Psychological Outcomes of Nipple Sparing Mastectomy

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Table of Contents

List of Tables

Study 1

Study 2

List of Figures

Study 1

Study 2

Abstract

***Objective*:** Women diagnosed with breast cancer often experience significant psychological distress from the time of diagnosis, as well as during and after their surgery. Decisional conflict, post-decision regret and body image disturbances have been shown to contribute to a woman's psychological distress and satisfaction with the outcome of her breast surgery. Nipple sparing mastectomy with immediate breast reconstruction (NSM+IBR) is a relatively new yet oncologically safe surgical technique that may help to minimise psychological distress from decisional conflict, regret and body image disturbances as it is a single-step procedure and preserves a woman's skin and areola complex. The current thesis is presented in three parts. First, a literature review of research investigating the effects of surgery for breast cancer on a woman's body image and the relationship of body image with distress, decisional conflict and regret is presented. The second section of the thesis comprises two chapters corresponding to empirical work investigating:

Study 1: Body image disturbance and psychological distress in women who have undergone NSM+IBR, including investigation of the mediating effect of self-compassion, and the moderating effect of appearance investment on this body image-distress relationship via self-compassion.

Study 2: Decisional conflict and post-decision regret in NSM+IBR, as well as factors that are associated with increased levels of decisional conflict and regret, such as satisfaction with reconstructed breasts, physical and sexual well-being after breast surgery, partner reactions to the woman's reconstructed breasts and the importance a woman places on her partner's reaction.

***Methods*:** Women diagnosed with breast cancer (N=80) who had previously undergone NSM+IBR completed online questionnaires including the Body Image Scale (Hopwood

et al., 2001), Depression, Anxiety and Stress Scales (Lovibond & Lovibond, 1992), Impact of Event Scale (Horowitz et al., 1979), Self-Compassion Scale (Short Form; Raes et al., 2011), Appearance Schemas Inventory (Revised; Cash et al., 2004), Decisional Conflict Scale (O'Connor, 1995), Decision Regret Scale (Brehaut, 2003), BREAST-Q (Pusic et al., 2009) and a measure of perceived partner reactions and the importance placed on this reaction (scale designed specifically for the current study).

***Results*:**

Study 1: Mean scores on general and cancer-specific psychological distress were within normal ranges and body image disturbance was moderately low. Body image was positively correlated with depression, stress, impact of event scale scores and appearance investment, and negatively correlated with self-compassion. Bootstrap moderated mediation analyses indicated a significant indirect (mediating) effect of self-compassion (depression, anxiety, stress) but only for women with high levels of appearance investment.

Study 2: Mean scores on decisional conflict and regret indicated that the majority of the current sample experienced low levels of decisional conflict and regret, although 15% indicated high levels of conflict, and 20% reported moderate to strong regret. Simple linear regression analyses indicated that the extent to which a woman cared about her partner's reaction to her reconstructed breasts uniquely contributed to decisional conflict, while a woman's satisfaction with her reconstructed breasts uniquely contributed to decision regret. No other factors were associated with conflict or regret.

***Conclusions*:** Findings suggest that NSM+IBR may minimise the adverse psychological impacts of mastectomy, with the majority of the current sample experiencing low levels of psychological distress, body image disturbance, decisional conflict and decision regret. However, NSM+IBR is not an available option for all women undergoing

mastectomy. As such, identifying women high in appearance investment and low in self-compassion may be of particular clinical relevance for identifying women who are at greater risk for poorer psychological adjustment post-surgery. Additionally, recognition of factors that contribute to decisional conflict and regret, such as the importance placed by a woman on her partner's reaction to her reconstructed breasts, and her satisfaction with her reconstructed breasts, respectively, may assist with interventions aimed at reducing decisional conflict and regret.

The research documented in the current thesis may, therefore, be of particular relevance for clinicians engaged in supportive psychological interventions dedicated to women who have undergone breast surgery by: i) providing additional support to women identified as at risk for greater distress; ii) assisting clinicians in modifying existing breast surgery body image interventions for the most favourable outcome (e.g., by including psycho-education and practice on increasing self-compassion and lowering appearance investment); iii) routinely involving partners in the decision-making process to help reduce decisional conflict and post-decision regret; and iv) working with women on their expectations of the outcome of surgery.

Statement of Candidature

I certify that the work in this thesis entitled 'Psychological Outcomes of Nipple Sparing Mastectomy' has not previously been submitted for a higher degree to any other university or institution other than Macquarie University.

I also certify that any sources of information used throughout the thesis are acknowledged, including any help or assistance that I have received in my work and preparation of this thesis.

The research presented in this thesis was reviewed and approved by the Cancer Institute of New South Wales and Macquarie University, reference numbers:

AU RED Reference: HREC/11/CIPHS/45

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Macquarie University Human Research Ethics Committee (5201100876D)

Signature _____

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Date _____

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Thesis by Publication

This thesis has been prepared according to the Macquarie University 'Thesis by publication' guidelines. Chapters Three and Four have been written and prepared as independent publications. As such, there is some overlap in the literature cited and rationales provided for each study. This has resulted in some unavoidable repetition, though I have tried to minimise this where possible. Before each manuscript, there is a brief introductory section that provides a rationale for the study in the context of the thesis, and details the individual contributions of myself as the primary author, and of my co-authors.

Chapter 1. General Introduction

Breast cancer is a leading cause of disease globally and the second most commonly diagnosed cancer (Siegel et al., 2012). Given the advances in early diagnosis and more effective treatment, the majority of women diagnosed with breast cancer will survive the disease and live longer than in previous years (Australian Institute of Health and Welfare, 2012; Coleman et al., 2011), making issues of psychosocial well-being, such as body image and psychological distress, an important focus of long-term breast cancer survivorship (Moreira & Canavarro, 2010).

Women with breast cancer are typically faced with several interventions as options for treatment, many of which take place over an extended period of time and often have associated side effects that can be appearance-altering, such as removal of a breast, hair loss and skin discolouration (Collins et al., 2011). Not surprisingly, these treatments and their associated side effects can significantly and negatively impact a woman's body image, that is, her perception of her physical appearance (Collins et al., 2011; Helms, O'Hea, & Corso, 2008) and overall attitude toward her body (Cash, Melnyk, & Hrabosky, 2004; Moreira, Silva, & Canavarro, 2010).

Breast surgery involving the loss of one or both breasts through mastectomy has the potential to negatively affect a woman's identity and body image (Collins et al., 2011; Helms et al., 2008), through breast asymmetry, extensive scarring, or the need for prostheses, which presents its own set of challenges (Gopie et al., 2013). Research suggests that the more invasive the breast surgery (i.e., mastectomy compared with lumpectomy), the greater the negative impact on psychological well-being (e.g., Gopie et al., 2013; Winters, Benson, & Pusic, 2010). Corresponding with the experience of body image disturbance, it is common for women to report heightened psychological distress, namely, depression, anxiety and stress (Begovic-Juhant, Chmielewski,

Iwuagwu, & Chapman, 2012; Gopie et al., 2011), particularly when a poor cosmetic outcome and body image disturbance are evident (Falk Dahl, Reinertsen, Nesvold, Fosså, & Dahl, 2010). Even after successful surgery and treatment of breast cancer, some women experience body image-related psychological distress beyond one year following a cancer diagnosis (Helms et al., 2008).

Breast reconstruction, as an immediate (at the time of mastectomy) or delayed (after mastectomy surgery) procedure, offers a surgical means to restore breast shape and appearance (Sheehan, Sherman, Lam, & Boyages, 2007). Reconstruction techniques may involve implants or autologous tissue (flap procedure) to recreate the breast shape (see Serletti, Fosnot, Nelson, Disa, & Bucky, 2011, for a comprehensive overview). Typically, implant breast reconstruction has entailed gradual stretching of the skin over several weeks to create a new envelope for the breast implant, followed by surgical insertion of the implant and optional nipple and areola complex reconstruction using tattooing and/or skin grafting procedures (Serletti et al., 2011). Flap reconstruction generally provides a better aesthetic result than implant reconstruction (Yueh et al., 2010), but carries with it the burden of more extensive surgery and additional donor site healing (D'Souza, Darmanin, & Fedorowicz, 2011; Gopie et al., 2013; Gopie, et al., 2011; Moreira & Canavarro, 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010). Irrespective of whether flap or implant reconstruction is used, several operations have typically been required to give the final cosmetic result (Serletti et al., 2011).

A procedure that may minimise some of the physical and practical challenges of breast reconstructive surgery is Nipple Sparing Mastectomy with immediate breast reconstruction (NSM+IBR). A relatively new, yet oncologically-safe procedure, NSM+IBR allows cancerous breast tissue to be removed and replaced with an implant

or flap, allowing a woman's original skin and nipple areola complex to be preserved (see Boneti et al., 2011; Moyer, Ghazi, Daniel, Gasgarth, & Carlson, 2012 for full details of procedure). As a single-step procedure, the additional risks, complications and time (for surgery and recovery) costs associated with multiple or revision surgeries are reduced (Serletti et al., 2011). Women generally favour re-creating a nipple areola complex following breast reconstruction (Djohan et al., 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010), so retaining one's own skin and nipple areola complex could result in less body image disturbance with the NSM+IBR procedure. Limited evidence indicates that women generally feel satisfied with the aesthetic outcomes of NSM+IBR, but that residual dissatisfaction with nipple position and sensation may remain (Didier et al., 2009; Djohan et al., 2010; Peled et al., 2014). Moreover, general psychosocial well-being (related primarily to body image concerns) appears to return to pre-breast surgery levels by one year following NSM+IBR (Peled et al., 2014), comparable to other reconstructive procedures (e.g., non-nipple sparing immediate or delayed breast reconstruction, using implants or autologous tissue; Atisha et al., 2008; Hu et al., 2009; Wilkins et al., 2000).

NSM+IBR is a relatively new procedure in Australia and other Westernised countries. As a consequence, few studies have investigated psychological outcomes in women who have undergone NSM+IBR, such as levels of body image disturbance and psychological distress. Studies that have investigated psycho-social outcomes amongst different methods of breast reconstruction have typically yielded conflicting results, indicating the need for further investigation into the mechanisms that underlie individual differences in psychosocial outcomes, such as potential mediating and moderating factors of the body image-distress relationship (Boquiren, Esplen, Wong, Toner, & Warner, 2013; Collins et al., 2011; Falk Dahl et al., 2010; Gopie, Kuile, Timman,

Mureau, & Tibben, 2014; Lam et al., 2012; Lee, Sunu, & Pignone, 2009; Winters et al., 2010). Additionally, no studies have investigated the factors that contribute to decisional conflict and regret in women who have opted for breast reconstruction after breast cancer, particularly regarding NSM+IBR.

This thesis reports on a program of research with the following aims. First, to investigate levels of body image disturbance, psychological distress, decisional conflict and decision regret in women who have undergone NSM+IBR in Australia. Secondly, this thesis was also interested in understanding the unique factors that influenced or contributed to the aforementioned psychological outcomes. This thesis investigated these research aims in the form of empirical work reported in Chapters Three and Four, each presented as a stand-alone study. The following chapter, Chapter Two, is a review of literature that investigates the effects of surgery for breast cancer on a woman's body image and the relationship of body image with distress, decisional conflict and regret.

Chapter 2. Review of the Literature

2.1 Breast Cancer in Context

Breast cancer is a leading cause of disease globally and the second most commonly diagnosed cancer (Siegel et al., 2012). It is one of the main contributors to the estimated 170 million years of healthy life lost worldwide (Siegel et al., 2012) and is the leading cancer cause of disease burden in Australian women (Australian Institute of Health and Welfare, 2012; Coleman et al., 2011). Equivalent to the rest of the world, the incidence rate for breast cancer in Australia is approximately 12 percent, which equates to an estimated 14, 643 new cases of breast cancer in Australia each year (Australian Institute of Health and Welfare, 2012). In 2011, approximately 15% of cancer deaths in women were attributed to breast cancer, making it the second leading cause of cancer-related death in Australian women (Australian Institute of Health and Welfare, 2012; Coleman et al., 2011).

Given the advances in early diagnosis and more effective treatment, the majority of women diagnosed with breast cancer will survive the disease and live for years after treatment (Australian Institute of Health and Welfare, 2012). In Australia, approximately 83% of women diagnosed with breast cancer are still alive 10 years after diagnosis (Australian Institute of Health and Welfare, 2012; Coleman et al., 2011), making issues of psychosocial well-being an important focus of long-term breast cancer survivorship (Alfano, Ganz, Rowland, & Hahn, 2012; Fallbjörk, Rasmussen, Karlsson, & Salander, 2013; Gao & Dizon, 2013; Moreira & Canavarro, 2010).

2.2 Body Image – Definition and Context

One important psychosocial concern is the body image of breast cancer survivors. Body image in the field of psycho-oncology has received much interest from researchers and clinicians alike, and the general consensus is that body image can be defined as a woman's subjective perception of her physical appearance (Collins et al., 2011; Helms et al., 2008), as well as her thoughts, feelings and overall attitude toward her body (Cash et al., 2004; Moreira et al., 2010). More recently, body image has been recognised as a multidimensional construct that not only involves (dis) satisfaction with one's appearance (Cash, 2011; Cash et al., 2004), but also the importance placed on appearance, otherwise known as investment in appearance (Cash, 2003; Cash et al., 2004). Body image has been shown to be closely associated with constructs such as self-esteem, as well as general psychosocial functioning (Cash & Smolak, 2011).

