	3	4	5	6	7 Extremely

In touch with my own needs

1 Not at all	2	3	4	5	6	7 Extremely

Accepting of my body

1 Not at all	2	3	4	5	6	7 Extremely

Kind

1 Not at all	2	3	4	5	6	7 Extremely

Calm

1 Not at all	2	3	4	5	6	7 Extremely

Connected with my emotions

1 Not at all	2	3	4	5	6	7 Extremely

Connected with others

1 Not at all	2	3	4	5	6	7 Extremely

Thank you - you have finished the writing exercise and surveys

Please put both surveys in the stamped envelop for return to the research team.

You are free to decide whether you wish to keep your writing exercise or share it with the research team. If you wish to share your writing exercise please also include it in the return envelope.

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline or Lifeline Counselling Services can provide more help. These services are provided free of charge. The contact details of these services are listed below.

NSW Cancer Council Helpline – phone number: 13 11 20

www.cancercouncil.com.au

Lifeline 24 hour Counselling Service – phone number: 13 11 14

www.lifeline.org.au

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, can be contacted on 9828 5180 or via email astrid.przezdziecki@students.mq.edu.au. This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of Dr Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Psychology Department Macquarie University.

3. Appendix C – Empirical Study III

3.1. Participant information and consent – Consumers Study III

Welcome

You are invited to give feedback on a study website that provides survivors with a writing activity focused on feelings towards their body after treatment for breast cancer.

Purpose of the study

The purpose of this study is to assess user acceptability of a website developed as part of an online intervention for women with breast cancer.

Who is conducting the study?

The study is being conducted by Astrid Przezdziecki, Clinical Psychologist, who can be contacted on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au. This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of A/Prof Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Centre for Emotional Health, Department of Psychology, Macquarie University.

What does the study involve?

This study will require approximately 20 minutes of your time in total and will be conducted in two parts.

1) You will be asked to browse a website developed as an online intervention, which includes viewing all three webpages and navigating around the website. You will be asked to view a a home page with instructions for an activity and then click a button to view the activity itself. You will be asked to read the instructions but not be required to complete the activity. You will be encouraged to click the submission button and view the following information page. You will also be asked to view the "about" page which contains further information about the researchers conducting the study.

2) After viewing all the website pages, we ask that you complete a short survey where you can provide ratings of the website and other feedback.

By filling out the question below, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the on-line questionnaire.

Your decision to participate in this survey is completely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions.

Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

What can I do if I would like to speak more about my feelings?

If you are a breast cancer survivor and would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline (phone number 131120) or Lifeline Counseling Services (phone number 13 11 14) can provide more help. These services are provided free of charge.

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, Clinical Psychologist can be contacted by phone on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

PARTICIPANT CONSENT

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study by viewing the website then completing the feedback questionnaire

❍ YES

3.2. Participant information and consent - Health Professionals Study III

Welcome

You are invited to give feedback on a study website that provides survivors with a writing activity focused on feelings towards their body after treatment for breast cancer.

Purpose of the study

The purpose of this study is to assess user acceptability of a website developed as part of an online intervention for women with breast cancer.

Who is conducting the study?

The study is being conducted by Astrid Przezdziecki, Clinical Psychologist, who can be contacted on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au. This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of A/Prof Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Centre for Emotional Health, Department of Psychology, Macquarie University.

What does the study involve?

This study will require approximately 20 minutes of your time in total and will be conducted in two parts.

1) You will be asked to browse a website developed as an online intervention, which includes viewing all three webpages and navigating around the website. You will be asked to view a home page with instructions for an activity and then click a button to view the activity itself. You will be asked to read the instructions but not be required to complete the activity. You will be encouraged to click the submission button and view the following information page. You will also be asked to view the "about" page which contains further information about the researchers conducting the study.

2) After viewing all the website pages, we ask that you complete a short survey where you can provide ratings of the website and other feedback.

By filling out the question below, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the on-line questionnaire.

Your decision to participate in this survey is completely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions.

Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, Clinical Psychologist can be contacted by phone on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

PARTICIPANT CONSENT

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study by viewing the website then completing the feedback questionnaire

❍ YES

3.3. User Acceptability Questionnaire Consumers – Study III

Directions

Thank you for participating in this study. Please read the following directions:

Step 1: Please open a new browser window or tab and visit:

http://www.mychangedbody.org.au.

You will view a home page with instructions for a writing activity and will be encouraged to click a button to view the activity. You will not be required to complete the activity, only view the webpages and navigate through the website for the purposes of providing feedback.

Step 2: After viewing all of the webpages, we ask that you come back to this page to complete a short survey providing feedback about the website. When you have finished browsing the website, please click next (>>) to continue.

Please indicate your gender

- ❍ Male
- ❍ Female

Please tell us your email address so that we can use this to be in touch with you during the study.

Please enter your email address again in the space below.

How old are you? Please enter your age in years

Please rate your experience in using online activities provided through a website

- ❍ No or very low levels of experience
- ❍ Low level of experience
- ❍ Neutral - neither low or high experience
- ❍ High level experience
- ❍ Very high level experience

Have you ever been diagnosed with breast cancer or DCIS? (please tick one)

- ❍ Yes
- ❍ No

If No (please move to next sec... Is Selected, Then Skip To “The website appeals to me”

How long ago were you diagnosed with breast cancer or DCIS? Please write the number of MONTHS since your diagnosis below.

What category of breast cancer were you diagnosed with?

- ❍ Ductal Carcinoma in Situ (DCIS)
- ❍ Lobular Carcinoma in Situ (LCIS)
- ❍ Early breast cancer (breast cancer that has only affected the breast tissue, or both the breast tissue and lymph nodes under the arm)
- ❍ Secondary breast cancer (also known as advanced or metastatic breast cancer cancer; occurs when the breast cancer cells spread to other, more distant parts of the body such as the bones, liver or lungs)
- ❍ I don't know

Did you receive surgery for breast cancer?

- ❍ Yes
- ❍ No

Did you receive chemotherapy for breast cancer?

- ❍ Yes
- ❍ No

Did you receive radiation treatment (radiotherapy) for breast cancer?

- ❍ Yes
- ❍ No

Did you receive hormonal treatments (e.g. Tamoxifen, Arimidex, Aromasin, Femara) for breast cancer?

- ❍ Yes
- ❍ No

Did you receive targeted therapy (e.g. Herceptin, Tykerb) for breast cancer?

- ❍ Yes
- ❍ No

Have you had reconstructive breast surgery after your treatment?

- ❍ Yes
- ❍ No

Have you been diagnosed with lymphoedema?

- ❍ Yes
- ❍ No

Please indicate the extent to which you agree with each of the following statements.

The website appeals to me

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The home page is welcoming

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I want to look at all sections of the website

- ❍ Strongly disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The topic of this website is interesting

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

It only took me a short time to feel comfortable with the website

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The presentation is well organised

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The website is easy to navigate

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme is appropriate

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme is appealing

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme helps the website to be clear and easy to read

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I like the design of this website

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The information contained in the website is clear

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The instructions for the writing activity are easy to understand

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

When I look at the website, I know what to do next

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The website feels complete

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The information is useful

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The content is user friendly

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I would be happy to return to this website on another occasion

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

Please comment on what you liked about this website.

Please let us know what could be improved on this website.

Thank you for completing the questionnaire about this website. Your feedback is greatly appreciated.

3.4. User Acceptability Questionnaire Health Professionals – Study III

Directions

Thank you for participating in this study. Please read the following directions:

Step 1: Please open a new browser window or tab and visit:

http://www.mychangedbody.org.au.

You will view a home page with instructions for a writing activity and will be encouraged to click a button to view the activity. You will not be required to complete the activity, only view the webpages and navigate through the website for the purposes of providing feedback.

Step 2: After viewing all of the webpages, we ask that you come back to this page to complete a short survey providing feedback about the website. When you have finished browsing the website, please click next (>>) to continue.

Please indicate your gender

- ❍ Male
- ❍ Female

Please tell us your email address so that we can use this to be in touch with you during the study.

Please enter your email address again in the space below.

How old are you? Please enter your age in years

Please rate your experience in using online activities provided through a website

- ❍ No or very low levels of experience
- ❍ Low level of experience
- ❍ Neutral - neither low or high experience
- ❍ High level experience
- ❍ Very high level experience

Please indicate your specialty:

- ❍ Surgery
- ❍ Oncologist
- ❍ Nursing
- ❍ Physiotherapy
- ❍ Occupational therapy
- ❍ Social work
- ❍ Psychology
- ❍ Other

How many years have you been working in the field of oncology? Please write the number of years below:

The website appeals to me

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The home page is welcoming

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I want to look at all sections of the website

- ❍ Strongly disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The topic of this website is interesting

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

It only took me a short time to feel comfortable with the website

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The presentation is well organised

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The website is easy to navigate

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme is appropriate

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme is appealing

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The colour scheme helps the website to be clear and easy to read

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I like the design of this website

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The information contained in the website is clear

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The instructions for the writing activity are easy to understand

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

When I look at the website, I know what to do next

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The website feels complete

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The information is useful

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

The content is user friendly

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

I would be happy to return to this website on another occasion

- ❍ Strongly Disagree
- ❍ Disagree
- ❍ Neither Agree nor Disagree
- ❍ Agree
- ❍ Strongly Agree

Please comment on what you liked about this website.

Please let us know what could be improved on this website.

Thank you for completing the questionnaire about this website. Your feedback is greatly appreciated.

4. Appendix D – Empirical Study IV

4.1. Participant information and consent – Study IV

Welcome

You are invited to take part in a study of feelings towards your body after treatment for breast cancer

Purpose of the study

The purpose of the study is to further understand women's experiences with how they feel about themselves, their body, weight and appearance after completing treatment for cancer.

Who is conducting the study?

The study is being conducted by Astrid Przezdziecki, Clinical Psychologist, who can be contacted on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au This research is being conducted to meet the requirements for the degree of Doctor of Philosophy (Psychology) under the supervision of A/Prof Kerry Sherman, ph 9850 6874, email kerry.sherman@mq.edu.au, Centre for Emotional Health, Department of Psychology, Macquarie University.

What does the study involve?

This study has two parts.

The first part is an on-line questionnaire to be filled in upon signing up for the study, and then follow up questionnaires one week, one month and 3 months after completing a writing activity. You will be asked about some background information and your contact details (name, phone, email address) in the first questionnaire. You will also be asked about your current feelings and the impact of cancer treatment upon your body. Your contact details will be used to email web links so that you can complete questionnaires on the three follow up occasions. It is expected that you will need no more than 30 minutes to complete each on-line questionnaire.

The second part of the study involves doing a writing activity. You will be allocated to one of two writing groups (structured or unstructured writing formats). You will be asked to do a writing exercise which will be on a website. You will be asked to write about your feelings and experiences during treatment for your cancer as well as its impact upon your body. You will be able to complete this activity in your own home using the password protected website. It is expected that this part will take about 30 minutes of your time. This activity is completely anonymous, your writing will not be saved and it cannot be accessed by anyone.

By filling out the questionnaire, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the on-line questionnaire.

Your decision to participate in this survey is completely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions.

Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline (phone number 131120) or Lifeline Counseling Services (phone number 13 11 14) can provide more help. These services are provided free of charge.

How can I get more information?

You may contact the primary investigator (Astrid Przezdziecki) if you have any questions regarding this research. Astrid Przezdziecki, Clinical Psychologist can be contacted by phone on (02) 9762 5301, or via email astrid.przezdziecki@students.mq.edu.au

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

PARTICIPANT CONSENT

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study and commence the questionnaire

❍ YES

4.2. Participant online questionnaires – Study IV

Directions

Thank you for participating in this study. This section will take about 30 minutes to complete. You will be asked for your contact details (email address) so that the link to the online writing activity can be sent to you after completing this questionnaire. In this questionnaire you will be asked some background information and questions about how you are feeling right now. Please read the directions carefully on each page. Unless otherwise indicated, answer each question as it applies to you right now. If a question is difficult to answer, please give your best answer based on the information, thoughts and feelings that you have right now, although you may leave questions unanswered if you do not feel comfortable answering the question(s). Each answer that you give is valuable to us and is strictly confidential.

Thank you

Please enter your full name (first and last name below)

First name
Last name

Please tell us your email address so that we can use this to be in touch with you during the study.

Please enter your email address again in the space below.

Please enter your best contact number in space below in case we need to get in touch with you.

How old are you? Please enter your age in years

Marital Status: What is your marital status? (Please tick one answer)

- ❍ Single, never married
- ❍ Married / Partnership
- ❍ Divorced / Separated
- ❍ Widowed

Country of Birth: What is your country of birth? (Please tick one)

- ❍ Australia
- ❍ New Zealand
- ❍ Britain / Ireland
- ❍ Asia
- ❍ Middle East
- ❍ Western Europe
- ❍ Eastern Europe
- ❍ Pacific Islander
- ❍ Africa
- ❍ South America
- ❍ North America
- ❍ Other _____

Level of Education: What is your highest level of education? (Please tick one)

- ❍ Less than Year 8
- ❍ Year 8 to Year 11 (School Certificate)
- ❍ High School Certificate (HSC)
- ❍ Vocational Education / TAFE
- ❍ Some university study
- ❍ Bachelor's degree
- ❍ Post Graduate degree
- ❍ Doctoral degree

Current occupational status (Please tick one)

- ❍ Employed full-time
- ❍ Employed part-time
- ❍ Unemployed due to illness
- ❍ Unemployed
- ❍ Retired / Homemaker / Student
- ❍ Other (Please specify below) _____

Have you ever been diagnosed with breast cancer or DCIS?

- ❑ Yes, breast cancer
- ❑ Yes, DCIS
- ❑ Yes, both breast cancer and DCIS
- ❑ No

If No (please move to next sec... Is Selected, Then Skip To End of Survey

The following question is displayed only if participants select having been diagnosed with breast cancer or both breast cancer and DCIS.

How long ago were you diagnosed with breast cancer? Please write the number of MONTHS since your diagnosis below.

The following question is displayed only if participants select having been diagnosed with DCIS or both breast cancer and DCIS.

Q70 How long ago were you diagnosed with DCIS? Please write the number of MONTHS since your diagnosis below.

The following question is displayed only if participants select having been diagnosed with breast cancer or breast cancer and DCIS

What stage of breast cancer were you diagnosed with?

- ❍ Stage 1 breast cancer
- ❍ Stage 2 breast cancer
- ❍ Stage 3 breast cancer
- ❍ Stage 4 breast cancer
- ❍ I don't know

Did you receive surgery for breast cancer or DCIS?

- ❍ Yes
- ❍ No

Did you receive chemotherapy for breast cancer or DCIS?

- ❍ Yes
- ❍ No

Did you receive radiation treatment (radiotherapy) for breast cancer or DCIS?

- ❍ Yes
- ❍ No

Did you receive hormonal treatments for breast cancer or DCIS?

- ❍ Yes
- ❍ No

Have you had reconstructive breast surgery after your treatment?

- ❍ Yes
- ❍ No

This question is displayed only if participants select having undergone reconstructive breast surgery.

What type of breast reconstruction have you had?

- ❍ Implant (saline or silicone)
- ❍ Nipple sparing mastectomy with implant
- ❍ TRAM Flap (Transverse rectus abdominus myocutaneous)
- ❍ LAT Flap (Latissimus dorsi)
- ❍ DIEP Flap (Deep inferior epigastric artery)
- ❍ SIEA Flap (Superficial inferior epigastric artery)

Positive and Negative Affect Scale PANAS

This scale consists of a number of words that describe different feelings and emotions. Read each item and then select to what extent you feel this way right now, that is, at the present moment.

	Not at all	A little	Moderately	Quite a bit	Extremely
Interested	❍	❍	❍	❍	❍
Distressed	❍	❍	❍	❍	❍
Excited	❍	❍	❍	❍	❍
Upset	❍	❍	❍	❍	❍
Strong	❍	❍	❍	❍	❍
Guilty	❍	❍	❍	❍	❍
Scared	❍	❍	❍	❍	❍
Hostile	❍	❍	❍	❍	❍
Enthusiastic	❍	❍	❍	❍	❍
Proud	❍	❍	❍	❍	❍
Irritable	❍	❍	❍	❍	❍
Alert	❍	❍	❍	❍	❍
Ashamed	❍	❍	❍	❍	❍
Inspired	❍	❍	❍	❍	❍
Nervous	❍	❍	❍	❍	❍
Determined	❍	❍	❍	❍	❍
Attentive	❍	❍	❍	❍	❍
Jittery	❍	❍	❍	❍	❍
Active	❍	❍	❍	❍	❍
Afraid	❍	❍	❍	❍	❍

Body Appreciation Scale BAS

Please indicate by ticking whether the statements below are true about you: never, seldom, sometimes, often or always

	Never	Seldom	Sometimes	Often	Always
I respect my body	❍	❍	❍	❍	❍
I feel good about my body	❍	❍	❍	❍	❍
On the whole, I am satisfied with my body	❍	❍	❍	❍	❍
Despite its flaws, I accept my body for what it is	❍	❍	❍	❍	❍
I feel that my body has least some good qualities	❍	❍	❍	❍	❍
I take a positive attitude towards my body	❍	❍	❍	❍	❍
I am attentive to my body's needs	❍	❍	❍	❍	❍
My self worth is independent of my body shape or weight	❍	❍	❍	❍	❍
I do not focus a lot of energy being concerned with my body shape or weight	❍	❍	❍	❍	❍
My feelings towards my body are positive, for the most part	❍	❍	❍	❍	❍
I engage in healthy behaviours to take care of my body	❍	❍	❍	❍	❍
I do not allow unrealistically thin images of women presented in the media to affect my attitudes toward my body	❍	❍	❍	❍	❍
Despite its imperfections, I still like my body	❍	❍	❍	❍	❍

Depression, Anxiety and Stress Scale DASS-21

Please read each statement and chose a response which indicates how much the statement applied to you OVER THE PAST WEEK. There are no right or wrong answers. Do not spend too much time on any statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of the time	Applied to me very much, or most of the time
I find it hard to wind down	❍	❍	❍	❍
I was aware of dryness of my mouth	❍	❍	❍	❍
I couldn't seem to experience any positive feeling at all	❍	❍	❍	❍
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	❍	❍	❍	❍
I found it difficult to work up the initiative to do things	❍	❍	❍	❍
I tended to over-react to situations	❍	❍	❍	❍
I experienced trembling (eg, in the hands)	❍	❍	❍	❍
I felt that I was using a lot of nervous energy	❍	❍	❍	❍
I was worried about situations in which I might panic and make a fool of myself	❍	❍	❍	❍
I felt that I had nothing to look forward to	❍	❍	❍	❍
I found myself getting agitated	❍	❍	❍	❍
I found it difficult to relax	❍	❍	❍	❍
I felt down-hearted and blue	❍	❍	❍	❍
I was intolerant of anything that kept me from getting on with what I was doing	❍	❍	❍	❍
I felt I was close to panic	❍	❍	❍	❍
I was unable to become enthusiastic about anything	❍	❍	❍	❍

I felt that I wasn't worth much as a person	❍	❍	❍	❍
I felt that I was rather touchy	❍	❍	❍	❍
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	❍	❍	❍	❍
I felt scared without any good reason	❍	❍	❍	❍
I felt that life was meaningless	❍	❍	❍	❍

Impact of Event Scale – Revised IES-R

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your breast cancer treatment. How much were you distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Any reminder brought back feelings about it	❍	❍	❍	❍	❍
I had trouble staying asleep	❍	❍	❍	❍	❍
Other things kept making me think about it	❍	❍	❍	❍	❍
I felt irritable and angry	❍	❍	❍	❍	❍
I avoided letting myself get upset when I thought about it or was reminded of it.	❍	❍	❍	❍	❍
I thought about it when I didn't mean to	❍	❍	❍	❍	❍
I felt as if it hadn't happened or wasn't real...	❍	❍	❍	❍	❍
I stayed away from reminders of it	❍	❍	❍	❍	❍
Pictures about it popped into my mind	❍	❍	❍	❍	❍
I was jumpy and easily startled	❍	❍	❍	❍	❍
I tried not to think about it	❍	❍	❍	❍	❍
I was aware that I still had a lot of feelings about it, but I didn't deal with them	❍	❍	❍	❍	❍
My feelings about it were kind of numb	❍	❍	❍	❍	❍
I found myself to be acting or feeling like I was back at that time	❍	❍	❍	❍	❍
I had trouble falling asleep	❍	❍	❍	❍	❍
I had waves of strong feelings about it	❍	❍	❍	❍	❍
I tried to remove it from my memory	❍	❍	❍	❍	❍

I had trouble concentrating	❍	❍	❍	❍	❍
Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea or a pounding heart	❍	❍	❍	❍	❍
I had dreams about it	❍	❍	❍	❍	❍
I felt watchful and on-guard	❍	❍	❍	❍	❍
I tried not to talk about it	❍	❍	❍	❍	❍

Body Image Scale BIS

In this section you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and choose the reply which comes closest to the way you have been feeling about yourself, DURING THE PAST WEEK.