It is widely agreed that body image is a prominent issue in a woman's experience of breast cancer (Chua, DeSantis, Teo, & Fingeret, 2015; Pruzinsky & Cash, 2002), largely because of the appearance-altering nature of breast cancer treatment (Chua et al., 2015; Fang, Shu, & Chang, 2013). The ways in which breast cancer survivors perceive and adapt to their changed bodies after breast cancer treatment has garnered widespread interest, and studies have moved beyond a medical appraisal of aesthetic outcome to more patient-centred appraisals (Boquiren et al., 2013; Fang, Chang, & Shu, 2014).

2.3 Breast Cancer Treatment – The Effects on Body Image

The treatment of breast cancer is often complex and may involve a combination of different treatments, such as breast surgery and adjuvant therapy (Carlson et al., 2009), many of which take place over an extended period of time (Serletti et al., 2011). Mastectomy is a common surgical choice for women undergoing breast surgery

(Fallbjörk, Frejeus, & Rasmussen, 2012; Fallbjörk et al., 2013; Lee et al., 2009; Nicholson, Leinster, & Sassoon, 2007; Potter, Thomson, Greenwood, Hopwood, & Winters, 2009) and involves the removal of one or both breasts. Mastectomy is often experienced as a relatively invasive surgical procedure by women and may result in breast asymmetry, extensive scarring, and the need for a breast prosthesis (Begovic-Juhant et al., 2012; Boneti et al., 2011; D'Souza et al., 2011; Djohan, Gage, & Bernard, 2008; Djohan et al., 2010; Fallbjörk et al., 2013; Moreira & Canavarro, 2010; Potter et al., 2009; Winters & Thomson, 2011; Winters et al., 2010). Additionally, adjuvant treatments frequently entail appearance-altering side effects. For example, chemotherapy often involves hair loss and weight fluctuations, and radiation treatment may lead to skin discolouration (Boquiren et al., 2013; Fang et al., 2014; Gao & Dizon, 2013; Gopie, 2013; Gopie et al., 2011; Helms et al., 2008; Winters & Thomson, 2011).

These appearance-altering treatment side-effects have been shown to lead to changes in the psychosocial well-being of women both during, and after, breast cancer surgery and treatment, particularly disturbances in body image and sexual functioning (Anagnostopoulos & Myrgianni, 2009; Begovic-Juhant et al., 2012; Boquiren et al., 2013; Chen, Liao, Chen, Chan, & Chen, 2012; Chua et al., 2015; Collins et al., 2011; Falk Dahl et al., 2010; Fang et al., 2014; Harcourt et al., 2003; Helms et al., 2008; Lam et al., 2012; Moreira & Canavarro, 2010; Moreira et al., 2011; Moreira et al., 2010). Research suggests that the more invasive the breast surgery (i.e., mastectomy compared with lumpectomy), the greater the negative impact on psychological well-being (Boquiren et al., 2013; Falk Dahl et al., 2010; Fobair et al., 2006; Ganz, Kwan, Stanton, Bower, & Belin, 2011; Gopie et al., 2013; Moreira & Canavarro, 2010; Winters et al., 2010; Yurek, Farrar, & Andersen, 2000). Corresponding with the experience of body image disturbance, cross-sectional (Al-Ghazal, Fallowfield, & Blamey, 1999; Begovic-

Juhant et al., 2012; Garrusi & Faezee, 2008; Gopie, et al., 2011; Przezdziecki et al., 2013), prospective (Gopie et al., 2014) and longitudinal studies (Falk Dahl et al., 2010; Lam et al., 2012) have typically shown that it is common for women to report heightened psychological distress, such as, depression, anxiety and stress, in the 12-month period following breast surgery, particularly when a poor cosmetic outcome and body image disturbances are evident (Helms et al., 2008).

2.4 Breast Reconstruction

Breast reconstruction, as an immediate (at the time of mastectomy) or delayed (after mastectomy surgery) procedure, offers a surgical means to restore breast shape and appearance (Sheehan et al., 2007), thereby aiming to minimise post-surgery body image disturbance and associated psychological distress (Chua et al., 2015; Duggal, Metcalfe, Sackeyfio, Carlson, & Losken, 2013; Fang et al., 2014; Fang et al., 2013; Susarla et al., 2015).

Reconstruction techniques may involve implants or autologous tissue (flap procedures) to recreate the breast shape (Moyer et al., 2012; Serletti et al., 2011). Typically, implant breast reconstruction has entailed gradual stretching of the skin over several weeks to create a new envelope for the breast implant, followed by surgical insertion of the implant and optional nipple and areola complex reconstruction using tattooing and/or skin grafting procedures (Serletti et al., 2011). Flap reconstruction has generally been shown to provide a better aesthetic result compared with implant reconstruction (Yueh et al., 2010), but carries with it the burden of more extensive surgery and additional donor site healing (D'Souza et al., 2011; Gopie et al., 2013; Gopie et al., 2011; Moreira & Canavarro, 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010). Irrespective of whether flap or implant reconstruction is used,

several operations are typically required to give the final cosmetic result (Serletti et al., 2011).

In a prospective study investigating women's motivations for undergoing breast reconstruction (Duggal et al., 2013), it was found that women endorsed questions related to body image, rather than sexuality or femininity, as their primary motivations for seeking breast reconstruction. It was further found that the majority of women elected to undergo breast reconstruction to restore their natural appearance when clothed and to improve body image and satisfaction, consistent with findings from previous studies (Chua et al., 2015; Duggal et al., 2013; Fallbjörk, Karlsson, Salander, & Rasmussen, 2010).

Nonetheless, it has also been found that, regardless of method used, women who have undergone breast reconstruction report feeling more comfortable with their bodies in both social and intimate situations (Brandberg et al., 2008; Gopie et al., 2011). Additionally, women electing to undergo breast reconstruction are more likely to be sexually active compared with women who do not elect to undergo breast reconstruction (Fallbjörk et al., 2010), suggesting that a woman's sexual well-being may be negatively impacted by mastectomy, and that sexual relations are an important factor motivating women to undergo breast reconstruction.

Despite some findings that breast reconstruction improves a woman's body image, sexual and psychological well-being (e.g., Cordeiro, 2008; Fang et al., 2014; Fang et al., 2013; Susarla et al., 2015), inconsistent or conflicting results towards this topic have been reported (e.g., Boquiren et al., 2013; Collins et al., 2011; Falk Dahl et al., 2010; Gopie et al., 2014; Lam et al., 2012; Lee et al., 2009; Winters et al., 2010). Evidence to date comparing outcomes of different surgical procedures is inconsistent, particularly when considering body image, with some studies reporting less body image

disturbance from immediate compared with delayed breast reconstruction (e.g., Al-Ghazal, Sully, Fallowfield, & Blamey, 2000; Didier et al., 2009), and other studies reporting inconclusive results (D'Souza et al., 2011). Typically, no differences, or conflicting reports have been found in body image between traditional types of surgery (e.g., breast conserving therapy (BCT), mastectomy only, mastectomy with breast reconstruction (delayed or immediate; Collins et al., 2011; Fang et al., 2013;. Harcourt et al., 2003; Lee et al., 2009). For example, cross-sectional studies have found that women who undergo breast reconstruction experience less body image disturbance than women undertaking mastectomy alone (e.g., Nicholson et al., 2007). Other studies have found no significant differences between these two groups (e.g., Al-Ghazal et al., 1999; Rowland et al., 2000; Yurek et al., 2000), even when pre-surgery body image was measured and longer-term (two years post-surgery) follow-ups were conducted (Harcourt et al., 2003; Parker et al., 2007).

Longitudinal studies have found that type of surgery predicted body image, sexual and psychological well-being in the short-term, but not the longer-term (Collins et al., 2011; Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010; Lam, Chan, Hung, Or, & Fielding, 2009; Lam et al., 2012; Parker et al., 2007). Moreira and others (2010) found that type of surgery was not significantly related to any indicator of adjustment. Similarly, in a longitudinal study of body image in long-term breast cancer survivors, type of surgery was also found not to be predictive of body image and sexual well-being trajectories of adjustment post-surgery (Lam et al., 2012). It was reported that a significantly higher number of women who underwent breast reconstruction were also among those identified as having poorer body image (Falk Dahl et al., 2010), suggesting that breast reconstruction did not restore or improve body image as was to be expected.

Additionally, there has been considerable debate over which surgical or reconstructive techniques provide the best psychological outcomes for patients (e.g., Fang et al., 2013; Gopie et al., 2014). This debate has typically involved the timing of reconstruction (immediate versus delayed) and method used (implants versus flap reconstruction; D'Souza et al., 2011), particularly given the advent of skin-sparing and nipple-sparing mastectomies, followed by immediate breast reconstruction (Susarla et al., 2015).

2.5 An Innovative Procedure – Nipple Sparing Mastectomy with Immediate Breast Reconstruction

A procedure that may minimise some of the physical and practical challenges of breast reconstructive surgery is Nipple Sparing Mastectomy with immediate breast reconstruction (NSM+IBR). A relatively new, yet oncologically-safe procedure (Endara, Chen, Verma, Nahabedian, & Spear, 2013), NSM+IBR allows cancerous breast tissue to be removed and replaced with an implant or flap, allowing a woman's original skin and nipple areola complex to be preserved (see Boneti et al., 2011; Moyer et al., 2012, for full details of procedure). As a single-step procedure, the additional risks, complications and time (for surgery and recovery) costs associated with multiple or revision surgeries are reduced (Serletti et al., 2011), which is an important factor considered by women when contemplating the decision to undergo breast reconstruction (Duggal et al., 2013).

Given that women generally favour re-creating a nipple areola complex following breast reconstruction (Djohan et al., 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010), retaining one's own skin and nipple areola complex may result in less body image disturbance, and therefore, less psychological distress following the NSM+IBR procedure (Didier et al., 2009; Yueh et al., 2009).

Indeed, in a study comparing women who underwent NSM+IBR (N = 310) with women who underwent non-nipple sparing mastectomy followed by immediate breast reconstruction and nipple areola complex reconstruction (N = 143), it was found that women in the NSM+IBR group reported better body image when looking at themselves naked or being seen naked by their partners (Didier et al., 2009).

NSM+IBR could therefore result in greater concordance with a patient's preferences, resulting in higher satisfaction with reconstructed breasts and overall surgery outcome (Djohan et al., 2010), thereby decreasing decisional conflict and regret. Limited evidence indicates that women generally feel satisfied with the outcomes of NSM+IBR, but that residual dissatisfaction with nipple position and sensation may remain (Didier et al., 2009; Djohan et al., 2010; Peled et al., 2014; Yueh et al., 2009). In a study by Didier and others (2009), women in the NSM+IBR group reported significantly higher patient satisfaction with surgical outcome, appearance and sensation of nipple, compared with women in the non-nipple sparing group. Moreover, general psychosocial well-being (related primarily to body image concerns and reduction of psychological distress) appears to return to pre-breast surgery levels by one year following NSM+IBR (Peled et al., 2014), a result comparable to other methods of breast reconstruction, such as delayed or immediate reconstruction, using implants or autologous tissue (Al-Ghazal, Fallowfield, & Blamey, 2000; Al-Ghazal et al., 2000; Elder et al., 2005; Fobair et al., 2006; Montazeri et al., 2008).

A recent study of 346 women with breast cancer (Susarla et al., 2015) compared clinical outcomes (complication and revision rates) and patient satisfaction (as measured by the BREAST-Q; Pusic et al., 2009) of immediate, single-stage reconstruction using implants with two-stage reconstruction using tissue expanders followed by implants. While satisfaction rates were generally high and equivalent between the two

reconstructive methods, it was found that immediate, single-stage reconstruction (of which 2.5% were NSM+IBR) was associated with higher satisfaction with sexual well-being, despite being 80% more likely to require surgical revisions (Susarla et al., 2015). No significant differences in complication rates were found among the two procedures (Susarla et al., 2015). These findings suggest that, despite the additional revisions required in immediate, single-stage reconstruction, these do not significantly impact patient satisfaction with reconstructed breasts, nor overall outcome of surgery (Susarla et al., 2015).

2.6 Body Image Disturbance and Psychological Distress

The link between body image disturbance and psychological distress after surgery has been well-documented (Begovic-Juhant et al., 2012; Falk Dahl et al., 2010; Fobair et al., 2006; Przezdziecki et al., 2013; Scott & Kayser, 2009; White, 2000). As body image is closely linked to a woman's identity, sexuality and self-esteem (Cash & Smolak, 2011), it is not surprising that most women express body dissatisfaction or disturbance, and report feeling less feminine and attractive following breast cancer surgery and adjuvant treatment (Begovic-Juhant et al., 2012; Falk Dahl et al., 2010; Fobair et al., 2006).