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	❍	❍	❍	❍
Have you felt less physically attractive as a result or your disease or treatment?	❍	❍	❍	❍
Have you been dissatisfied with your appearance when dressed?	❍	❍	❍	❍
Have you been feeling less feminine as a result of your disease or treatment?	❍	❍	❍	❍
Did you find it difficult to look at yourself naked?	❍	❍	❍	❍
Have you been feeling less sexually attractive as a result of your disease or treatment?	❍	❍	❍	❍
Did you avoid people because of the way you felt about your appearance?	❍	❍	❍	❍
Have you been feeling the treatment has left your body less whole?	❍	❍	❍	❍
Have you felt dissatisfied with your body?	❍	❍	❍	❍
Have you been dissatisfied with the appearance of your scar?	❍	❍	❍	❍

Beliefs about Appearance Questionnaire – ASI-R Short Form

The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally disagree or agree with each statement. There are no right or wrong answers. Just be truthful about your personal beliefs.

	Strongly disagree	Mostly disagree	Neither agree or disagree	Mostly agree	Strongly agree
I spend little time on my physical appearance	❍	❍	❍	❍	❍
When I see good-looking people, I wonder about how my own looks measure up	❍	❍	❍	❍	❍
I try to be as physically attractive as I can be	❍	❍	❍	❍	❍
I have never paid much attention to what I look like	❍	❍	❍	❍	❍
I seldom compare my appearance to that of other people I see	❍	❍	❍	❍	❍
I often check my appearance in a mirror just to make sure I look okay	❍	❍	❍	❍	❍
When something makes me feel good or bad about my looks, I tend to dwell on it	❍	❍	❍	❍	❍
If I like how I look on a given day, it's easy to feel happy about other things	❍	❍	❍	❍	❍
If somebody had a negative reaction to what I look like, it wouldn't bother me	❍	❍	❍	❍	❍
When it comes to my physical appearance, I have high standards	❍	❍	❍	❍	❍
My physical appearance has had little influence on my life	❍	❍	❍	❍	❍
Dressing well is not a priority for me	❍	❍	❍	❍	❍
When I meet people for the first time, I wonder what they think about how I look	❍	❍	❍	❍	❍

In my everyday life, lots of things happen that make me think about what I look like	❍	❍	❍	❍	❍
If I dislike how I look on a given day, it's hard to feel happy about other things	❍	❍	❍	❍	❍
I fantasize about what it would be like to be better looking than I am	❍	❍	❍	❍	❍
Before going out, I make sure that I look as good as I possibly can	❍	❍	❍	❍	❍
What I look like is an important part of who I am	❍	❍	❍	❍	❍
By controlling my appearance, I can control may of the social and emotional events in my life	❍	❍	❍	❍	❍
My appearance is responsible for much of what's happened to me in my life	❍	❍	❍	❍	❍

Self-Compassion Scale SCS

Please read each statement carefully before answering. Next to each statement indicate how often you behaved like this towards yourself. Choose an answer based on the scale from "Almost never" to "Almost always"

	Almost never	Rarely	Sometimes	Quite Often	Almost always
I'm disapproving and judgmental about my own flaws and inadequacies	❍	❍	❍	❍	❍
When I'm feeling down I tend to obsess and fixate on everything that's wrong	❍	❍	❍	❍	❍
When things are going badly for me, I see the difficulties as part of life that everyone goes through	❍	❍	❍	❍	❍
When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world	❍	❍	❍	❍	❍
I try to be loving towards myself when I'm feeling emotional pain	❍	❍	❍	❍	❍
When I fail at something important to me I become consumed by feelings of inadequacy	❍	❍	❍	❍	❍
When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am	❍	❍	❍	❍	❍
When times are really difficult, I tend to be tough on myself	❍	❍	❍	❍	❍
When something upsets me, I try to keep my emotions in balance	❍	❍	❍	❍	❍
When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people	❍	❍	❍	❍	❍
I'm intolerant and impatient towards those aspects of my personality I don't like	❍	❍	❍	❍	❍
When I'm going through a very hard time, I give myself the caring and tenderness I need	❍	❍	❍	❍	❍
When I'm feeling down, I tend to feel like most other people are probably happier than I am	❍	❍	❍	❍	❍

When something painful happens I try to take a balanced view of the situation	❍	❍	❍	❍	❍
I try to see my failings as part of the human condition	❍	❍	❍	❍	❍
When I see aspects of myself that I don't like, I get down on myself	❍	❍	❍	❍	❍
When I fail at something important to me I try to keep things in perspective	❍	❍	❍	❍	❍
When I'm really struggling, I tend to feel like other people must be having an easier time of it	❍	❍	❍	❍	❍
I'm kind to myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When something upsets me I get carried away with my feelings	❍	❍	❍	❍	❍
I can be a bit cold-hearted towards myself when I'm experiencing suffering	❍	❍	❍	❍	❍
When I'm feeling down I try to approach my feelings with curiosity and openess	❍	❍	❍	❍	❍
I'm intolerant of my own flaws and inadequacies	❍	❍	❍	❍	❍
When something painful happens I tend to blow the incident out of proportion	❍	❍	❍	❍	❍
When I fail at something that's important to me, I tend to feel alone in my failure	❍	❍	❍	❍	❍
I try to be understanding and patient to those aspects of my personality I don't like	❍	❍	❍	❍	❍

What can I do if I would like to speak more about my feelings?

If you would like to receive emotional support or further discuss your experiences of cancer treatment, the NSW Cancer Council Helpline or Lifeline Counseling Services can provide more help. These services are provided free of charge. The contact details of these services are listed below.

NSW Cancer Council Helpline - phone number: 13 11 20, www.cancercouncil.com.au

Lifeline 24 hour Counseling Service - phone number 13 11 14www.lifeline.org.au

In addition, the BCNA's online service directory may also list counsellors in your area - visit www.bcna.org.au > Sharing & support > Find services in your area. Thank you for completing the questionnaire.

Please click the button (>>) below to be taken to the second part of this study. You will be redirected to a website with instructions on how to complete the activity.

5. Appendix E – Ethical approval of studies

5.1. Ethics approval of empirical study I

Office of the Deputy Vice-Chancellor
(Research)

Research Office
Research Hub, Building C5C East
Macquarie University
NSW 2109 Australia
T: +61 (2) 9850 4459
http://www.research.mq.edu.au/
ABN 90 952 801 237

MACQUARIE University
SYDNEY·AUSTRALIA

22 April 2016

Ms Astrid Przezdziecki
Department of Psychology
Faculty of Human Sciences
Macquarie University
NSW 2109

Dear Ms Przezdziecki

Reference No: HE27NOV2009-D00198

Title: *Mindful Eating Investigation in Women Diagnosed with Breast/Gynaecological Cancers: Impact upon self-esteem and body image*

This letter is to confirm that the ethics application cited above met the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

The application received approval from the Macquarie University Human Research Ethics Committee on 13 January 2010. An amendment to the application was approved on 8 April 2010.

The above project was conducted by Ms Astrid Przezdziecki, PhD candidate, under the supervision of Associate Professor Andrew Baillie and Associate Professor Kerry Sherman.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Dr Karolyn White
Director, Research Ethics & Integrity
Chair, Macquarie University Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

5.2. Ethics approval of empirical study II

From: Ethics Secretariat <ethics.secretariat@mq.edu.au>

Date: Fri, 15 Jun 2012 12:03:24 +1000
Subject: Approved- Ethics application- Sherman (Ref: 5201200298)
To: Dr Kerry Sherman <kerry.sherman@mq.edu.au>
Cc: Ms Astrid Przezdziecki <astrid.przezdziecki@students.mq.edu.au>

Dear Dr Sherman

Re: "Pilot Study: Short term self-compassion exercise for body image in breast cancer survivors" (Ethics Ref: 5201200298)

Thank you for your recent correspondence. Your response has addressed the issues raised by the Human Research Ethics Committee and you may now commence your research.

This research meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). The National Statement is available at the following web site:

http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72.pdf.

The following personnel are authorised to conduct this research:

Dr Kerry Sherman
Ms Astrid Przezdziecki

NB. STUDENTS: IT IS YOUR RESPONSIBILITY TO KEEP A COPY OF THIS APPROVAL EMAIL TO SUBMIT WITH YOUR THESIS.

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Human Research (2007).

2. Approval will be for a period of five (5) years subject to the provision of annual reports.

Progress Report 1 Due: 15 June 2013
Progress Report 2 Due: 15 June 2014
Progress Report 3 Due: 15 June 2015
Progress Report 4 Due: 15 June 2016
Final Report Due: 15 June 2017

NB. If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

4. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

http://www.mq.edu.au/policy/

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have final approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

Please retain a copy of this email as this is your official notification of final ethics approval.

Yours sincerely
Dr Karolyn White
Director of Research Ethics
Chair, Human Research Ethics Committee

5.3. Ethics approval of online empirical studies III and IV

Office of the Deputy Vice-Chancellor
(Research)

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http://www.research.mq.edu.au/
ABN 90 952 801 237

MACQUARIE University
SYDNEY·AUSTRALIA

5 February 2015

A/Prof Kerry Sherman
Department of Psychology
Faculty of Human Sciences
MACQUARIE UNIVERSITY NSW 2109

Dear A/Prof Sherman

Reference No: 5201401083

Title: *"Online Self-Compassion Activity for Body Image in Breast Cancer Survivors"*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)) at its meeting on 27 November 2014 at which further information was requested to be reviewed by the Ethics Secretariat.

The requested information was received with correspondence on 20 January 2015.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

This letter constitutes ethical and scientific approval only.

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement,* which is available at the following website:

http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

Professor Tony Eyers
Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

Details of this approval are as follows:

Approval Date: 5 February 2015

The following documentation has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
Correspondence from Ms Jessica Alcorso responding to the issues raised by the HREC (Medical Sciences)		Received 20/01/2015
Invitation to Participate – User Acceptability	2	29/10/2014
Invitation to Participate – Main Study	2	29/10/2014
Part 1 – User Acceptability Questionnaire – Consumers	3	29/10/2014
Part 1 – User Acceptability Questionnaire – Health Professionals	3	29/10/2014
Part 2 – Stream A (Breast Cancer) Questionnaire	3	29/10/2014
Part 2 – Stream B (Lymphoedema) Questionnaire	3	29/10/2014
Participant Questionnaire		

6. Appendix F – Awards and grants during candidature

6.1. Australasian Society of Behavioural Health and Medicine Award

From: Kerry Sherman [mailto:kerry.sherman@mq.edu.au]
Sent: Monday, 7 February 2011 8:41 AM
To: Astrid Przezdziecki; Astrid Przezdziecki
Cc: Sheleigh Lawler
Subject: Congratulations from ASBHM

Dear Astrid,

On behalf of the ASBHM Program Committee, I would like to congratulate you on submitting an excellent Rapid Comminucations Poster abstract. The committee has judged your abstract to be of a very high standard, and accordingly we are awarding you a $250 Travel Scholarship to attend the conference. Congratulations! Please contact the ASBHM Treasurer, Dr Sheleigh Lawler via email (s.lawler@sph.uq.edu.au) to arrange for your payment.

I hope that you enjoy the conference.

Regards,
Kerry.

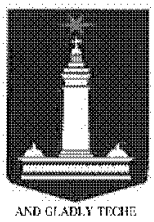
Dr Kerry Sherman
Centre for Emotional Health

President, Australasian Society for Behavioural Health and Medicine

Department of Psychology
Macquarie University NSW 2109
AUSTRALIA
Ph: +61 2 09850 6874
Fax: +61 2 9850 8062

6.2. Centre for Emotional Health Student Publication of the Year

MACQUARIE UNIVERSITY



This is to certify that

Astrid Przezdziecki

was awarded the 2012

Centre for Emotional Health Student Publication Prize

for publication in the journal with the highest journal citation impact factor

EXECUTIVE DEAN

REGISTRAR

6.3. Liverpool Cancer Therapy Allied Health Award

UNSW | Health South Western Sydney Local Health District

Date: May 2012

Title: University of NSW Oncology Research Award

Recipient: Astrid Przezdziecki

Dear Astrid

Congratulations, you have been successful in your application for the University of NSW Oncology Research Award to cover costs for travel and accommodation up to $2,500 to attend the International Psycho-Oncology Society 14th World Congress and COSAs 39th Annual Scientific Meeting in Brisbane in November.

These funds are awarded on a re-imbursement basis, and can be accessed by providing receipts up to the value of $2,500 to Narelle Barnett who will assist you in expediting this claim, by completing an S1 form, and obtaining appropriate approvals and follow-up on your payment.

Kind regards

Dion Forstner Sandy Avery

UNSW

University of NSW Oncology Research Award
Liverpool Hospital

AWARDED TO

Astrid Przezdziecki

$2,500^{00}

Health South Western Sydney Local Health District

6.4. COSA – PoCoG Conference Grant.

Clinical Oncological Society of Australia

PoCoG

OZPOS

Award

COSA-PoCoG-OZPOS Travel Grant

Presented to:

Astrid Przezdziecki

2012 Annual Scientific Meeting

Impact through Translation: Cancer Research Informing Practice

Prof Bogda Koczwara
COSA President

Prof Phyllis Butow
PoCoG Chair

Dr Haryana Dhillon
OZPOS President

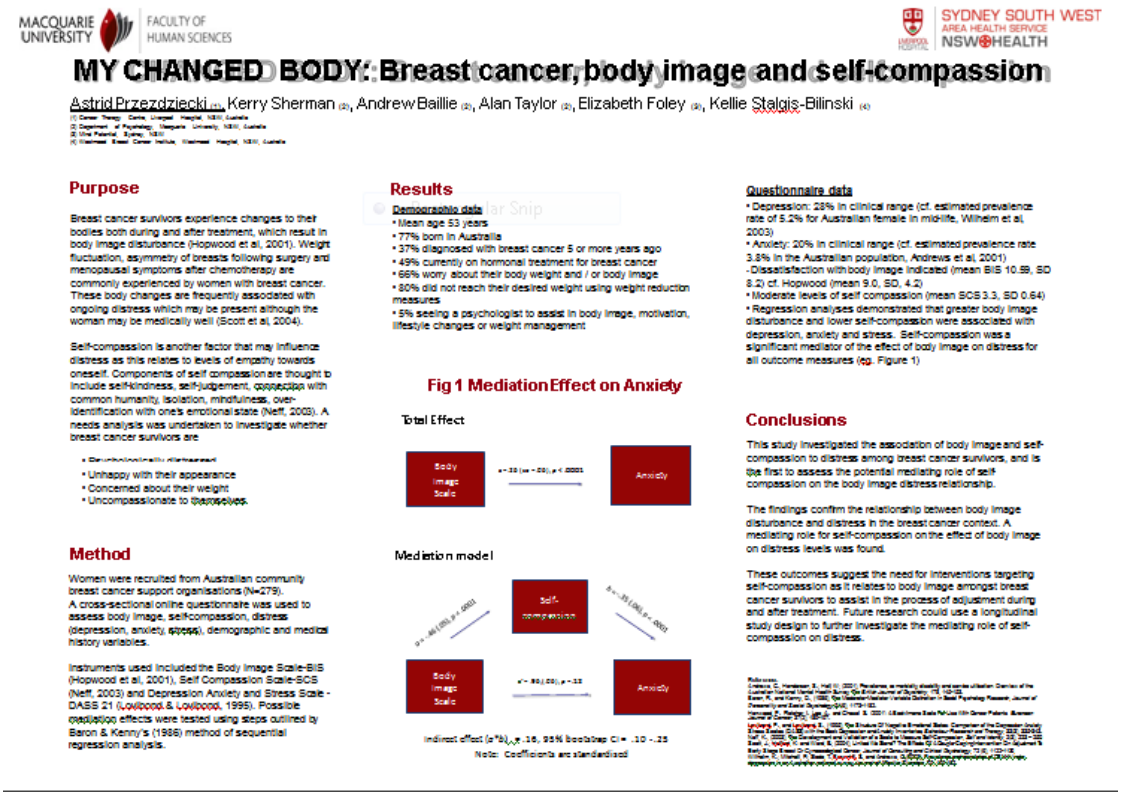
The COSA ASM is Australia's largest and most diverse oncology meeting, each year bringing together hundreds of Australian and international cancer care professionals and researched from a wide range of disciplines.

7. Appendix G – Accepted conference presentations

7.1. Australasian Society of Behavioural Health and Medicine

Australasian Society of Behavioural Health and Medicine (ASBHM), Christchurch New Zealand, February 2011

ASBHM Travel Grant recipient



MACQUARIE UNIVERSITY | FACULTY OF HUMAN SCIENCES

SYDNEY SOUTH WEST AREA HEALTH SERVICE | NSW HEALTH

MY CHANGED BODY: Breast cancer, body image and self-compassion

Astrid Przezdziecki [1], Kerry Sherman [2], Andrew Baillie [2], Alan Taylor [2], Elizabeth Foley [3], Kellie Stalgis-Bilinski [4]

Purpose

Breast cancer survivors experience changes to their bodies both during and after treatment, which result in body image disturbance (Hopwood et al, 2001). Weight fluctuation, asymmetry of breasts following surgery and menopausal symptoms after chemotherapy are commonly experienced by women with breast cancer. These body changes are frequently associated with ongoing distress which may be present although the woman may be medically well (Scott et al, 2004).

Self-compassion is another factor that may influence distress as this relates to levels of empathy towards oneself. Components of self compassion are thought to include self-kindness, self-judgement, connection with common humanity, isolation, mindfulness, over-identification with one's emotional state (Neff, 2003). A needs analysis was undertaken to investigate whether breast cancer survivors are

- Unhappy with their appearance
- Concerned about their weight
- Uncompassionate to themselves

Method

Women were recruited from Australian community breast cancer support organisations (N=279). A cross-sectional online questionnaire was used to assess body image, self-compassion, distress (depression, anxiety, stress), demographic and medical history variables.

Instruments used included the Body Image Scale-BIS (Hopwood et al, 2001), Self Compassion Scale-SCS (Neff, 2003) and Depression Anxiety and Stress Scale - DASS 21 (Lovibond & Lovibond, 1995). Possible mediation effects were tested using steps outlined by Baron & Kenny's (1986) method of sequential regression analysis.

Results

Demographic data
- Mean age 53 years
- 77% born in Australia
- 37% diagnosed with breast cancer 5 or more years ago
- 49% currently on hormonal treatment for breast cancer
- 66% worry about their body weight and / or body image
- 80% did not reach their desired weight using weight reduction measures
- 5% seeing a psychologist to assist in body image, motivation, lifestyle changes or weight management

Fig 1 Mediation Effect on Anxiety

Total Effect

Mediation model

Indirect effect ($a*b$)$_{xy}$ = .16, 95% bootstrap CI = .10 -.25

Note: Coefficients are standardised

Questionnaire data
- Depression: 28% in clinical range (cf. estimated prevalence rate of 5.2% for Australian female in mid-life, Wilhelm et al, 2003)
- Anxiety: 20% in clinical range (cf. estimated prevalence rate 3.8% in the Australian population, Andrews et al, 2001)
- Dissatisfaction with body image indicated (mean BIS 10.99, SD 8.2) cf. Hopwood (mean 9.0, SD, 4.2)
- Moderate levels of self compassion (mean SCS 3.3, SD 0.64)
- Regression analyses demonstrated that greater body image disturbance and lower self-compassion were associated with depression, anxiety and stress. Self-compassion was a significant mediator of the effect of body image on distress for all outcome measures (eg. Figure 1)

Conclusions

This study investigated the association of body image and self-compassion to distress among breast cancer survivors, and is the first to assess the potential mediating role of self compassion on the body image distress relationship.