Psychological distress and diminished quality of life for women after breast cancer treatment is frequently associated with disturbances in their body image, associated with both the cancer itself and its treatment, as well as sexual dysfunction (Begovic-Juhant et al., 2012; Boquiren et al., 2013; Falk Dahl et al., 2010; Fang et al., 2014; Fobair & Spiegel, 2009; Moreira & Canavarro, 2010; Moreira et al., 2011; Przezdziecki et al., 2013; Reich, Lesur, & Perdrizet-Chevallier, 2008; Skrzypulec, Tobor, Drosdzol, & Nowosielski, 2009). Specifically, women with lower body image

satisfaction, or greater body image disturbance, are more likely to experience higher levels of psychological distress (depression and anxiety) and adjustment difficulties following surgery (Begovic-Juhant et al., 2012; Moreira & Canavarro, 2010; Moreira et al., 2011; Przezdziecki et al., 2013; Reich et al., 2008).

Fortunately, after successful surgery and treatment of breast cancer, many women with breast cancer return to their pre-diagnosis levels of physical and psychosocial functioning (Al-Ghazal et al., 2000; Elder et al., 2005; Fobair et al., 2006; Montazeri et al., 2008; Peled et al., 2014). Research has consistently shown that levels of psychological distress are highest in the period immediately following diagnosis and treatment (Begovic-Juhant et al., 2012), but tend to diminish over the following year (Lam et al., 2009; Lam et al., 2012; Moreira & Canavarro, 2010; Moreira et al., 2010; Peled et al., 2014; Schwarz et al., 2008; Vahdaninia, Omidvari, & Montazeri, 2010). However, a subset of women (approximately one-third) continue to experience body image-related psychological distress beyond one year following breast cancer diagnosis (Fang et al., 2014; Helms et al., 2008; Lam et al., 2012; Przezdziecki et al., 2013; Sackey, Sandelin, Frisell, Wickman, & Brandberg, 2010). For example, in a longitudinal study of 248 breast cancer survivors by Falk Dahl and others (2010), 31% of women reported body image disturbances four years after breast cancer surgery, and 27% of these women continued to report such disturbances seven years after surgery, which was associated with lower quality of life.

Body image disturbances have been shown to be particularly related to depressive symptoms (Begovic-Juhant et al., 2012; Boquiren et al., 2013; Fang et al., 2014; Moreira & Canavarro, 2010), and it has been reported that the prevalence of depression is higher among women with breast cancer than in women with gynaecological cancers (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi,

2001). It is possible that the visual changes to one's body as a result of breast cancer treatment may provide a more salient reminder of cancer than for women with essentially internal gynaecological surgery scarring, and consequently have a greater impact on a woman's attitude towards her body.

In a longitudinal study of 56 women diagnosed with breast cancer, aspects of body image (i.e., self-consciousness, equated with body consciousness and body image disturbance, and the self-evaluative salience component of appearance investment) were significantly associated with depression six months after surgery (Moreira & Canavarro, 2010). In a study of 76 women with breast cancer, Begovic-Juhant and others (2012) found that depressive symptoms were most accurately accounted for by body image.

In a more recent study by Fang et al. (2014), the concept of body consciousness (McKinley & Hyde, 1996) was explored in women with breast cancer who had undergone: a) mastectomy only; b) breast conserving surgery; or, c) mastectomy with reconstruction. As an extended concept of body image, body consciousness is defined as a woman's awareness of how she appears to others and is measured by the Objectified Body Consciousness Scale (McKinley & Hyde, 1996). Body consciousness also involves an evaluation of her body compared with society's ideal standard of the feminine body (i.e., body surveillance), resulting in body shame or dissatisfaction if her evaluation is negative (McKinley & Hyde, 1996). The study found a mediating effect of cancer-related body image discomfort (negative feelings about one's appearance; Fang et al., 2014) on the relationship between body consciousness and depressive symptoms (Fang et al., 2014), such that body consciousness predicted depressive symptoms through the unique indirect (mediating) effects of cancer-related body image discomfort. This relationship was strongest for women who had undergone mastectomy without reconstruction, and cancer-related body image discomfort was significantly lower among

women who had undergone breast conserving surgery, compared with women who had mastectomy only or mastectomy with reconstruction (Fang et al., 2014).

In one longitudinal study (Lam et al., 2012), the first-year trajectory of body image and sexual well-being in 211 breast cancer survivors was investigated, from the five days following breast surgery (baseline), and at one month, four months, and eight months post-surgery. Almost 60% of these women were then followed up and assessed six years after breast surgery. It was found that the majority of women (63.5%) reported relatively high body image scores (as measured by the Chinese Social Adjustment Scale; Lam 2002), corresponding with better body image, and that these scores remained stable over the first year post-surgery. However, approximately 20% of the women in this study experienced a gradual decline in body image over the first year from an initial point of high (i.e., good) body image, and another subgroup of these women (approximately 17%) experienced the reverse outcome with initial low (i.e., poor) body image scores that steadily improved over time (Lam et al., 2012). In this study, the specific first-year body image trajectory exhibited by an individual was predictive of her body image and sexual well-being at six-year follow-up, as well as general and cancer-specific psychological distress, such as anxiety, depressive symptoms and intrusive thoughts about cancer. Specifically, women with better body image scores that remained stable in the first year post-surgery also demonstrated enhanced body image and sexual well-being at six-year follow-up. However, women with poorer body image in the first year post-surgery continued to report general and cancer-specific psychological distress at six-year follow-up. This demonstrates once again the link between body image disturbance and psychological distress in women with breast cancer.

It can be concluded that women display a range of responses to breast cancer diagnosis and treatment. Women with breast cancer appear to be particularly vulnerable

to body image disturbances and associated psychological distress in the first year following breast surgery and adjuvant treatment. Although the majority of women return to pre-surgery levels of body image and psychological well-being in the 12 months following treatment, a subset of women will continue to display elevated levels of body image-related psychological distress beyond 12 months. Consequently, it is important for oncology clinicians and researchers to be aware of the potential range of women's responses to a diagnosis of breast cancer and subsequent treatment. The well-documented association between body image disturbance and psychological distress further points to a need for careful screening and psychological assessment of women most at risk of poor adjustment, particularly in the first year following diagnosis and treatment, and for appropriate psychological interventions to be recommended. It is also equally important to be able to identify and assist those who would continue to experience significant body image disturbance and associated psychological distress beyond this first year.

2.7 Individual Differences in Psychological Outcomes – The Role of Mediating and Moderating Factors

Identification of women who are most at risk of poor psychological adjustment to breast surgery in the first year post-surgery and beyond may be assisted by understanding the underlying factors of individual differences in psychological outcomes, such as potential mediating and moderating factors of the body image-distress relationship (Boquiren et al., 2013; Collins et al., 2011; Falk Dahl et al., 2010; Gopie et al., 2014; Lam et al., 2012; Lee et al., 2009; Winters et al., 2010). Previous studies have reported conflicting results with regards to which methods of breast surgery or reconstruction provide the most favourable body image and psychological outcomes for

women, even when the same Body Image scale (Hopwood, Fletcher, Lee, & Al Ghazal, 2001) is used (e.g., Collins et al., 2011; D'Souza et al., 2011; Didier et al., 2009; Fang et al., 2013; Lee et al., 2009).

These disparities in findings may reflect the diversity in treatment combinations for breast cancer (Boquiren et al., 2013), but also suggest that factors beyond surgery type and adjuvant treatment should be investigated (e.g., Boquiren et al., 2013; Fobair et al., 2006; Ganz et al., 2011). In accordance with a broader conceptualisation of body image, it has even been suggested that factors beyond physical appearance would impact body image (Falk Dahl et al., 2010). These factors may also assist oncology clinicians and researchers in understanding why a subset of women continue to experience significant body image disturbance and psychological distress following the first year post-diagnosis and treatment, when the majority of women experience a return to pre-surgery levels of psychological well-being. Accordingly, the role of mediating and moderating factors has been steadily gaining attention in the field of oncology (e.g., Boquiren et al., 2013; Fang et al., 2014; Moreira et al., 2010).

2.8 The Mediating Role of Self-compassion

One such psychological factor may be self-compassion, one's capacity to be kind and accepting towards oneself in the midst of suffering, and to view one's suffering as part of a wider human condition, rather than feeling isolated and alone (Neff, Kirkpatrick, & Rude, 2007; Raes, Pommier, Neff, & Van Gucht, 2011). Self-compassion is thought to comprise three components: self-kindness (as opposed to self-judgement), mindful awareness of one's emotions (versus over-identification) and understanding the universality of human suffering (contrasted with isolation of self), using a six-subscale measure (Neff et al., 2007).

Self-compassion has been associated with general psychological well-being (Leary, Tate, Adams, Batts Allen, & Hancock, 2007; Neff et al., 2007; Przezdziecki et al., 2013; Raes et al., 2011) and negatively associated with psychological distress, such as depression, anxiety and stress (MacBeth & Gumley, 2012; Neff, 2003), in both clinical (e.g., in psychological treatment) and non-clinical settings (e.g., community or university). In a sample of 91 American college undergraduates, individuals who scored highly on measures of self-compassion also scored highly on measures of life satisfaction and subjective well-being (Allen & Leary, 2010; Neff et al., 2007). In the same study, when faced with a perceived threat to one's ego (writing about one's greatest weakness in a mock job interview), those high in self-compassion also experienced less anxiety (Neff et al., 2007). In another study of 40 American college undergraduates, it was found that increases in self-compassion over a one-month period were associated with increased feelings of social connection, decreased self-criticism, depression, anxiety, thought suppression and ruminative thinking, thus displaying reduced avoidance of painful thoughts and feelings (Allen & Leary, 2010; Neff et al., 2007). This suggests that not only do self-compassionate individuals experience enhanced psychological well-being, but that they are able to cope with negative or stressful events with a reduced need for avoidant behaviours, which can be unhelpful over time (Neff et al., 2007). In a systematic review of the self-compassion literature (MacBeth & Gumley, 2012), it was found that higher levels of self-compassion were associated with lower levels of depression, anxiety and stress, supporting self-compassion as a way of enhancing psychological well-being (Hofmann, Grossman, & Hinton, 2011).

In a wider context of body image research, self-compassion has been investigated as a mediating factor in the field of eating disorders, a field in which body image is a particular focus. Self-compassion has been found to exhibit indirect (mediating) effects

on the relationship between body image dissatisfaction (i.e., equated with body image disturbance), and both general and eating disorder psychopathology (i.e., psychological distress) in women (Ferreira, Pinto-Gouveia, & Duarte, 2013; Pinto-Gouveia, Ferreira, & Duarte, 2014). That is, women who express dissatisfaction with their bodies tend to display a greater desire to be thin and engage in potentially harmful weight control behaviours, through their attitude towards their own perceived flaws or inadequacies (Ferreira et al., 2013; Pinto-Gouveia et al., 2014).

Similarly, while self-compassion does not appear to predict dieting behaviours, it does predict the emotional impact of perceived diet breaking through self-kindness and acceptance (Wasylkiw, MacKinnon, & MacLellan, 2012). In a study of 189 female undergraduate students, self-compassion was found to partially mediate the relationship between body preoccupation and depressive symptoms (Wasylkiw et al., 2012). Taken together, these findings suggest that the relationship between body image disturbance and psychological distress in women may be mediated by self-compassion.

Although strongly correlated (r = .59 - .62; Neff 2003a), self-compassion has been shown to be distinct from self-esteem and significantly predict psychological distress (such as anxiety, depression and stress), even when controlling for self-esteem (Berry, Kowalski, Ferguson, & McHugh, 2010; Neff et al., 2007; Neff & Vonk, 2009). Self-compassion has been thought to be more concerned with demonstrating self-kindness, understanding and seeing the common humanity in one's flaws, rather than having an overall positive self-evaluation (Neff et al., 2007; Neff & Vonk, 2009). As such, self-compassion can be encouraged even when a person's self-evaluation is negative, making it an important factor when considering the body image disturbances (and therefore possible negative evaluations of the self) after breast cancer diagnosis and treatment.

Given the above, there has been increased interest in how the benefits of self-compassion may be applied to the field of oncology, particularly in how self-compassion may influence adjustment to changes after a cancer diagnosis and treatment side effects. The rapid changes to one's body during breast cancer treatment can impact a woman's views and beliefs about her body, resulting in increased psychological distress (Boquiren et al., 2013). However, if a woman undergoing these challenges to her body image is able to respond with self-kindness and acceptance of this as part of her cancer experience, this may ease her experience of psychological distress (Przezdziecki et al., 2013).

While research on self-compassion in an oncology context is just emerging, one study of 279 breast cancer survivors investigated the relationship between body image disturbance and psychological distress and the mediating role of self-compassion (Przezdziecki et al., 2013). It was found that body image disturbances were associated with increased psychological distress, and that self-compassion exhibited a unique indirect (mediating) effect on this relationship, particularly for measures of anxiety and stress (Przezdziecki et al., 2013). Although additional research into the mediating role of self-compassion is required before definitive conclusions may be drawn, this suggests that interventions aimed only at addressing body image disturbances may have limited impact, and that clinicians and researchers' understanding of how women adjust to bodily changes after breast cancer treatment would be enhanced by understanding underlying mechanisms such as self-compassion.