The findings confirm the relationship between body image disturbance and distress in the breast cancer context. A mediating role for self-compassion on the effect of body image on distress levels was found.

These outcomes suggest the need for interventions targeting self-compassion as it relates to body image amongst breast cancer survivors to assist in the process of adjustment during and after treatment. Future research could use a longitudinal study design to further investigate the mediating role of self-compassion on distress.

7.2. IPOS-COSA Congress

International Psycho-Oncology Society (IPOS) and Clinical Oncology Society of Australia (COSA) Congress, Brisbane, Australia, November 2012

COSA-PoCoG-OZPOS Travel Grant recipient

MACQUARIE UNIVERSITY

MODIFYING BODY IMAGE RELATED RESPONSES IN BREAST CANCER SURVIVORS USING A SELF-COMPASSION BASED WRITING ACTIVITY

Kerry A. Sherman[1,2], Astrid Przezdziecki[1] , Elisabeth Foley [3],

[1]*Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, Australia*
[2]*Westmead Breast Cancer Institute, Westmead Hospital, Sydney, Australia*
[3]*Mind Potential, Sydney, Australia*

BACKGROUND

The needs of breast cancer survivors regarding post treatment body image adjustment are not always adequately met in survivorship. Self-compassion, the capacity to adopt a kind, caring attitude to oneself in times of distress or loss, has been linked with decreased psychological distress across a number of domains (Neff, 2003 a,b). Research among non-oncology populations has confirmed the association between self-compassion and a healthy body image (Wasylkiw et al. 2012).

Aim: Self-compassion enhancement programs are in their infancy , and based upon available evidence, a novel intervention using a structured writing activity was developed for use in a breast cancer population. The aim of the study was to determine the affective and cognitive impact of inducing a self-compassionate outlook in breast cancer survivors regarding adverse bodily changes.

METHODS

Participants were recruited through an Australian breast cancer consumer organisation with N=105 included in the final study (Figure 1). All participants were female, aged over 18 years and had an adequate command of the English language and computer skills.

An online background questionnaire was completed initially (Table 1) to gather demographic, medical and self-compassion data. Participants were asked to complete a paper based writing activity that focussed on their body image difficulties. Women were randomly allocated to one of two writing conditions (unstructured writing or writing using self-compassionate prompts). Both conditions required participants to write for approximately 4 pages. Participant self rating of affect (low-irritable, anxious, positive) and cognitions reflecting a body focussed self-compassionate mindset were assessed immediately prior to, and following, completion of the writing activity. Affective and cognitive mean scores were calculated with a possible range from 1-7, using a format previously utilised in self-compassion interventions (Leary et al. 2007).

RESULTS

- **MANCOVA controlling for pre-intervention levels of affect and mindset indicated a significant main effect for the experimental condition** $F(4, 98) = 3.39$, $p=0.01$, $\eta_p^2 = 0.12$
- **Univariate tests revealed significantly lower low/irritable affect, improved positive affect and greater body focussed self-compassionate mindset in the experimental group compared with participants in the control condition, (Table 2)**
- **No significant interactions were found between baseline levels of self-compassion and writing condition** $F(4, 96) = 0.52$, $p=0.72$.

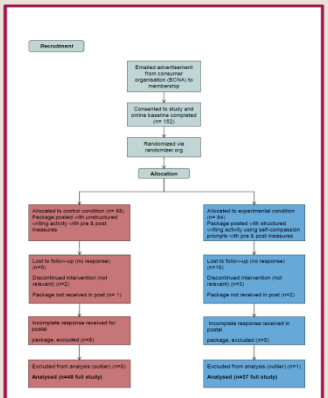


Figure 1: Study flow diagram

VARIABLES	MEAN (SD) or *n* (%)
Age	54.55 (9.79)
Marital status ***Married or partnered***	114(75.5%)
Country of birth ***Australia***	121 (80.1%)
Education ***University & above***	91(60.7%)
Chemotherapy	107 (71.3%)
Radiation	101 (66.9%)
Hormonal treatment	71 (46%)
Time since diagnosis	
<1 year	17 (11.5%)
1-2 years	19 (12.8%)
2-3 years	21 (14.2%)
3-4 years	43 (29.1%)
≥ 5 years	48 (32.4%)

Table 1: Selected demographic and medical information

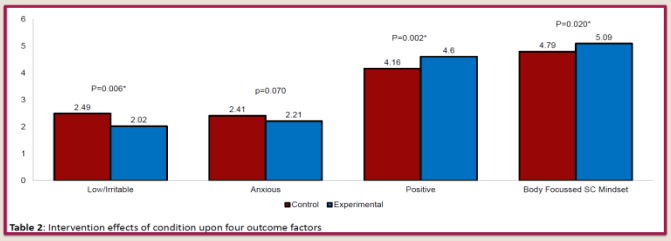


Table 2: Intervention effects of condition upon four outcome factors

CONCLUSIONS

This study is the first of its kind to evaluate the effects of self-compassionate writing for women who have experienced bodily alteration due to breast cancer treatment. When exposed to the memory of a distressing event related to body image, women in the experimental condition who were given self-compassionate focussed writing prompts displayed decreased low/irritable affect, improved positive affect and increased body focussed self-compassionate mindset , compared with the responses of women in the control condition who undertook an unstructured writing task. A self-compassionate approach may assist in the regulation of negative affect and the maintenance of positive affect towards oneself when faced with difficult body image experiences during survivorship.

A self-compassionate mindset also appears to have been activated by writing about ones experiences according to prompts, with these individuals displaying greater levels of thoughts, attitudes and perspectives associated with a self-compassionate outlook.

This quick, cost effective, self-administered writing activity produced immediate effects upon both affective and cognitive responses, and lends itself to many possible clinical applications both as an adjunct to existing programs for survivors or as a stand alone activity.

BCI westmead breast cancer institute

FURTHER INFORMATION:

Contact A/Prof Kerry A. Sherman

EMAIL: kerry.sherman@mq.edu.au

PHONE: +61 407 920 583

References:

Leary, M., Tate, E., Adams, C., Allen, A., Hancock, J., (2007). Self-compassion and reactions to unpleasant events: The implications of treating oneself kindly. *Journal of Personality and Social Psychology,* 92: 887-904. Doi:10.1037/0022-3514.92.5.887

Neff, K., (2003a). Self-compassion: An alternate conceptualization of a healthy attitude toward oneself: *Self and Identity,* 4, 263-287

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7.3. International Congress of Behavioral Medicine (ICBM)

Groningen, The Netherlands, 20-23rd August 2014 – Poster Presentation

MACQUARIE UNIVERSITY

Modifying Body Image Related Responses in Breast Cancer Survivors Using a Self-Compassion Based Writing Activity

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[2]Westmead Breast Cancer Institute, Westmead Hospital, Sydney, Australia

BACKGROUND

The needs of breast cancer survivors regarding post treatment body image adjustment are not always adequately met in survivorship. Self-compassion, the capacity to adopt a kind, caring attitude to oneself in times of distress or loss, has been linked with decreased psychological distress across a number of domains (Neff, 2003 a,b). Research among non-oncology populations has confirmed the association between self-compassion and a healthy body image (Wasylkiw et al. 2012).

Aim: Self-compassion enhancement programs are in their infancy , and based upon available evidence, a novel intervention using a structured writing activity was developed for use in a breast cancer population. The aim of the study was to determine the affective and cognitive impact of inducing a self-compassionate outlook in breast cancer survivors regarding adverse bodily changes.

METHODS

Participants were recruited through an Australian breast cancer consumer organisation with N=105 included in the final study (Figure 1). All participants were female, aged over 18 years and had an adequate command of the English language and computer skills.

An online background questionnaire was completed initially (Table 1) to gather demographic, medical and self-compassion data. Participants were asked to complete a paper based writing activity that focussed on their body image difficulties. Women were randomly allocated to one of two writing conditions (unstructured writing or writing using self-compassionate prompts). Both conditions required participants to write for approximately 4 pages. Participant self rating of affect (low-irritable, anxious, positive) and cognitions reflecting a body focussed self-compassionate mindset were assessed immediately prior to, and following, completion of the writing activity. Affective and cognitive mean scores were calculated with a possible range from 1-7, using a format previously utilised in self-compassion interventions (Leary et al. 2007).

RESULTS

- MANCOVA controlling for pre-intervention levels of affect and mindset indicated a significant main effect for the experimental condition $F(4, 98) = 3.39$, $p=0.01$, $\eta_p^2 = 0.12$
- Univariate tests revealed significantly lower low/irritable affect, improved positive affect and greater body focussed self-compassionate mindset in the experimental group compared with participants in the control condition, (Table 2)
- No significant interactions were found between baseline levels of self-compassion and writing condition $F(4, 96) = 0.52$, $p=0.72$.

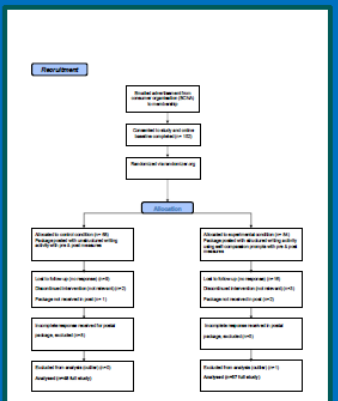

Figure 1: Study flow diagram

VARIABLES	MEAN (SD) or *n* (%)
Age	54.55 (9.79)
Marital status	
Married or partnered	114(75.5%)
Country of birth	
Australia	121 (80.1%)
Education	
University & above	91(60.7%)
Chemotherapy	107 (71.3%)
Radiation	101 (66.9%)
Hormonal treatment	71 (46%)
Time since diagnosis	
<1 year	17 (11.5%)
1-2 years	19 (12.8%)
2-3 years	21 (14.2%)
3-4 years	43 (29.1%)
≥ 5 years	48 (32.4%)

Table 1: Selected demographic and medical information

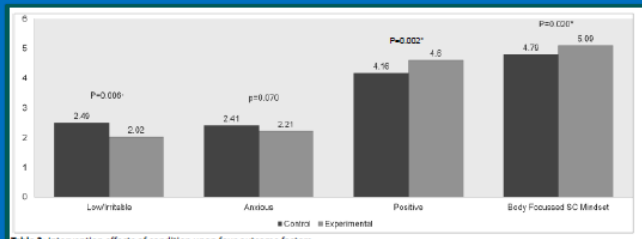

Table 2: Intervention effects of condition upon four outcome factors

CONCLUSIONS

This study is the first of its kind to evaluate the effects of self-compassionate writing for women who have experienced bodily alteration due to breast cancer treatment. When exposed to the memory of a distressing event related to body image, women in the experimental condition who were given self-compassionate focussed writing prompts displayed decreased low/irritable affect, improved positive affect and increased body focussed self-compassionate mindset , compared with the responses of women in the control condition who undertook an unstructured writing task. A self-compassionate approach may assist in the regulation of negative affect and the maintenance of positive affect towards oneself when faced with difficult body image experiences during survivorship.