2.9 The Moderating Role of Appearance Investment

While there has been much debate in the literature about surgical aspects that may explain differences in body image disturbances and subsequent psychological distress for women after breast surgery, it is possible that one's investment in appearance,

in addition to surgical factors, may account for these differences (Chua et al., 2015). Appearance investment is a concept that has been largely under-researched in the psycho-oncology literature but has recently gained increased attention (Boquiren et al., 2013; Chua et al., 2015).

Appearance investment comprises self-evaluative salience (importance placed on physical appearance in defining one's self-worth) and motivational salience (one's efforts to maintain or achieve a certain level of attractiveness; Cash, 2011; Cash et al., 2004), with these components found to be distinct from one another (Chua et al., 2015; Moreira et al., 2010). Theoretically (White, 2000), it has been proposed that when faced with body image changes after breast cancer, women who place greater importance on their physical appearance are at greater risk of poor adjustment.

Self-evaluative salience has been conceptualised as a vulnerability factor, as high levels have been found to be negatively associated with satisfaction with appearance (Moreira & Canavarro, 2010; Moreira et al., 2010). In a longitudinal study of 56 women with breast cancer, it was found that initial levels of self-evaluative salience (measured in the initial period of two to four days following surgery) predicted poorer body image and appearance satisfaction six-months post-surgery (Moreira & Canavarro, 2010). That is, the greater the importance placed on one's physical appearance, the greater the difficulty in adjusting to one's changed body following breast surgery.

In the same study, higher initial levels of motivational salience predicted higher satisfaction with appearance six months post-surgery and lower body shame and self-consciousness about appearance (Moreira & Canavarro, 2010). Thus, motivational salience appears to function as a protective factor, in that, women who make greater efforts with their physical appearance may be buffered against body image-related difficulties following surgery (Moreira & Canavarro, 2010).

In a cross-sectional study of 68 newly-diagnosed breast cancer patients and 66 breast cancer survivors, the relationship between self-consciousness about appearance and increased depression and reduced quality of life were only significant at moderate to high levels of self-evaluative salience, demonstrating a significant moderating effect of self-evaluative salience (Moreira et al., 2010). This finding further delineates the distinction between self-evaluative and motivational salience.

It has previously been suggested that women who elect for breast reconstruction may be higher in appearance investment than women who choose not to proceed with breast reconstruction, based on women in previous qualitative and quantitative studies identifying restoration of physical appearance (such as looking good in clothes, attractiveness to partner) as a motivation for seeking breast reconstruction (Chua et al., 2015; Duggal et al., 2013; Fallbjörk et al., 2010). This is consistent with research that has shown that women of a younger age tend to be higher in appearance investment, and that younger age is associated with greater uptake of breast reconstruction (Fobair et al., 2006; Helms et al., 2008). Further investigating the moderating role of appearance investment is therefore pertinent to understanding the variation in women's responses to mastectomy and breast reconstruction.

2.10 A Note on Younger Breast Cancer Survivors

There is evidence to suggest that younger women, typically classified as aged in their forties or younger (Duggal et al., 2013; Falk Dahl et al., 2010; Rosenberg et al., 2013), are more vulnerable to experiencing greater body image disturbance and psychological distress following breast surgery (Chen et al., 2012; Fallbjörk et al., 2013; Fobair et al., 2006; Helms et al., 2008; Rosenberg et al., 2013; Scott & Kayser, 2009; Tiggemann & Lynch, 2001). It has consistently been found that younger breast cancer

survivors report higher levels of body image dissatisfaction, and greater concerns about their physical attractiveness and femininity, and lower social well-being (Begovic-Juhant et al., 2012). Research has also found that age-related factors may underlie decisions regarding reconstructive surgery, with younger age (forties or younger) being consistently associated with the decision to undergo breast reconstruction (Agarwal, Pappas, Neumayer, & Agarwal, 2011; Fallbjörk et al., 2010; Fallbjörk et al., 2013), and the likelihood of undergoing breast reconstruction decreasing with increasing age (Agarwal et al., 2011; Morrow et al., 2014). Such age-related factors may include appearance investment, as it is often suggested that younger women are more invested in their physical appearance than older women (Fobair et al., 2006; Helms et al., 2008).

2.11 The Breast Reconstruction Decision: Decisional Conflict and Post-Decision Regret

The process of decision-making involves a choice between two or more options and aims to accomplish specific, and often optimal, outcomes (e.g., Chien, Chuang, Liu, Li, & Liu, 2013). Given the lack of medical guidelines for breast surgery, women diagnosed with breast cancer must make complex and preference-sensitive decisions about treatment, often during a period of increased time pressure and when they are experiencing psychological distress (Ashraf et al., 2013; Bride et al., 2013; Fernandes-Taylor & Bloom, 2011; Gopie et al., 2011; Lee et al., 2011; Resnicow et al., 2014; Zhong et al., 2013). In a qualitative study on decision-making with regard to breast reconstruction, (Harcourt & Rumsey, 2004) most of the women interviewed (82% of 93 women) made instantaneous and “intuitive” decisions about whether or not to undergo

breast reconstruction, and tended to feel confident about their decision. A further 15% of women required additional information from their surgeons and time to consult with family and friends before making their decision, while the remaining three percent were classed as "indecisive" and reported feeling uncertain of their decision (Harcourt & Rumsey, 2004). This study highlights differences in the way in which women approach the task of decision-making, in terms of the information and time required, and who is involved, which may in turn influence a woman's appraisal of her treatment decision.

There are several factors shown to influence an individual's appraisal of treatment decisions, such as the amount of decisional conflict experienced during and after the process, and regret over time (Dillard et al., 2013; O'Brien et al., 2009; O'Connor, 2012; Resnicow et al., 2014). This appears to be particularly the case if the woman experiences adverse outcomes (Payne, Biggs, Tran, Borgen, & Massie, 2000; Zhong et al., 2013). Consequently, a woman's appraisal of her treatment decisions is particularly important as it will likely influence her subsequent psychosocial well-being (Ashraf et al., 2013; Bride et al., 2013; O'Connor, 2012; Sheehan et al., 2007).

Decisional conflict refers to feeling uncertain or ineffective in the decision-making process, particularly when making a decision that involves personal risk (O'Connor, 1995; O'Connor & Jacobsen, 2007). Decisional conflict has been shown to occur not only during the decision-making period but also after the decision has been made (e.g., Chien et al., 2013), and contributes to the experience of post-decision regret (Chien et al., 2013). High levels of decisional conflict cause delays in decision-making and influence psychological and physical health (Brehaut et al., 2003; Kokufu, 2012; Lam et al., 2013). Women diagnosed with breast cancer have to synchronise their treatment values and preferences and those of their physicians with available treatment options (Gopie et al., 2011; Kokufu, 2012). Previous studies have shown that when the

level of decisional conflict experienced is high, appraisal of the quality of decision is typically low, and that the individual patients feel more helpless about managing their illness (Kokufu, 2012).

Decision regret broadly refers to the distress experienced after making a treatment decision (Connolly & Reb, 2005; Zhong et al., 2013) and has been associated with lower quality of life and increased psychological distress (Clark, Wray, & Ashton, 2001; Fernandes-Taylor & Bloom, 2011; Sheehan et al., 2007). Decision regret in the context of breast reconstruction has been under-researched, but is increasingly recognised as an important outcome in evaluating medical decision-making (Fernandes-Taylor & Bloom, 2011; Sheehan et al., 2007; Zhong et al., 2013).

Previous research has shown that regret is associated with low participation in decision-making (Gopie et al., 2011; Lantz et al., 2005), dissatisfaction with information received pre-surgery (Sheehan et al., 2007; Zhong et al., 2013) and psychosocial characteristics such as poor body image and anxiety (Sheehan, Sherman, Lam, & Boyages, 2008). Qualitative data suggest that regret in younger breast cancer survivors is associated, for some, with the decision to have breast reconstruction (due to pain and loss of sensation), and for others, with the decision to delay reconstructive surgery (Fernandes-Taylor & Bloom, 2011). Importantly, the discrepancy (or lack of) between a woman's expectations of breast reconstruction and the actual outcome may also contribute to her experience of post-decision regret (Abu-Nab & Grunfeld, 2007; Sheehan et al., 2007). In a longitudinal, eight-year study of 78 women who had undergone nipple-sparing mastectomy with immediate breast reconstruction (Djohan et al., 2010), it was found that high patient satisfaction with reconstructed breasts and nipple-areola complex was associated with low regret (operationalised as a willingness to undergo the procedure again, if they were to make their decision again). Accordingly,

factors such as a woman's satisfaction with her reconstructed breasts (e.g., how her reconstructed breasts look clothed or unclothed) may influence her level of post-decision regret, with greater satisfaction likely associated with less regret.

Women with poorer physical health outcomes who experience major post-surgical complications (e.g., haematoma, tissue necrosis; Zhong et al., 2013) are also more likely to report regret following surgery. However, neither timing (immediate versus delayed) nor method of reconstruction (flap versus implant) have been associated with decision regret (Fernandes-Taylor & Bloom, 2011; Zhong et al., 2013) in breast cancer populations.

Similarly, a woman's sexual well-being can be negatively affected by breast cancer surgery and treatment (Murray, Turner, Rehan, & Kovacs, 2014; Neto et al., 2013), and so affect her appraisal of decisions made. In the study on first-year trajectories of psychosocial adjustment following breast cancer treatment (Lam et al., 2012), sexual well-being was measured as a woman's appraisal of her intimate appearance and partner intimacy (Lam et al., 2012). For women whose sexual well-being was initially high, but then declined over the first year, and for those whose sexual well-being was initially low but improved, decisional conflict during the decision-making process, disappointment with surgical outcome and psychological distress six years post-surgery was greater than for women with a stable level of sexual well-being (Lam et al., 2012).

Another factor that may influence a woman's responses to her breast surgery and reconstruction is her perceptions of her partner's or spouse's reactions to this surgery. Unfortunately, consideration of partner reactions to a woman's breast surgery has largely been neglected in research (Falk Dahl et al., 2010). There is some evidence that marital status is associated with surgical decision making, in that married women are 23% more likely to receive breast conserving treatment (i.e., lumpectomy rather than mastectomy)

than single women (Voti et al., 2006). Additionally, it has been documented that perceived partner social support and reactions to physical sequelae of surgery influences a woman's emotional well-being (e.g., Talley, Molix, Schlegel, & Bettencourt, 2010; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005) and sexual health after breast cancer (Emilee, Ussher, & Perz, 2010). Other studies have found that a husband's evaluation of a woman's physical appearance better predicts her marital satisfaction than her own negative body image (Ming, 2002), suggesting that partner reactions could have an important influence on a woman's appraisal of breast cancer decision-making. In the study by Harcourt & Rumsey (2004), those women who required additional time to consult with their family and friends highlights a subgroup of women who may benefit from involving significant others in the decision-making process. A more recent study (Duggal et al., 2013) found that almost 40% of the women in their sample who had a diagnosis of breast cancer (N = 155) thought they would be more attractive to their partners if they underwent breast reconstruction, making partner reactions to breast reconstruction an important issue for consideration.

Decision aids are evidence-based tools that highlight alternatives, pros and cons of each decision, and the importance of personal values in decision-making (O'Connor et al., 2009; Obeidat, Finnell, & Lally, 2011; Sheehan et al., 2007; Whelan et al., 2004). Ample evidence indicates that decision aids are able to reduce the level of decisional conflict (Lam et al., 2013; Sheehan & Sherman, 2012; Whelan et al., 2004) and improve women's appraisal of their decisions in women with early stage breast cancer (Lam et al., 2013; O'Brien et al., 2009; Obeidat et al., 2011; Whelan et al., 2004). Studies have typically found that decision aids do not make a difference to decision regret one month after surgery (e.g., Lam et al., 2013; Whelan et al., 2004). However, at four and 10-months post-surgery, those women who had used decision aids reported lower decisional

regret (Lam et al., 2013). It may be that those women who require additional information and time to make a decision (Harcourt & Rumsey, 2004) would particularly benefit from decision aids.

However, specific factors that reduce decisional conflict are unclear and warrant further investigation (O'Brien et al., 2009). This review of the relevant literature has indicated that decisional conflict and regret may also be influenced by factors such as a woman's satisfaction with her reconstructed breasts, physical and sexual well-being post-surgery, her perceived partner reactions to her changed body and the importance placed on this reaction.

2.12 Overview of the Current Thesis

The current thesis aims to contribute to the oncology literature by investigating the following aims in two empirical studies, presented in the following two chapters. Firstly, to investigate levels of body image disturbance, psychological distress, decisional conflict and post-decision regret in women who have undergone NSM+IBR. Secondly, to determine if self-compassion exhibits unique indirect (mediating) effects on the relationship between body image disturbance and psychological distress, and the moderating role of appearance investment in this relationship. A third aim is to identify factors that may account for variations in decisional conflict and regret, such as satisfaction with reconstructed breasts, post-surgery physical and sexual well-being, perceived partner reactions to a woman's body after reconstruction and the importance placed on this reaction.