A self-compassionate mindset also appears to have been activated by writing about ones experiences according to prompts, with these individuals displaying greater levels of thoughts, attitudes and perspectives associated with a self-compassionate outlook.

This quick, cost effective, self-administered writing activity produced immediate effects upon both affective and cognitive responses, and lends itself to many possible clinical applications both as an adjunct to existing programs for survivors or as a stand alone activity.

BCI westmead breast cancer institute

FURTHER INFORMATION:

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References:

Leary, M., Tate, E., Adams, C., Allen, A., Hancock, J., (2007). Self-compassion and reactions to unpleasant events: The implications of treating oneself kindly. *Journal of Personality and Social Psychology*, 92: 887-904. Doi:10.1037/0022-3514.92.5.887

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7.4. World Cancer Congress (WCC)

WCC, Melbourne, Australia December 2014 – E Poster Presentation

2014 MELBOURNE AUSTRALIA | JOINING FORCES – ACCELERATING PROGRESS | UICC WORLD CANCER CONGRESS

Modifying body image related affect & cognitions in breast cancer survivors using a self-compassion based writing activity

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Macquarie University, Australia
Liverpool Hospital, Australia
Westmead Breast Cancer Institute, Australia

EP5.3

Abstract 730

Disclosure of Interest: None Declared

Background

- Body image difficulties can cause ongoing distress for some survivors
- Self-compassion (SC) is the ability to direct kindness & warmth to oneself during times of difficulty
- SC interventions are not routinely used in psycho-oncology
- Proof of concept needed that a SC writing activity would show potential benefits in assisting survivors' affect and cognitions.

Method

- N= 105 survivors
- Control (n=48) unstructured expressive writing
- Experimental (n=57) writing according to SC prompts
- Writing length 4 pages

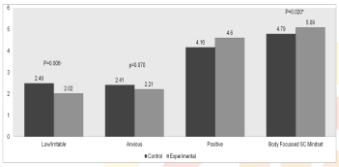
Outcomes

Writing topic: own distressing body image experiences

Pre – immediate post results indicate

- Less low / irritable affect
- Improved positive affect
- Greater SC mindset

compared with control subjects

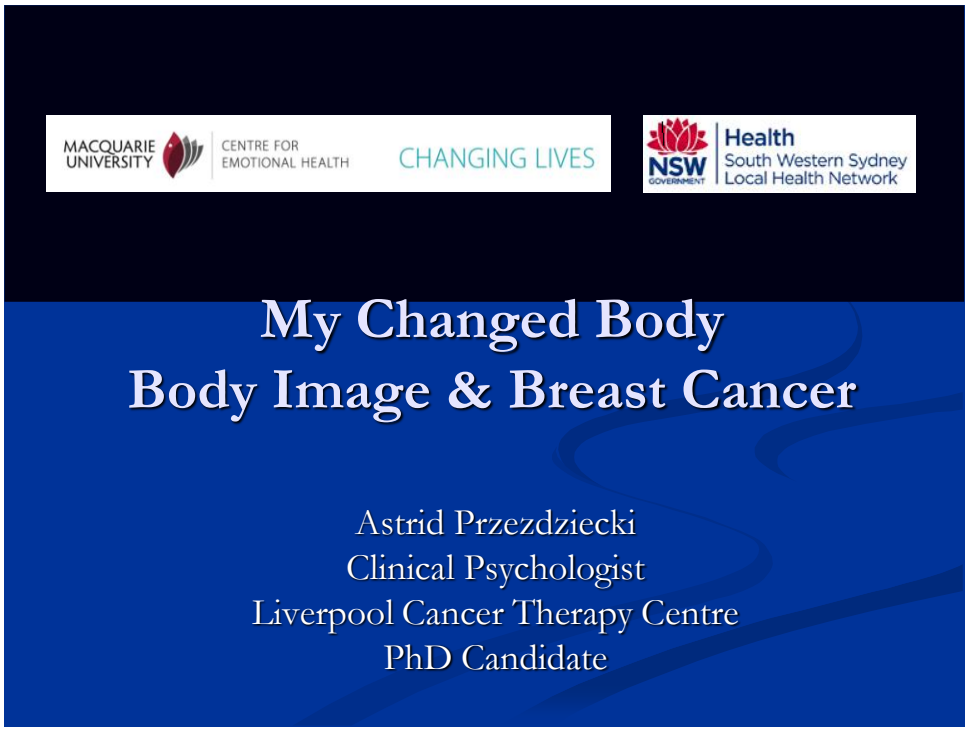


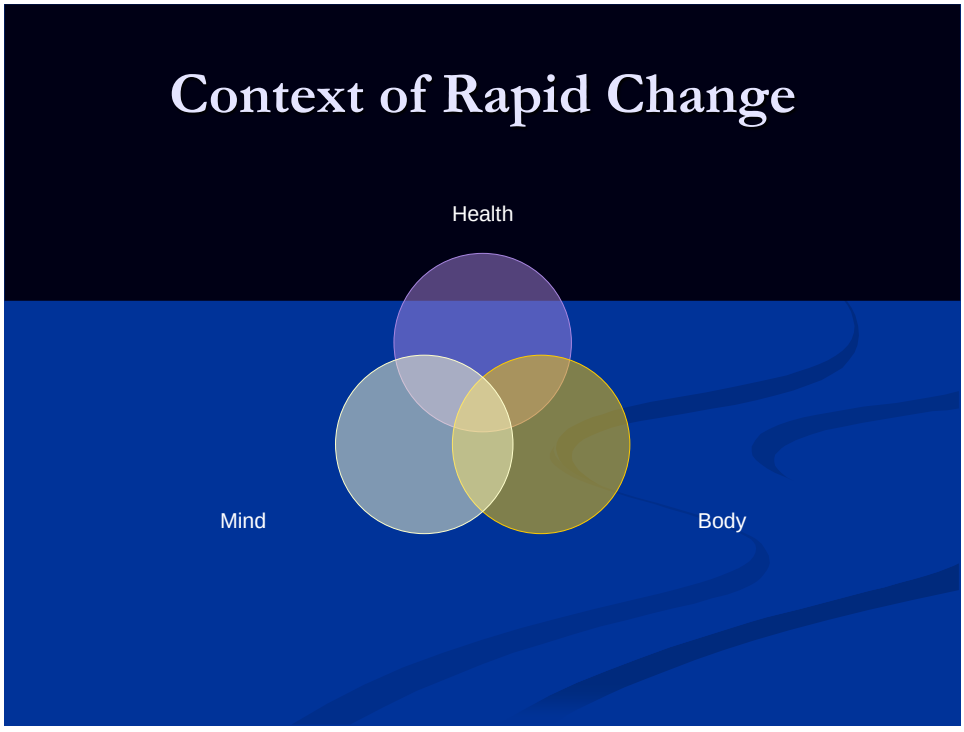
Preliminary evidence for use of SC writing as low cost, simple activity with immediate results for breast cancer survivors faced with body image distress

8. Appendix H – Invited seminars

8.1. Association of Genetic Support of Australia (AGSA)

Presentation for women with genetic risk towards breast cancer on 9th October 2011





What is body image?

- What is body image?
- What happens to a woman's body after treatment? What are the additional difficulties?

What is body image?

- How we see or perceive our body.
- Influenced by many factors such as family, culture, media
- Often tied in with self-judgement and comparison with others
- Further challenged with medical treatments or surgery

Breast Treatment

- May be preventive or curative
- May involve loss of part of a breast, a total breast or both breasts
- May be combined with other treatments (further surgery, chemotherapy, radiation, hormone treatments)

Impact

- Sudden
- Often quick and short preparation
- Immediate changes (both visible and non-visible changes)
- Ongoing changes (depending on treatment)
- Unsure how to discuss the topic
- Others may not know how to best offer support
- Pressures from media and society

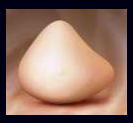
Change

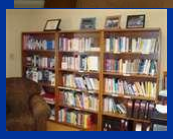
- A woman's body changes over time – it is inevitable and part of life
- Often a gradual process
  - Puberty
  - Pregnancy
  - Menopause
  - Aging
- Such changes are expected and understood
- Understandable desire to fit in with society

Knowing what to expect…

- Information
  - Cancer council – prosthesis literature
  - Breast Care Nurse – support, information and referral. Look Good Feel Better Program
  - Breast reconstruction and surgical options (implant or fat transfer). Techniques becoming more detailed, eg nipple reconstruction

Personalised Options




Psychological Reactions

- Often mixed feelings which also change with time
- A helpful approach from others and oneself can make a big difference in coping with rapid changes


Permanent changes…

- Sensation
- Movement (esp if arm or arm pit is involved)
- Size
- Appearance (esp. scarring)
- Reminder of the diagnosis and experience of medical treatment

Common & Normal Reactions to Changes in Body Image

- People have four basic, normal responses in reaction to circumstances, events, experiences
  - Happiness
  - Anger
  - Fear
  - Sadness

- Can have more than one feeling at time

Happiness / Relief

- Normal reaction to a pleasurable event or removal of a problem
  - I'm glad that something can be done
  - I'm fortunate to have a treatment program
  - I'm relieved that the tests have come back okay
  - I'll organise to have surgical reconstruction later

Fear

- Normal reaction to uncertainty or threat of danger
  - What if …?

Anger

- Normal reaction to a situation of unfairness or injustice
  - This shouldn't be happening to me.
  - I've been doing all the right things but still had to have surgery!
  - Why was I born into a family with a genetic predisposition? I didn't know about this earlier.
  - My friends don't have to face this – they just don't understand what it is like

Sadness

- Normal reaction to loss
  - My life will never be the same again
  - I have so many clothes that I can't wear anymore
  - I cannot carry heavy things in my affected arm and have to be careful in the future
  - Sensation on my chest is different now

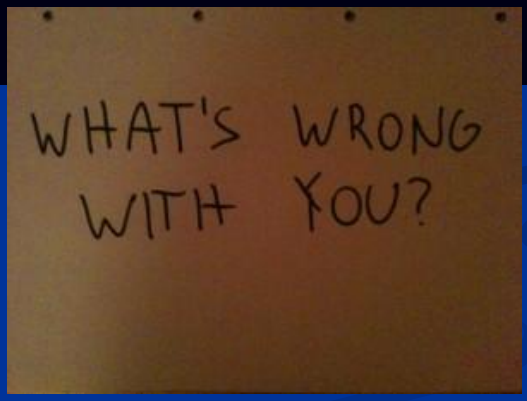
Reactions

- All are normal and understandable
- Feelings do change with time
- Gradual adjustment needed to such quick changes – giving oneself adequate time, information and support
- Gratitude increases as sadness diminishes
- Getting used to a changed body, having enough time to do this without pressure

What if things are not improving?

- Things to watch…
  - Mood: strong, severe emotions that don't shift and interfere with daily activities (work, home duties) – can't cope
  - Thoughts: Feeling "stuck" in distressing thoughts, like a loop or broken record
  - Activities: Unable to gradually resume activities such as social, hobbies or trying something new
  - Difficulties in communication or lack of support from partner and family or friends

Comments



Fundamental approach

- How do you feel towards your body?
- Can you name something about your body that you like or is okay?
- Are you able to look at yourself in the mirror? What happens then?
- Do you avoid touching the scar?
- Can you let your partner see you without your top?
- How compassionate are you to towards yourself?

How?

- Expressive writing
- Meditation
- Art or Phototherapy (Jo Spence)
- Yoga
- Counselling
- Any awareness based activity

Self Criticism

- Involves being both the attacker and the victim
- Rumination = persistent self attacking
- "I think about it all the time" or "I can't help thinking about it"
- Increase in adrenalin and cortisol
- Leads to reactivity, poor decisions and impact on mood. Can affect communication with others.

Self Criticism

- Society encourages us to be continually critical about our bodies
- Media shows us the "perfect body" which needs to be achieved
- Often those around us can encourage self-criticism (family, friends, work mates).

Self-Compassion

- Three domains:
  - Awareness
  - Kindness
  - Common humanity

Kristen Neff, 2003

Self-Compassion

- Ability to show kindness to oneself while suffering or in pain (physical, emotional, intellectual)

- Isn't it the same as:
  - Self care?
  - Self indulgence?
  - Self esteem?

Awareness

- Objective awareness of all feelings, thoughts, physical sensations and situations
- How things are, not necessarily how one would like it to be (change, disfigurement, loss)
- Facing the situation without avoidance or exaggeration – sitting with everything
- Not just the "positives"

How do I relate to my body?

Common Humanity

- Seeing one's experiences as part of the human condition, i.e. we all have setbacks and which are distressing. It is normal to have emotional responses. This is an inevitable part of life.
- These feelings are part of a ***universal experience*** rather than personal, isolating and shaming.

How?

- Support groups
- Cancer Connect
- Survivors autobiographies
- Blog communities
- Counselling

Self-Compassion

"This is a moment of suffering,
Suffering is a part of life,
May I be kind to myself in this moment
May I give myself the compassion I need"

Dr Kristen Neff

Self-Compassion

- Particularly important in times of:
  - Rapid changes
  - Set-back
  - Disappointment
  - Loss
  - Failure
  - Negative events

Resources & Articles

- www.self-compassion.org for a comprehensive listing of articles and resources.
- Links to other pages and websites
- Videos and mp3 recordings
- Self-compassion scale available and free to use

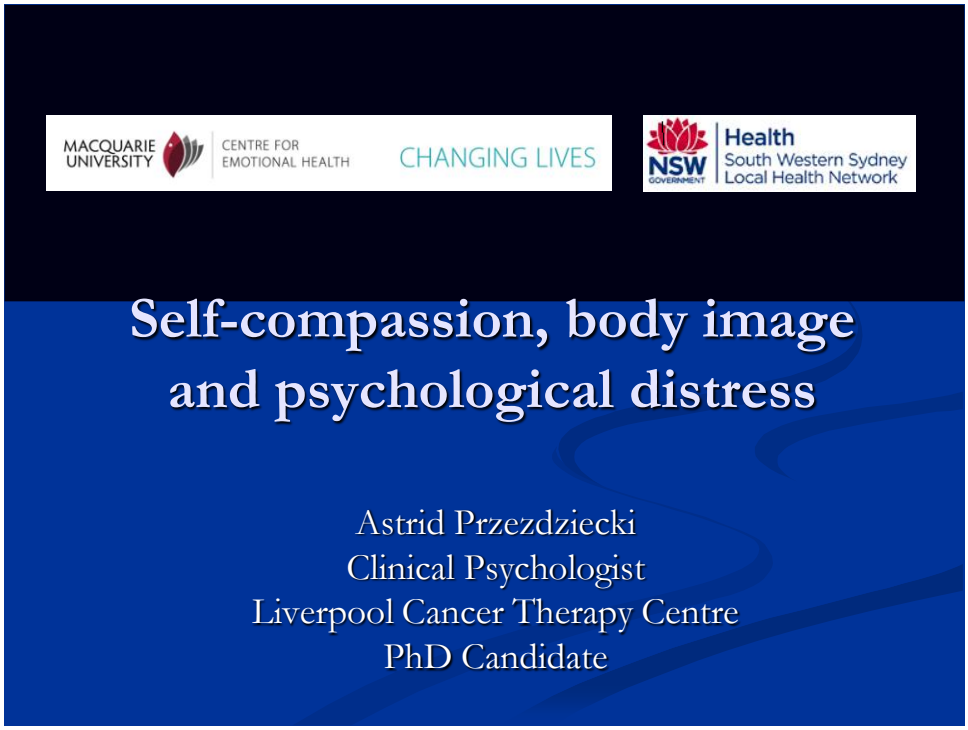
Summary

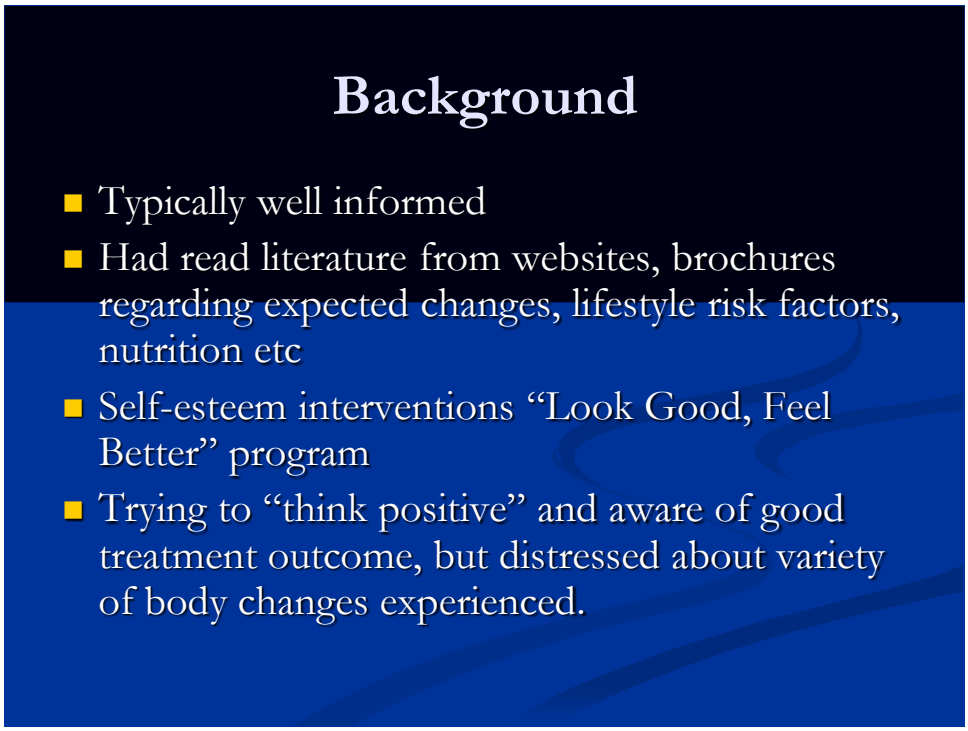
- Rapid change to body image can be stressful
- Normal to have a mixed feelings
- Notice how you relate to your body
- Be aware of all that is going on for you (even what is uncomfortable)
- Self-compassion provides a buffer against self-criticism

8.2. LCTC Staff Presentation

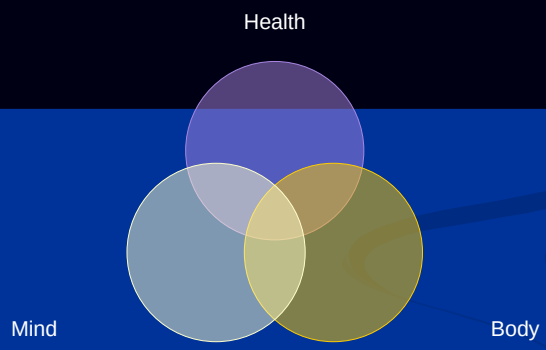
Presentation to staff of Liverpool Cancer Therapy Centre (LCTC), Liverpool Hospital, NSW

November, 2011





Context of Rapid Change



Context

- Referrals of breast cancer survivors
  - Medically doing well
  - Depressed mood
  - Relationship problems
  - Sexuality and intimacy difficulties
  - Body image disturbance
  - Weight gain and lifestyle changes

Body Image Disturbance

- Large factor was difficulties in body image
  - Breast irregularities / loss
  - Weight gain
  - Arm limitations
  - Lymphedema
  - Sexual difficulties
  - Physical deconditioning
  - Fatigue
  - Other reminders (changes to hair, nails, skin)

Cognitions and emotions

- Able to be aware of objective reality
- Survivorship had come at a cost
- Had a second chance at life
- Partners often said that treatment didn't change how much they cared for pt
- Response "I ***know*** that… but it doesn't change the way I ***feel*** about myself"

Implications

- Ongoing distress
- Disruption to current relationships or formation of new relationships
- Low motivation, shame, self-blame
- Inability to initiate or resume healthy lifestyle changes (weight reduction, dietary modification, exercise) despite access to information
- "I know what I should be doing, but…"

What next?