It was hypothesised that levels of body image disturbance, psychological distress, decisional conflict and post-decision regret would be within the normal ranges for

women who have undergone NSM+IBR. It was further hypothesised that self-compassion would exhibit a significant mediating effect on the body image-distress relationship, and that appearance investment would have a significant moderating effect on this relationship. A final hypothesis was that factors such as satisfaction with reconstructed breasts, post-surgery physical and sexual well-being, perceived partner reactions to a woman's body after reconstruction and the importance placed on this reaction, would contribute uniquely to a woman's experience of decisional conflict or post-decision regret.

Chapter 3. Body Image and Psychological Distress in Nipple Sparing Mastectomy: The Roles of Self-Compassion and Appearance Investment

As noted in Chapter 2, NSM+IBR is a relatively new procedure and limited empirical work has investigated psychological outcomes, such as body image disturbances and psychological difficulties, in women who have undergone NSM+IBR. This chapter comprises an empirical study that examines body image disturbance and psychological distress in women who have undergone NSM+IBR. As individual differences in psychological factors may account for conflicting findings on which surgical procedures yield the most favourable psychological outcomes, the mediating role of self-compassion and the moderating role of appearance investment on the body image-distress relationship are also investigated.

The primary author (Samantha Woon) was the major contributor to this paper and designed the concept of the study, collected and analysed the data, with input and advice from Kerry Sherman. The primary author drafted the first version of the manuscript, with Kerry Sherman reviewing and providing feedback on multiple versions of the manuscript. Elisabeth Elder and James French assisted with collection of data, reviewed and provided feedback on the manuscript prior to submission for review.

Please note, because this paper has developed over time, it is referenced in Appendix D as:

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Body image and psychological distress in nipple sparing mastectomy: The roles of self-compassion and appearance investment

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3.1 Abstract

***Objective*:** Women with breast cancer face threats to body image following surgery. Nipple-sparing mastectomy with immediate breast reconstruction (NSM+IBR) may minimise body image disturbance as this preserves the woman's skin and areola complex. This study assessed body image disturbance and psychological distress in women undergoing NSM+IBR. To further understand mechanisms that explain the body image-distress relationship, this study focused on the mediating effect of self-compassion and how appearance investment might moderate this mediated relationship.

***Methods*:** Women diagnosed with breast cancer (N=80) who had undergone NSM+IBR completed online questionnaires including the Body Image Scale, general- (Depression, Anxiety and Stress Scales) and cancer-specific (Impact of Event Scale) psychological distress, Self-Compassion Scale and appearance investment (Appearance Schemas Inventory – Revised).

***Results*:** Mean general and cancer-specific psychological distress scores were within normal ranges and body image disturbance was moderately low. Body image was positively correlated with depression, stress, impact of event scale scores and appearance investment, and negatively correlated with self-compassion. Bootstrap analyses indicated a significant indirect effect of self-compassion on the relationship between body image disturbance and distress (depression, anxiety, stress). Appearance investment moderated the body image to self-compassion path of this mediated relationship.

***Conclusions*:** Moderately low levels of psychological distress and body image disturbance suggest that NSM+IBR may minimise adverse psychological impacts of mastectomy. As predicted, increased body image disturbance was associated with psychological distress and influenced by self-compassion and appearance investment,

suggesting a potential role for these individual characteristics as the focus of psychological interventions to minimise the negative impacts of mastectomy.

3.2 Body image and psychological distress in nipple-sparing mastectomy: The roles of self-compassion and appearance investment

Women with breast cancer typically face several treatment options, which may take place over an extended period of time (Serletti et al., 2011). These interventions, including surgery, chemotherapy, radiation therapy and hormone treatments, have associated side effects that can be appearance-altering (e.g., breast removal, hair loss, skin discolouration, weight fluctuations; Collins et al., 2011). These treatments and their associated side effects can lead to negative changes in a woman's body image, defined as a perception of her physical appearance (Collins et al., 2011; Helms et al., 2008) and overall attitude toward her body (Cash et al., 2004; Moreira et al., 2010). Breast surgery involving the loss of one or both breasts through mastectomy, may negatively affect a woman's identity and body image (Collins et al., 2011; Helms et al., 2008) through breast asymmetry, scarring, or the need for prostheses (Gopie et al., 2013). Research suggests that the more invasive the breast surgery (i.e., mastectomy compared with lumpectomy), the greater the negative impact on psychological well-being (e.g., Gopie et al., 2013; Winters et al., 2010). Corresponding with the experience of body image disturbance, it is common for women to report heightened psychological distress, namely, depression, anxiety and stress (Begovic-Juhant et al., 2012; Gopie et al., 2011), particularly with a poor cosmetic outcome (Falk Dahl et al., 2010). Even after successful breast cancer surgery and treatment, some women experience body image-related psychological distress beyond one year following cancer diagnosis (Helms et al., 2008). The link between body image disturbance and psychological distress appears particularly pronounced in younger women, typically defined as women aged in their forties or younger (Rosenberg et al., 2013).

Breast reconstruction, as an immediate (at the time of mastectomy) or delayed (after mastectomy) procedure, offers a surgical means to restore breast shape and appearance (Sheehan et al., 2007). Reconstruction techniques may involve implants or autologous tissue (flap procedures) to recreate the breast shape (see Serletti et al., 2011 for a comprehensive overview). Typically, implant breast reconstruction has entailed gradual stretching of the skin over several weeks to create a new envelope for the breast implant, followed by surgical insertion of the implant and optional nipple areola complex reconstruction using tattooing and/or skin grafting procedures (Serletti et al., 2011). Flap reconstruction generally provides a better aesthetic result than implant reconstruction, but involves the burden of more extensive surgery and donor site healing (D'Souza et al., 2011; Gopie et al., 2013; Gopie et al., 2011; Moreira & Canavarro, 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010). Irrespective of whether flap or implant reconstruction is used, several operations are typically required to give the final cosmetic result (Serletti et al., 2011).

A procedure that may minimise some of the physical and practical challenges of breast reconstructive surgery is Nipple Sparing Mastectomy with immediate breast reconstruction (NSM+IBR). A relatively new, yet oncologically-safe procedure, NSM+IBR allows cancerous breast tissue to be removed and replaced with an implant or flap, allowing a woman's original skin and nipple areola complex to be preserved (see Boneti et al., 2011, for full details of procedure). As a single-step procedure, the additional risks, complications and time costs associated with multiple or revision surgeries are reduced (Serletti et al., 2011). Women generally favour re-creating a nipple areola complex following breast reconstruction (Djohan et al., 2010; Serletti et al., 2011; Winters & Thomson, 2011; Winters et al., 2010), so retaining one's own skin and nipple areola complex could result in less body image disturbance with NSM+IBR. Limited

evidence indicates that women generally feel satisfied with NSM+IBR outcomes, but that residual dissatisfaction with nipple position and sensation may remain (Didier et al., 2009; Peled et al., 2014). Moreover, general psychosocial well-being (related primarily to body image concerns) appears to return to pre-surgery levels by one year following NSM+IBR (Peled et al., 2014).

Despite the potential benefits of procedures such as NSM+IBR, no published studies have investigated comparisons of psychosocial outcomes of NSM+IBR with other types of breast surgery. There also remains inconsistency regarding which surgical procedures provide the most favourable patient outcomes in terms of body image (e.g., Z. E. Winters et al., 2010), when comparing immediate with delayed breast reconstruction procedures, even when the same Body Image scale (Hopwood et al., 2001) was used (e.g., Collins et al., 2011; D'Souza et al., 2011; Didier et al., 2009; Fang et al., 2013; Lee et al., 2009). This suggests that factors beyond surgical and treatment considerations, such as individual differences in psychological characteristics, are likely implicated in a woman's adjustment to her changed body after surgery.

One such psychological factor may be self-compassion, one's capacity to be kind and accepting towards oneself in the midst of suffering, and to view one's suffering as part of a wider human condition, rather than feeling isolated and alone (Neff et al., 2007; Raes et al., 2011). Self-compassion has been associated with psychological well-being generally (Leary et al., 2007; Neff et al., 2007; Przezdziecki et al., 2013; Raes et al., 2011), and negatively associated with psychological distress (i.e., anxiety, depression) in clinical (e.g. in psychological treatment) and non-clinical (e.g., community or university; Neff, 2003) settings. The rapid changes to one's body during breast cancer treatment can impact a woman's views and beliefs about her body, resulting in increased psychological distress (Przezdziecki et al., 2013). However, if a woman undergoing

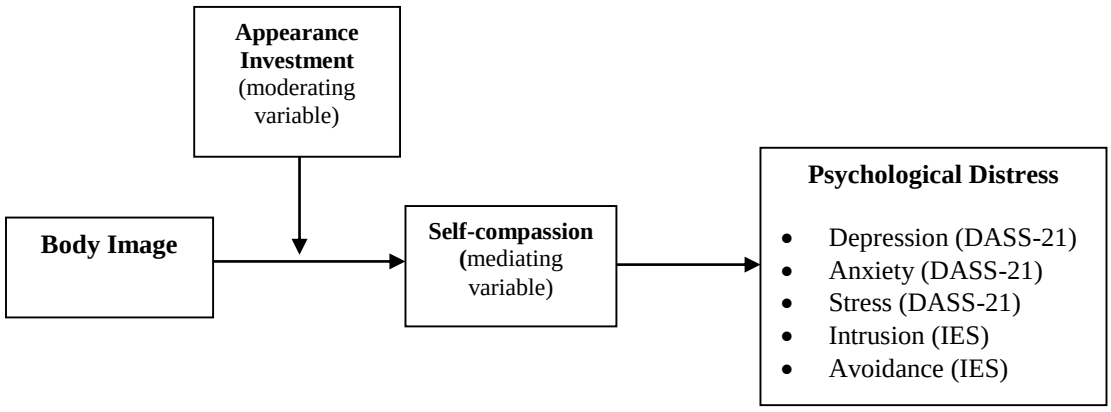
these challenges to her body image is able to respond with self-kindness and acceptance of this as part of her cancer experience, this may ease her experience of psychological distress (Przezdziecki et al., 2013). While oncology-based research on self-compassion is emerging, one study of breast cancer survivors demonstrated that self-compassion mediated the relationship between body image disturbance and psychological distress (Przezdziecki et al., 2013). In a non-oncology context, body dissatisfaction (i.e., equated with body image disturbance) in women predicted self-compassion, which in turn predicted psychological functioning (Ferreira et al., 2013) and depressive symptoms (Wasylkiw et al., 2012). Hence, it is likely that self-compassion may mediate the relationship between body image disturbance and psychological distress in women undergoing NSM+IBR surgery.

Another psychological factor that may explain differences in patient outcomes is appearance investment, comprising self-evaluative salience (importance placed on physical appearance in defining one's self-worth) and motivational salience (one's efforts to maintain or achieve a certain level of attractiveness; Cash, 2011; Cash et al., 2004; Moreira & Canavarro, 2012). Theoretically (White, 2000), it has been proposed that when facing body image changes after breast cancer, women who place greater importance on their physical appearance are at greater risk of poor adjustment. This prediction has been empirically supported whereby higher levels of appearance investment were predictive of depression (Moreira et al., 2010) and poorer quality of life (Moreira & Canavarro, 2012; Moreira et al., 2010). Appearance investment has been shown to moderate this relationship so that for women with high self-evaluative salience, increased self-consciousness about bodily appearance was associated with increased depressive symptoms (Moreira & Canavarro, 2012). Given that body image disturbance has been shown to predict self-compassion, it was expected that this relationship would

be stronger in women with higher investment, where the importance placed on one's appearance would influence a woman's ability to be self-compassionate when faced with disturbances in body image.

Taken together, preliminary evidence indicates that self-compassion and appearance investment may be implicated in a woman's psychological adjustment following breast surgery. These factors have not yet been investigated in the context of developments in breast surgery, such as NSM+IBR. The aims of this study were to investigate in women undergoing NSM+IBR: (i) the relationship between body image disturbance, general and cancer-specific psychological distress; (ii) the indirect effect of self-compassion on the body image-distress relationship; and (iii) the moderating effect of appearance investment on the body image-self-compassion relationship. That is, greater body image disturbance would be associated with increased psychological distress and that appearance investment would moderate the relationship between body image disturbance and distress via self-compassion, such that the body image-self-compassion path will be stronger when appearance investment is high. A figure of the variables under investigation and the relationships between the variables is presented below.

Figure 1. Relationships Between Study 1 Variables



3.3 Method

Sample and Procedures

Participants identified from breast clinic records of two oncoplastic surgeons (EE, JF) were invited to participate through a mail-out that included a website address to access the online questionnaire. Recruitment from the Westmead Breast Cancer Institute and Norwest Private Hospital in Sydney, Australia occurred between February 2012 and October 2013. All women who underwent NSM+IBR at these locations from the time the surgery was first offered in 2009, until recruitment ceased in October 2013, were invited to participate. Women with known psychiatric difficulties were excluded by breast clinic staff prior to researchers inviting women into the study. Participants were also invited into the study through an emailed invitation to members of the Breast Cancer Network of Australia research pool. Inclusion criteria were: having undergone NSM+IBR, being over 18 years of age, and able to complete a questionnaire in English. There were no other exclusion criteria. A total of 113 women from the breast clinics were invited. Of these, 11 women were uncontactable, 13 declined participation, 39 were contacted and indicated a willingness to participate but did not, leaving 50 breast clinic recruits. Thirty-one women from the Breast Cancer Network Australia responded to the emailed invitation. Thus, 81 women consented to participate in the study. At their request, paper questionnaires were mailed to five women, who completed and returned them by mail. The remaining participants completed the online questionnaire. All investigations were approved by the relevant Human Research Ethics Committees.

Measures

Body image. The 10-item cancer-specific Body Image Scale (Hopwood et al., 2001) assessed the impact of surgery on an individual's body image (e.g., 'Have you felt less physically attractive as a result of your disease or treatment?"). Participants rated items on a 4-point Likert-type scale (0 'Not at all' to 3 'Very much'). Total scores range from zero to 30, with higher scores indicating greater body image disturbance ($\alpha = .91$). The Body Image Scale was designed specifically to assess body image disturbances in women with breast cancer (Hopwood et al., 2001), and is widely used for this purpose, thereby allowing for ease of comparison of results across different studies. A general (rather than cancer-specific) measure of body image was not used in the current study to minimise study burden on participants.

General psychological distress. The 21-item short form of the Depression, Anxiety and Stress Scales (DASS-21; (Lovibond & Lovibond, 1995), measured depression, anxiety and stress, with seven items for each subscale (e.g., "I found it difficult to wind down" (Stress)). Each item is scored from 0 ('Did not apply to me at all') to 3 ('Applied to me most of the time or very much') and a separate score out of 21 is calculated for each subscale. Cronbach's alpha for the DASS-21 total score was .92 (Stress = .87; Anxiety = .78; Depression = .89).

Breast cancer-specific psychological distress. The 15-item Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979) measured cancer-specific psychological distress using the Intrusion (e.g., "Pictures about it popped into my head") and Avoidance (e.g., "I tried not to talk about it") subscales. Items are rated on a 4-point Likert-type scale, 0 ('Not at all'), 1 ('Rarely'), 3 ('Sometimes') and 5 ('Often'). Participants were instructed to respond to the scale in relation to their breast surgery. Cronbach's alpha of the current sample was high (Intrusion = .86; Avoidance = .88).

Self-compassion. The 12-item short form of the Self-Compassion Scale (Raes et al., 2011) was used. Items (e.g., "I try to see my failings as part of the human condition") are rated on a 5-point Likert-type scale (1 'Almost never' to 5 'Almost always'). A total score was computed, with higher scores indicating higher levels of self-compassion (α = .91).

Investment in appearance. The 20-item Appearance Schemas Inventory-Revised (Cash et al., 2004) assessed appearance investment regarding motivational (e.g., "I try to be as physically attractive as I can be") and self-evaluative (e.g., "My appearance is responsible for much of what's happened to me in my life") salience. Items are rated on a 5-point Likert-type scale (1 'Strongly disagree' to 5 'Strongly agree). Total mean scores for each subscale were calculated, with higher scores indicating higher levels of investment in appearance (α = .85 self-evaluative salience; α = .88 motivational salience).

Demographic and medical characteristics. Demographic information collected included: age, country of birth, education level, employment status, marital status, household income, insurance coverage. Medical information regarding characteristics of breast cancer diagnosis, surgery type, and family history of breast cancer were also collected.

Data Analyses

Data were analysed using the Statistical Package for the Social Sciences (SPSS, version 21). Of the 81 consenting participants, one with extensive missing data was removed. Missing values for nine women with incomplete data were estimated based on maximum-likelihood procedures to preserve distributional characteristics (Schafer & Graham, 2002). Of the remaining 80 participants, 75 were diagnosed with breast cancer.

The remaining five women did not have a cancer diagnosis and had undergone NSM+IBR for preventive reasons. No differences were found between these two groups on any of the outcome variables (F = .64, df (58), p = .67). *T*-tests and chi-square analyses were undertaken to compare means of demographic and medical characteristic variables between participants recruited from the breast clinic and Breast Cancer Network Australia. The samples differed on education level and type of reconstruction (i.e. using implants, TRAM or DIEP flap procedures); consequently these variables were dummy coded and included as covariates. Correlations were used to identify the association between numeric (Pearson's) and ordinal or dichotomous (Spearman's) variables. Bootstrap analyses were conducted to test for indirect effects of self-compassion moderated by appearance investment using the PROCESS macro (Hayes, 2012), which generates a 95% percentile-based confidence interval based on 5000 bootstrap samples, controlling for the identified covariates. Separate analyses of moderated indirect effects were conducted for each of the distress outcome variables (i.e., depression, anxiety, stress, intrusion and avoidance). A power analysis was conducted using 'G-Power', which indicated that, to achieve an anticipated effect size of 0.2, with power of at least 0.8, and six predictors for a critical p of 0.05, a sample size of 75 was required. The current study with a sample of 80 women achieved an actual power of 0.87 and effect size of 0.30.

3.4 Results

Sample characteristics are provided in Table 1 below.

Table 1. *Sample demographic characteristics*

Variable	Percentage	Number (n)	Mean	SD
Age	-	-	47.73	8.64
Marital Status			-	-
No partner	20.00	16		
Married or partnership	80.00	64		
Country of Birth			-	-
Australia	65.00	52		
New Zealand	3.75	3		
UK/Ireland	16.25	13		
Asia	6.25	5		
Europe	5.00	4		
Africa	3.75	3		
Education			-	-
Less than 12 years	23.80	19		
12 years	7.50	6		
Vocational Training	30.00	24		
Some university	2.50	2		
Bachelor's degree or above	36.30	29		
Family history of breast cancer	36.30	29	-	-
Underwent prior breast surgery	28.70	23	-	-
Diagnosed with breast cancer	93.80	75	-	-
Time since diagnosis			-	-
Less than 1 year	31.25	25		
1-2 years	40.00	32		
2-3 years	13.75	11		
3-4 years	3.75	3		
5 or more years	11.25	9		
Type of treatment received*			-	-
Chemotherapy	60.00	48		
Radiation	21.30	17		
Hormonal treatment	50.00	40		
Type of mastectomy			-	-
Single (one breast)	52.50	42		
Double (both breasts)	47.50	38		
Type of reconstruction			-	-
NSM + implants	90.00	72		
NSM + flap	8.80	7		

*Participant may have received more than one type of treatment.

Correlations between the variables of interest and means and standard deviations are presented in Table 2 below.

Table 2. *Correlations between variables of interest*

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
1. Age												
2. Education^	– 0.36**											
3. Reconstruction^ Type	0.07	0.06										
4. Body Image	– 0.23*	0.13	– 0.12									
5. Depression	– 0.19	0.07	– 0.17	0.43**								
6. Anxiety	– 0.12	– 0.12	– 0.23*	0.18	0.59**							
7. Stress	– 0.13	0.09	– 0.25*	0.30**	0.68**	0.64**						
8. Intrusion	– 0.01	– 0.02	– 0.20	0.43**	0.58**	0.19	0.47**					
9. Avoidance	– 0.14	0.09	– 0.22	0.54**	0.54**	0.22*	0.52**	0.72**				
10. Self-compassion	0.20	0.15	0.06	– 0.32**	– 0.63**	– 0.53**	– 0.50**	– 0.30**	– 0.36**			
11. Self-evaluative salience	– 0.20	– 0.08	– 0.13	0.36**	0.54**	0.47**	0.51**	0.44**	0.45**	– 0.59**		
12. Motivational salience	– 0.02	– 0.03	– 0.18	– 0.05	0.05	0.20	0.05	– 0.02	0.01	– 0.04	0.41**	
13. Time since diagnosis (length in months)	0.06	0.19	0.36**	0.02	– 0.02	– 0.10	– 0.17	– 0.17	– 0.21	0.21	– 0.15	– 0.12
Mean	47.73	-	-	5.79	3.90	3.88	7.83	6.45	7.76	3.47	2.91	3.79
SD	8.64	-	-	5.86	5.52	5.25	7.00	6.92	8.20	0.77	0.59	0.66

N = 80 for full sample, for Reconstruction type *n*=79. ^Spearman's correlations used for ordinal variables.
** Correlation is significant at the 0.01 level (two-tailed).
* Correlation is significant at the 0.05 level (two-tailed).

Participants ranged from 27 – 66 years of age. The DASS-21 distress mean scores fell within normal ranges for all three subscales (Lovibond & Lovibond, 1995). Mean IES cancer-specific distress scores were elevated, but within the subclinical range (Horowitz et al., 1979). Body image (disturbance) was lower than previously reported by breast cancer patients (M = 5.79, SD= 5.86 *v* M = 8.07 SD = 5.02, 1 year post-operatively; Hopwood et al., 2001; $t(238) = 3.13$, $p = 0.0019$). Moderate levels of self-compassion were demonstrated (Neff, 2003; Raes et al., 2011). The mean appearance investment scores were lower for self-evaluative salience than those reported by American college women (M = 3.39, SD = .70; Cash, 2003; $t(546) = 5.79$, $p < 0.001$), and comparable to the college sample for motivational salience (M = 3.72, SD = .66; Cash, 2003; $t(546) = 0.88$, $p = .38$).

Analyses of Moderated Indirect Effects

Only the self-evaluative component of appearance investment was utilised in these tests of indirect effects, as the motivational component was not significantly associated with self-compassion or any of the outcome variables. Applying a bootstrapping analysis (Hayes, 2012), and controlling for age, education level and reconstruction type, the results of the moderated indirect effect analyses are shown in Table 3 below. For depression, anxiety, and stress only, the indirect effect of self-compassion was moderated by appearance investment (Preacher & Hayes, 2008), so that the indirect effect was strongest (and significant) when appearance investment was high.

Table 3. *Coefficient estimates for the conditional indirect effects models*

Model	Effect of IV on MV		Effect of MV on DV		Direct effect		Indirect effect			
	B	***p***	**B**	***P***	**B**	***P***	**β**	**SE**	**95% CI** **Lower**	**Upper**
BI-SC-Depression										
Self-compassion	– 0.04	0.05	– 3.92	0.005	0.23	0.01				
$AI\text{-}SE_{Mean}$							0.03	0.07	– 0.09	0.17
$AI\text{-}SE_{Low}$							– 0.03	0.10	– 0.25	0.16
$AI\text{-}SE_{High}$							0.09	0.05	0.01*	0.23*
BI-SC-Anxiety										
Self-compassion	– 0.04	0.05	– 3.68	0.005	– 0.03	0.78				
$AI\text{-}SE_{Mean}$							0.03	0.06	– 0.09	0.17
$AI\text{-}SE_{Low}$							– 0.03	0.10	– 0.25	0.15
$AI\text{-}SE_{High}$							0.09	0.05	0.02*	0.24*
BI-SC-Stress										
Self-compassion	– 0.04	0.05	– 4.31	0.005	0.13	0.30				
$AI\text{-}SE_{Mean}$							0.04	0.07	– 0.10	0.19
$AI\text{-}SE_{Low}$							– 0.03	0.12	– 0.31	0.16
$AI\text{-}SE_{High}$							0.10	0.06	0.02*	0.25*
BI-SC-Intrusion										
Self-compassion	– 0.04	0.05	– 1.50	0.14	0.44	0.005				
$AI\text{-}SE_{Mean}$							0.01	0.03	– 0.02	0.13
$AI\text{-}SE_{Low}$							– 0.01	0.05	– 0.16	0.06
$AI\text{-}SE_{High}$							0.04	0.04	– 0.02	0.14
BI-SC-Avoidance										
Self-compassion	– 0.04	0.05	– 2.43	0.03	0.61	0.005				
$AI\text{-}SE_{Mean}$							0.02	0.04	– 0.05	0.13
$AI\text{-}SE_{Low}$							– 0.02	0.07	– 0.22	0.09
$AI\text{-}SE_{High}$							0.06	0.04	0.00	0.18

Note. Bootstrap sample size = 5,000. *N*=79. BI = body image; SC = Self-compassion; IV = independent variable (body image); MV = mediating variable; DV = dependent variable (distress); CI = confidence interval.
** Significant at the 0.01 level. * Significant at the 0.05 level.

3.5 Discussion

This study assessed patient-reported outcomes concerning body image disturbance and psychological distress in women undergoing the innovative NSM+IBR surgery procedure. It was predicted that individual characteristics of self-compassion would demonstrate indirect effects on the body image-distress relationship, and that appearance investment would have moderating effects on this relationship. NSM+IBR surgery offers the potential for better cosmetic outcomes and less body image disturbance following breast reconstruction, compared with traditional non-nipple sparing approaches (Al-Ghazal et al., 2000). Consistent with this premise, women in this study reported less body image disturbance (Hopwood et al., 2001) and subclinical levels of distress, similar to, or lower than (Przezdziecki et al., 2013; Sheehan et al., 2007) previously reported in samples of women undergoing non-nipple sparing mastectomy (e.g., Hopwood et al., 2001; Przezdziecki et al., 2013). Given that most women in the current study were between one to two years post-diagnosis, this finding is not surprising as previous reports indicate that by 12 months post-diagnosis, distress generally diminishes to pre-diagnosis levels (e.g., Peled et al., 2014). The overall low levels of psychological distress, and in particular, low levels of body image disturbance may also be be a reflection of the nipple-sparing surgical approach whereby a woman's skin and nipple and areola complex are retained in the breast reconstruction process (Serletti et al., 2011). These findings add to emerging reports that women undergoing NSM+IBR experience high levels of satisfaction with the surgery (Didier et al., 2009; Djohan et al., 2010).