- Medical advice & monitoring
- Information
- Services
- Resources
- Programs
- Support

Self-Compassion

- Ability to show kindness to oneself while suffering

- Isn't it the same as:
  - Self care?
  - Self indulgence?
  - Self esteem?

Self Compassion vs Self Esteem

- Is it just another term for the same thing?
- Self compassion is a different construct to self esteem and is conducive to many indicators of well-being

Neff, Kirkpatrick & Rude (2007)

Self-Esteem

- Self-esteem is based on the extent that the self is evaluated as ***competent*** in important areas of life

W. James (1890)

Self-Esteem

- Pressures from society, family and ourselves
  - Career
  - Finances
  - Achievements
  - Abilities
  - Physical attributes / Body image
  - Etc
- Women breast cancer survivors often have setbacks in many of these areas

Kindness

- A kind approach to understanding one's own difficulties or suffering
- Being kind and warm in the face of failure or setbacks, rather than harshly judgemental and self-critical
- How we would treat our friend or loved one who is in pain or distress

Awareness

- Objective awareness of feeling, thoughts, physical sensations and situations
- How things are, not necessarily how one would like it to be (change, disfigurement, loss)
- Facing the situation without avoidance or exaggeration
- Also described as "mindfulness"

Common Humanity

- Seeing one's experiences as part of the human condition, i.e. we all have setbacks which are distressing. It is an inevitable part of life.
- These feelings are part of a ***universal experience*** rather than personal, isolating and shaming.

Study

- N = 279
- Anonymous survey
- Women breast cancer survivors who had completed active breast cancer treatment (surgery, chemotherapy, radiation)
- No further treatment planned apart from hormone (for those indicated)

Results

- Mean age 53.4 years (23-73 years)
- 77% born in Australia
- 37% had been diagnosed 5 or more years
- 49% were receiving hormone treatment

Other Measures

- Body Image Scale (Hopwood, 2001), measure of body image disturbance in oncology patients
- Self-Compassion Scale (Neff, 2003), measure of compassion directed towards the self.

Results

- Data and results still being evaluated
- Initial overview points to strong influence of self compassion in adjustment to body image changes brought on by cancer treatment

Resources & Articles

- www.self-compassion.org for a comprehensive listing of articles and resources.
- Links to other pages and websites
- Videos and mp3 recordings
- Self-compassion scale available and free to use

Self-compassion

- Is it a relatively stable trait?
- Can it be manipulated?
- To what extent?
- How could this be done?
- Needs to be further explored by longitudinal studies and interventions

9. Appendix I Summary and overview of theoretical framework

The summary below was produced to overview, and link, the various theoretical aspects as background reading for health professionals not involved in this research

Overview of theoretical framework

This thesis brought together a number of theories in order to understand the potential usefulness of self-compassion, and to empirically test an intervention designed to assist women with body image difficulties related to breast cancer treatment. Theories proposed by Baumeister (Ego depletion and Escape theory), Higgins (Self-discrepancy), and Cash (Body image) are reviewed in this section relation and cross-linked. Furthermore, theoretical understandings of self-compassion are summarised and linked to difficulties associated with survivor body image

Baumeister's Theory of Ego Depletion. Individuals who have faced a serious life threatening illness, such as breast cancer, are considered likely to be in a depleted state regarding their personal resources (Kaplan & Berman, 2010), known as "ego-depletion" (Baumeister, Muraven, & Tice, 2000). Many medical regimens are difficult, time-consuming, costly and require people to make themselves do things they find unpleasant, thus making demands on resources over time (Terry & Leary, 2011). In such circumstances, the individual may be less able to function effectively, such as emotionally regulating oneself or exerting volition (Baumeister, Muraven, & Tice, 2000). The impact of negative feelings such as shame, self-blame, non-acceptance or anger about one's breast cancer diagnosis or medical condition can compromise one's ability to self-regulate (Brion, Leary, & Drabkin, 2014; Terry & Leary, 2011).

Theories of Body Image – Higgins and Cash. At the same time as experiencing threats to emotional self-regulation from the demands of diagnosis, negative alteration to a woman's body has also occurred due to the nature of her breast cancer treatment. Cancer

related body image disturbance has been recognised as a significant predictor of psychological distress (Carver, et al., 1998; Sharpe, Patel, & Clarke, 2011). In the general population, internalization of an ideal body by Western society standards can result in the experience of a discrepancy between the ideal and one's actual figure, and prompts body dissatisfaction and over-concern since this ideal is achievable by only a few individuals (Carraca, et al., 2011). Additional negative bodily alteration, such as those due to breast cancer treatment, are likely to further increase any discrepancy between one's current self and one's ideal self, according to Higgins' self-discrepancy theory (Higgins, 1987). Discrepancies between the different components of the self (i.e., ideal and actual) in relation to body image have been shown to relate to negative emotions (Altabe & Thompson, 1996). Applications of Higgins' theory have been further investigated by Cash and colleagues. Cash has proposed that self-ideal discrepancies are a basis for self-evaluation, and are a central determinant of body image dissatisfaction and distress (Cash & Pruzinsky, 2002).

Cash has described two attitudinal dimensions of body image: appearance evaluation and appearance investment. According to Cash, appearance evaluation refers to one's *satisfaction* with appearance, while appearance investment relates to the *importance* placed upon physical attributes of appearance (Cash, 2011; Cash, Melnyk, & Hrabosky, 2004). In addition, according to Cash, appearance investment is subdivided into two further components: self-evaluative salience (SES) and motivational salience (MS). Self-evaluative salience (SES) refers to the importance one places upon their physical appearance as a basis for their personal self-worth (Cash, Melnyk, & Hrabosky, 2004; Cash & Grasso, 2005). Self-evaluative salience has been associated with more distorted body image cognitions, more body image dissatisfaction, lower self-esteem and greater interference with psychosocial functioning (Cash, Melnyk, & Hrabosky, 2004; Cash, Phillips, Santos, & Hrabosky, 2004; Jakatdar, Cash, & Engle, 2006; Ip & Jarry, 2008; Moreira, Silva, & Canavarro, 2010).

Baumeister's Escape Theory. Baumeister theorised that people may use non-helpful behaviours to escape or avoid aversive self-awareness, especially if they fall short of expected standards (Baumeister, 1997). When individuals are confronted with aversive self-awareness such as recognition of a larger discrepancy between one's actual and ideal self, negative affect is elicited and they are motivated to escape that self-awareness (Baumeister, 1997; Vartanian, 2012). As such, greater awareness of one's actual body after cancer treatment compared to one's ideal body (or even one's body prior to cancer treatment), may trigger negative self-evaluation which could stretch one's emotion regulation strategies, and contribute to attempts at avoidance or other non-helpful behaviours (Vartanian, 2012). Research has found that common problematic coping behaviours found in breast cancer patients may include avoidance, disengagement and self-blame (Malik & Kiran, 2013). As such, Escape Theory has been applied to situations in which individuals experience aversion to the awareness of their perceived personal inadequacies, faults or other deficiencies (Heatherton & Baumeister, 1991). Research in other fields has found that individuals may respond to perceived failures by self-evaluation focussed on negative body perceptions (such as feeling fat or ugly), which then fuels unhelpful escape strategies (Heatherton & Baumeister, 1991). As such, body image investment (especially self-evaluative salience), self-discrepancy, and strategies to escape awareness of inadequacies are likely to have an important role in contributing to an individual's suffering and distress.

Theoretical nature of self-compassion. As mentioned earlier, given the psychologically and physically challenging context in which breast cancer survivors typically find themselves, their personal resources may already be considerably depleted (Kaplan & Berman, 2010). Self-compassion does not encourage the individual to suppress their uncomfortable thoughts, emotions, experiences or memories, but instead to hold these with an attitude of kindness, warmth and acceptance (Neff K. , 2003a; Neff K. , 2003b). Self-compassionate individuals, therefore, are not encouraged to engage in behaviours recognised

to be resource depleting such as control, suppression or regulation of unpleasant emotions or thoughts (Baumeister, Muraven, & Tice, 2000). This may be of particular value when an individual is unable to escape the constant awareness of negative treatment induced changes to their body image. Avoidance or suppression of unresolved problems and distressing situations may create an "internal noise" that continues to drain one's finite personal resources (Kaplan & Berman, 2010). Furthermore, this issue may be even more important for individuals with high levels of self-evaluative salience (SES) in which bodily appearance holds a central place in their concept of personal self-worth.

It has been recognised that certain activities may be restorative or assist in offsetting depletion of personal resources (Kaplan & Berman, 2010). For example, expressive writing may assist in reduction of cognitive and emotional suppression that is associated with stress (Pennebaker, 1997). Self-compassion may be another approach that assists in offsetting the depletion of personal resources and, therefore, assists in self-regulation (Terry & Leary, 2011). Given that self-compassion encourages the experience of personal difficulties in a context of kindness, it may relieve regulatory pressures on the individual. Furthermore, based on current understandings of self-compassion, it should also aid emotional regulation when an individual needs to deal with disease, illness, injury, difficult treatment regimens and distressing changes (Terry & Leary, 2011). Given that self-compassion is associated with lower feelings of embarrassment and shame when experiencing or recalling personal difficulties in general (Leary, Tate, Adams, Allen, & Hancock, 2007), it is therefore likely that self-compassion will assist with distress related to adverse bodily changes due to medical treatments.

More specifically, women with higher levels of self-evaluative salience would be most likely to obtain the greatest benefit from self-compassion enhancement. Theoretical literature asserts that cancer patients with high levels of personal investment in physical

attributes should experience more negative psychological consequences following changes in that attribute (White, 2000). Empirical evidence amongst breast cancer patients has shown that those who place greater importance on their appearance are more vulnerable to poor adjustment when facing appearance changes (Moreira & Canavarro, 2010). Theoretically, it has been argued that self-compassion removes the process of self-evaluation, thus reducing focus on self-judgement and conditional acceptance of self (Neff K. , 2003a). As such, greater levels of self-compassion are likely to have most impact on individuals with high levels of self-evaluative salience, and hence reduce negative affect regarding adverse bodily changes in these individuals most strongly.