The predicted associations between body image disturbance and greater levels of psychological distress (Begovic-Juhant et al., 2012; Falk Dahl et al., 2010) were largely confirmed, with the exception of anxiety. Body image disturbance was also significantly

related to self-compassion and appearance investment, as predicted, such that greater self-compassion and lower self-evaluative salience were associated with less body image disturbance, consistent with prior studies of women with breast cancer (Leary et al., 2007; Moreira & Canavarro, 2010, 2012; Moreira et al., 2010; Neff et al., 2007). Of key interest to this research was the investigation of the indirect effect of self-compassion on the body image-distress relationship, and the potential moderating effect of appearance investment on this indirect effect. Notably, self-compassion was found to exhibit indirect effects on the relationship between body image and depression, anxiety and stress (Preacher & Hayes, 2008). These findings build on earlier reporting of the mediating role of self-compassion in breast cancer populations (Przezdziecki et al., 2013), with this effect now demonstrated in the current sample of women who generally exhibited low levels of body image disturbance and related distress. This extends research on the important role of self-compassion in women's self-perceptions (in particular, body image), consistent with previous research that supports self-compassion as a beneficial approach to daily distress (e.g., Leary et al., 2007; Wasylkiw et al., 2012). We further demonstrated that the indirect effect of self-compassion on the body image-distress relationship was evident only at higher levels of appearance investment, extending prior research in the breast cancer context on the moderating role of appearance investment (Cash et al., 2004; Moreira & Canavarro, 2010, 2012; Moreira et al., 2010). This suggests that women whose personal appearance weighs heavily on how they view themselves are likely to be more critical of their bodies post-surgery (Moreira & Canavarro, 2012). While it is possible that NSM+IBR was an attractive surgical option for women high in appearance investment, thereby self-selecting into the study and biasing the current sample, this is not indicated by the mean levels of appearance investment in the current study, which were comparable to those of the normative sample. It may be that women

in the current sample, the majority of whom were one to two years post-diagnosis, were past this phase of initial adjustment to their changed appearance (Fang et al., 2014).

Contrary to previous research, time since diagnosis was not associated with body image disturbance or psychological distress. However, a similar finding has been noted in a recent study, whereby the relationship between time since surgery and similar outcome variables was not significant (Fang et al., 2014). A significant negative relationship was found between age and body image disturbance, supporting previous research that younger women, comprising approximately 60% of the current sample, may experience greater body image disturbance (Rosenberg et al., 2013). This relationship was found even though levels of reported distress fell within subclinical levels, suggesting that NSM+IBR may be an acceptable surgical option for addressing body image disturbances in younger women. The significant correlation of reconstruction type with anxiety and stress indicated that flap-based procedures with NSM+IR were associated with lower levels of distress. However, it is important to note that only seven women in the entire sample underwent a flap procedure, while the remaining 72 women received implants. These results should therefore be interpreted with caution.

Implications for Practice

The current study supports NSM+IBR as an acceptable surgical option for women with breast cancer that helps overcome physical and practical challenges of non-nipple sparing mastectomy and reconstruction, with the potential for added psychological benefits for body image and distress. The current results suggest that NSM+IBR should be made available to women who are considering their options for

breast surgery, with the potential benefits explained and balanced with an individual's breast cancer stage and adjuvant treatment required.

However, NSM+IBR is not an available option for all women undergoing mastectomy, and clinically, being able to identify women pre-surgery with higher levels of self-evaluative salience and lower levels of self-compassion may aid in identifying women who are more likely to experience higher levels of distress, or are at greater risk for poorer psychological adjustment post-surgery. This study may therefore be of particular relevance for clinicians engaged in psychological interventions dedicated to women who have undergone breast surgery by: i) providing more support to women identified as at risk for greater distress, or ii) assist clinicians in modifying existing breast surgery body image interventions (e.g., by including psycho-education and practice on increasing self-compassion and lowering appearance investment).

Limitations

This is one of the first studies to assess the psychological aspects of NSM+IBR, however, it is limited by the relatively small sample size, but one that represents more than 60% of the available pool of individuals (limited to two oncoplastic surgeons at two cancer institutions in a five-year period) undergoing this emerging surgical technique. The exclusion of women with known psychological difficulties at the recruitment stage of the study may have biased the sample, consequently, conclusions regarding the potential benefits of NSM+IBR on psychological adjustment post-surgery should be made and interpreted with caution. That most women in the current sample were approximately one to years post-breast cancer diagnosis may also be a confounding factor when considering the level of psychological adjustment post-surgery in the current sample. Given the current cross-sectional approach, it is also difficult to infer causal

relationships between the variables, which may be clinically and practically useful in identifying women who are likely to experience significant distress post-surgery, as well as variables that may function as protective factors. The lack of inclusion of a more general measure of body image in the current study may also be viewed as a limitation, as it is possible that the effect of breast surgery may be apparent only when measured using cancer-specific, rather than general, measures of body image.

Another limitation of the current study is the lack of control or comparison group with other types of surgery (i.e. breast cancer surgery patients who did not undergo NSM+IBR). This lack of comparison group further limits the conclusions that may be drawn about the benefits of NSM+IBR.

Future Research

Future studies with a continued focus on NSM+IBR, and the roles of self-compassion and appearance investment with larger sample sizes would be warranted. As the pool of women who undergo NSM+IBR increases, researchers could compare levels of distress and body image disturbances between women who have undergone NSM+IBR and women who have undergone traditional mastectomy. It would also be of interest to compare different types of immediate breast reconstruction. Future studies could also incorporate the use of cancer-specific and general measures of body image, to determine the effect of breast surgery on both these domains.

Conclusions

The current study found that, for the majority of women undergoing NSM+IBR, body image disturbance and distress are typically within normal limits. Self-compassion was found to have a significant indirect effect on the body-image distress relationship,

at high levels of appearance investment. Consequently, these are factors which require further research, and may have useful clinical implications when helping women adjust to bodily changes post-surgery.

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Conflict of Interest

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Chapter 4. Decisional Conflict and Decision Regret Following Nipple Sparing Mastectomy

As decisional conflict and post-decision regret have also been shown to contribute to psychological distress following breast surgery, this chapter comprises an empirical paper investigating levels of decisional conflict and regret in women who have undergone NSM+IBR. As there is limited literature on factors that contribute to NSM+IBR, factors that may account for decisional conflict and regret were also examined, such as a woman's satisfaction with her reconstructed breasts, her post-surgery physical and sexual well-being, as well as her perceived partner's response or reaction to her body following breast reconstruction, and the importance placed on this reaction.

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Decisional Conflict and Regret Following Nipple-Sparing Mastectomy

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4.1 Abstract

***Objective*:** Women diagnosed with breast cancer must make complex, preference-sensitive decisions about surgical options under time pressure and often while experiencing psychological distress. Charged with ensuring a favourable psychological, cosmetic and oncologically-sound outcome, women are vulnerable to experiencing decisional conflict and regret following the mastectomy decision-making process. The aim of this study was to assess levels of post-decisional conflict and regret in women who had undergone nipple-sparing mastectomy and immediate breast reconstruction (NSM+IBR), an innovative mastectomy type that preserves the woman's skin, nipple and areola complex. Decisional conflict and regret may be a reflection of a woman's perceptions of the surgical outcomes. Accordingly, a further aim of this study was to assess the extent to which a woman's satisfaction with the surgical outcome, her post-surgical sexual and physical well-being, and her perceptions of her partner's reactions to her mastectomy were associated with decisional conflict and regret.

***Methods*:** Women diagnosed with breast cancer (N=80) who had previously undergone NSM+IBR completed an online questionnaire incorporating the Decisional Conflict Scale, the Decision Regret Scale, the BREAST-Q, and a measure of the woman's perceptions of her partner's reactions to the breast surgery and the importance she placed on her partner's reaction.

***Results*:** Mean scores on decisional conflict and regret indicated that the majority of participants experienced low levels of decisional conflict and regret, although 15% of the sample reported high levels of conflict and 20% reported moderate to high levels of regret. Linear regression analyses indicated that a woman's satisfaction with her reconstructed breasts uniquely contributed to decision regret, while how much a woman

cared about her partner's reaction to her reconstructed breasts uniquely contributed to decisional conflict.

***Conclusions*:** As expected, satisfaction with reconstructed breasts is significantly associated with decision regret, where adverse outcomes are associated with higher levels of regret. Interestingly, how much a woman cared about her partner's reaction to her reconstructed breasts was not associated with regret but with decisional conflict. These results may assist in identifying women both during the decision-making process and post-surgery, who require psychological intervention with regard to resolving decisional conflict and regret.

4.2 Decisional Conflict and Regret Following Nipple-Sparing Mastectomy

The process of decision-making involves a choice between two or more options and aims to accomplish specific, and often optimal, outcomes (e.g., Chien et al., 2013). Given the lack of medical guidelines for breast surgery, women diagnosed with breast cancer must make complex and preference-sensitive decisions about treatment, often during a period of increased time pressure and when they are experiencing psychological distress (Bride et al., 2013; Fernandes-Taylor & Bloom, 2011; Lee et al., 2011; Resnicow et al., 2014; Zhong et al., 2013). Both during and after the decision-making process, feeling conflicted, uncertain or regretful about decisions can significantly impact a woman's psychological recovery from breast cancer (Dillard et al., 2013; Lam et al., 2013; O'Brien et al., 2009; O'Connor, 2010; Resnicow et al., 2014). There are several factors shown to influence an individual's appraisal of treatment decisions, such as the amount of decisional conflict experienced during and after the process, and regret over time (Dillard et al., 2013; O'Brien et al., 2009; O'Connor, 2012; Resnicow et al., 2014). This appears to be particularly the case if she experiences adverse outcomes (Payne et al., 2000; Zhong et al., 2013). It has also been suggested that the process of decision-making, particularly, shared decision-making between a woman and her surgeon, is as important as the ultimate decision (Mac Bride et al., 2013), with women who perceive less or more involvement than their desired level of involvement in the decision-making process reporting lower satisfaction than women who perceived a level of involvement in accordance with what they desired (Mac Bride et al., 2013). Consequently, a woman's appraisal of her treatment decisions is particularly important as it will likely influence her subsequent psychosocial well-being (Ashraf et al., 2013; Bride et al., 2013; O'Connor, 2012; Sheehan et al., 2007).

Decisional conflict refers to feeling uncertain or ineffective in the decision-making process, particularly a decision that involves personal risk (O'Connor, 1995; O'Connor & Jacobsen, 2007). Decisional conflict has been shown to occur not only during the decision-making period but also after the decision has been made (Chien et al., 2013). High levels of decisional conflict cause delays in decision-making and influence psychological and physical health for women with breast cancer (Brehaut et al., 2003; Kokufu, 2012; Lam et al., 2013). Individuals facing a diagnosis of serious illnesses, such as breast cancer, have to synchronise their treatment values and preferences, as well as those of their physicians with available treatment options (Kokufu, 2012). Previous studies have shown that when the level of decisional conflict experienced is high, appraisal of the quality of the decision made regarding breast cancer treatment is typically low, and that the woman concerned is more likely to feel helpless about managing her illness (Kokufu, 2012).

Similarly, decisional regret in the context of breast reconstruction is increasingly recognised as an important outcome in evaluating medical decision-making (Fernandes-Taylor & Bloom, 2011; Sheehan et al., 2007; Zhong et al., 2013). Decision regret broadly refers to the distress experienced after making a treatment decision (Connolly & Reb, 2005; Zhong et al., 2013) and has been associated with lower quality of life and increased psychological distress (Clark et al., 2001; Fernandes-Taylor & Bloom, 2011; Sheehan et al., 2007). Previous research has shown that regret is associated with low participation in decision-making (Lantz et al., 2005), dissatisfaction with information received pre-surgery (Sheehan et al., 2007; Zhong et al., 2013) and psychosocial characteristics such as poor body image and anxiety (Sheehan et al., 2008). Qualitative data suggest that regret in younger breast cancer survivors is associated, for some, with the decision to have breast reconstruction (due to pain and loss of sensation), and for others, with the

decision to delay reconstructive surgery (Fernandes-Taylor & Bloom, 2011). Women with poorer physical health outcomes who experience major post-surgical complications (e.g., hematoma, tissue necrosis; Zhong et al., 2013) are also more likely to report regret following surgery. Neither timing (immediate versus delayed) nor method of reconstruction (flap versus implant) have been associated with decision regret (Fernandes-Taylor & Bloom, 2011; Zhong et al., 2013) in breast cancer populations.

There is ample evidence that decision aids (i.e., evidence-based tools to assist the decision making process) are effective in reducing decisional conflict (Lam et al., 2013; Sheehan & Sherman, 2012; Whelan et al., 2004) and regret (Lam et al., 2013), and in improving appraisal of decisions in women with early stage breast cancer (Lam et al., 2013; O'Brien et al., 2009; Obeidat et al., 2011; Sherman, Harcourt, Lam, Shaw, & Boyages, 2014). However, there is a lack of understanding regarding the specific factors that are associated with decisional conflict and regret in these women; thus, further investigation is warranted (O'Brien et al., 2009; Sherman et al., 2014).

One factor that may influence outcomes of the decisional process is the specific type of surgery chosen. While there is evidence that neither timing (immediate versus delayed) nor method of breast reconstruction (flap versus implant) are associated with decision regret (Fernandes-Taylor & Bloom, 2011; Zhong et al., 2013), no studies have examined nipple-sparing mastectomy in this context. Nipple-sparing mastectomy and immediate breast reconstruction (NSM+IBR) is an oncologically-safe innovative procedure which allows cancerous breast tissue to be removed and replaced with either an implant or flap, allowing a woman's original skin and nipple areola complex to be preserved (Boneti et al., 2011). As NSM+IBR is a single-step procedure, the additional risks, complications and time (for surgery and recovery) costs associated with multiple or revision surgeries are reduced (Serletti et al., 2011). There is evidence that women

generally favour re-creating a nipple areola complex following breast reconstruction (Djohan et al., 2010; Serletti et al., 2011; Winters et al., 2010), so retaining one's own skin and nipple areola complex could result in greater concordance with a patient's preferences and higher satisfaction with reconstructed breasts, thereby decreasing decisional conflict and regret. Recent evidence suggests that women generally feel satisfied with the outcomes of NSM+IBR one year following surgery, but that residual dissatisfaction with nipple position and sensation may remain (Peled et al., 2014; Susarla et al., 2015). Moreover, general psychosocial well-being (related primarily to body image concerns) appears to return to pre-breast surgery levels by one year following NSM+IBR (Peled et al., 2014), comparable to other methods of breast reconstruction, such as delayed or immediate, using implants or autologous tissue (Al-Ghazal et al., 2000; Al-Ghazal et al., 2000; Elder et al., 2005).

Importantly, the discrepancy (or lack of) between a woman's expectations of breast reconstruction and the actual outcome may also contribute to her experience of post-decision regret (Abu-Nab & Grunfeld, 2007; Sheehan et al., 2007). In a longitudinal, eight-year study of 78 women who had undergone nipple-sparing mastectomy with immediate breast reconstruction (Djohan et al., 2010), it was found that high patient satisfaction with reconstructed breasts and nipple-areola complex was associated with low regret (operationalised as a willingness to undergo the procedure again, if they were to make their decision again). Accordingly, factors such as a woman's satisfaction with her reconstructed breasts (e.g. how her reconstructed breasts look clothed or unclothed) may influence her level of post-decision regret, with greater satisfaction likely associated with less regret.

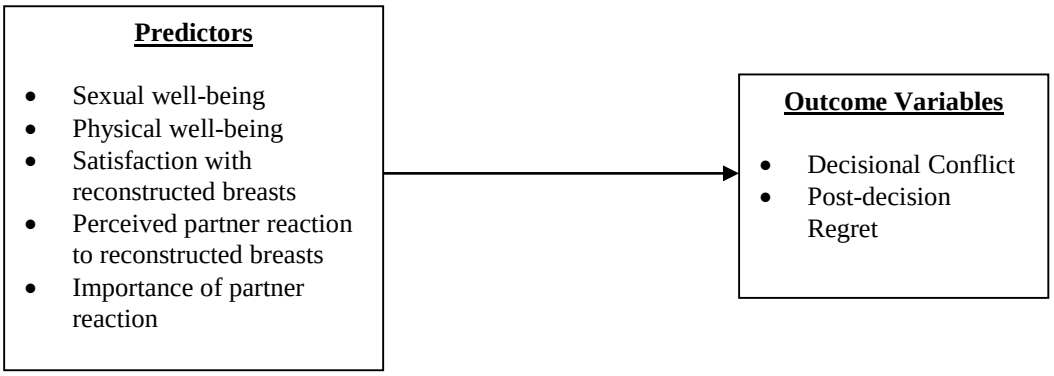
In addition, for many women, breast cancer surgery and treatment will negatively impact on their sexual well-being and sense of intimate self (Murray et al., 2014; Neto

et al., 2013), and so affect the appraisal of decisions made. One study that assessed the long-term trajectories of psychosocial adjustment following breast cancer treatment (Lam et al., 2012), found that women whose level of sexual well-being (measured as appraisal of intimate appearance and partner intimacy), changed over time (either from high to low, or initially low but improved over time) experienced the greatest decisional conflict during the decision-making process, and reported higher levels of disappointment and psychological distress six years after breast surgery (Lam et al., 2012).

The effect of perceived partner reactions on a woman's experience of decisional conflict or regret following breast cancer surgery has been neglected in research; yet, marital status has been associated with surgical decision making. One study of women with breast cancer found that those who were married were 23% more likely to receive breast conserving treatment than single women (Voti et al., 2006). Additionally, perceived partner social support and reactions to physical sequelae of surgery have been shown to influence a woman's emotional well-being (e.g., Talley et al., 2010; Wimberly et al., 2005) and sexual health after breast cancer (Emilee et al., 2010). Similarly a partner's evaluation of her physical appearance following breast cancer treatment has been found to be a stronger predictor of a woman's overall marital satisfaction than her own perceived body image (Ming, 2002). Many women believed that they would be more attractive to their partners if they underwent breast reconstruction (Duggal et al., 2013), and valued this more than women who did not elect for reconstruction (Adachi, Ueno, Fujioka, Fujitomi, & Ueo, 2007), making partner reactions to breast reconstruction an important issue to consider. These findings suggest that partner reactions may have an important influence on a woman's appraisal of her breast cancer-related decision-making.

The aim of the current study was to investigate levels of decisional conflict and regret in women undergoing NSM+IBR. It was predicted that levels of decisional conflict and regret would be at least comparable with (or lower than) that documented for women undergoing other forms of breast reconstruction (i.e., delayed breast reconstruction or reconstruction using flap procedures). We were particularly interested in whether a woman's level of satisfaction with the outcome of this breast reconstructive surgery, her physical wellbeing and perceived sexual well-being post-surgery were associated with these decisional outcomes. In addition, we explored the association between perceived partner reactions to the breast surgery, and the importance the woman placed on this reaction, on decisional conflict and regret in NSM+IBR. Figure 2 below displays the variables under investigation in the current study.

Figure 2. Relationships Between Variables for Study 2



4.3 Method

Sample and procedures

The current sample consists of the same sample as in Study 1. As such, details concerning sample and procedures, as well as other aspects of this study, have previously been reported in Chapter 3. Participants identified from breast clinic records of two oncoplastic surgeons involved with the study (EE, JF) were invited to participate through a mailed study invitation that included a website address to access the online questionnaire. Recruitment from the Westmead Breast Cancer Institute and Norwest Private Hospital in Sydney, Australia occurred from February 2012 to October 2013. All women who underwent NSM+IBR at these locations from the time the surgery was first offered in 2009, until study recruitment ceased in October 2013, were invited to participate. Women with known psychiatric difficulties were excluded by breast clinic staff prior to researchers inviting women into the study. It is not known how many women were excluded prior to invitation into the study using this process. In addition, participants were invited into the study through an emailed invitation to members of the Breast Cancer Network of Australia research pool. Inclusion criteria were: having undergone NSM+IBR, being over 18 years of age, and able to complete a questionnaire in English. There were no other exclusion criteria. A total of 113 women from the breast clinics were invited. Of these, 11 women were unable to be contacted, 13 declined to participate, 39 were contacted and indicated a willingness to participate but did not, leaving 50 participants recruited from the breast clinics. Thirty-one women from the Breast Cancer Network Australia responded to the emailed invitation. Thus, a total of 81 women consented to participate in the study. At their request, paper questionnaires were mailed to five women, who completed and returned them by mail. The remainder of participants completed the questionnaire online. All investigations were approved by the relevant Human Research Ethics Committees.

Measures

Decisional conflict. The 16-item Decisional Conflict Scale (O'Connor, 2010) measured decisional conflict or uncertainty in relation to participants' decision to undergo NSM+IBR. The scale consists of five subscales: Uncertainty, Informed, Values clarity, Support and Effective decision. Items are rated on a 5-point Likert-type scale, from 1 ('Strongly agree') to 5 ('Strongly disagree'). Total scores range from zero to 100, with higher scores indicating higher decision-related distress. Scores lower than 25 are associated with no decision-making difficulty while scores higher than 37.5 are associated with high decisional conflict and problems with uncertainty, being informed, values clarity, effective decision-making and support (O'Connor, 2010). The scale has established reliability and validity. Cronbach's alpha of the current sample was high at .97.

Post-decision regret. A reliable and valid measure, the 5-item Decision Regret Scale (Brehaut et al., 2003) assessed participants' experience of regret over the decision to undergo NSM+IBR. Items are rated on a 5-point Likert-type scale, from 1 ('Strongly agree') to 5 ('Strongly disagree'). Mean scores were obtained and then transformed by subtracting one and then multiplying by 25. Scores range from zero to 100, with higher scores indicating higher levels of regret (Brehaut et al., 2003). Cronbach's alpha of the current sample was .86.

Satisfaction with breasts. This 16-item scale from the Breast-Q Reconstruction module (Pusic et al., 2009) measures body image in terms of a woman's satisfaction with her reconstructed breasts clothed and unclothed. Items are rated on a 4-point Likert scale from 1 ('Very dissatisfied') to 4 ('Very satisfied'). Scores range from zero to 100, with higher scores indicating higher levels of satisfaction with breasts. The scale is scored

using the Breast-Q 'Q-score' software. The BREAST-Q has established psychometric properties and Cronbach's alpha for this scale in the current study was .94.

Physical well-being of chest and upper body. This 16-item scale from the Breast-Q Reconstruction module (Pusic et al., 2009) measured physical well-being of the chest and upper body and asked about physical problems such as pain in these areas. The items also asked about problems with sleep or mobility due to physical problems in this area. Items are rated on a 5-point Likert scale from 1 ('None of the time') to 5 ('All of the time'). Scores range from zero to 100, with higher scores indicating greater physical well-being. Women without partners have the option to select the response 'Not applicable' to these items. The scale is scored using the Breast-Q 'Q-score' software. The BREAST-Q has established psychometric properties and Cronbach's alpha for this scale in the current study was .87.

Sexual well-being. This 6-item scale from the Breast-Q Reconstruction module (Pusic et al., 2009) assessed sexual well-being in terms of a woman's feeling of sexual attractiveness and confidence, clothed and unclothed. Items are rated on a 5-point Likert scale from 1 ('None of the time') to 5 ('All of the time'). Scores range from zero to 100, with higher scores indicating greater sexual well-being. Women without partners have the option to select the response 'Not applicable' to these items. The scale is scored using the Breast-Q 'Q-score' software. The BREAST-Q has established psychometric properties and Cronbach's alpha for this scale in the current study was .87.

Women's perceptions of partner reactions. Based on theoretical and exploratory interest, five questions were generated to assess women's perceptions of their partners' reactions to their reconstructed breasts, and if their partner's reactions influenced their own reaction to their reconstructed breasts. Principal components factor analysis using maximum likelihood was conducted, indicating that the questions loaded

on two factors: Partner reaction, and how much a woman cared about her partner's reaction. Items are rated on a five-point Likert scale, from 1 ('Strongly agree') to 5 ('Strongly disagree'), with higher scores indicating greater perceived partner acceptance and comfort with reconstructed breasts, and greater importance placed on partner reaction. The Cronbach's alpha for both subscales was acceptable, (Partner Reaction $\alpha = .86$; Care about Partner Reaction $\alpha = .73$).

Demographic and medical characteristics. Demographic information collected included: age, country of birth, education level, employment status, marital status, household income, insurance coverage. Medical information regarding characteristics of the breast cancer diagnosis, surgery type, and family history of breast cancer were also collected.

Data Analyses

The variables of interest in the current study were decisional conflict and regret, satisfaction with reconstructed breasts, sexual and physical well-being, partner reactions to reconstructed breasts and the importance placed on this reaction. Data were analysed using the Statistical Package for the Social Sciences (SPSS, version 21). Of the 81 consenting participants, one participant with extensive missing data was removed. Of the remaining 80 participants, 75 were diagnosed with breast cancer, the remaining five women did not have a cancer diagnosis and had undergone NSM+IBR for preventive reasons. No significant differences were found between these two groups on any of the outcome variables ($F = .64$, $p = .667$). Complete data on all variables of interest for the present paper were available for 68 women, as women without partners did not complete the partner reaction questionnaires.

T-tests and chi-square analyses were undertaken to compare means of the demographic and medical characteristic variables between participants recruited from the breast clinic and Breast Cancer Network Australia. The samples differed on education level and type of reconstruction (i.e., implant, TRAM or DIEP flap-based procedures), consequently these variables were dummy coded and included as covariates. Pearson's correlations were used to identify the association between numeric variables and Spearman's correlations were used for ordinal or dichotomous variables. Due to restricted sample size, only those demographic and medical status variables significantly related to the outcome variable (at a conservative $p \leq .10$) were fitted into the regression model. Separate simple linear regression analyses were conducted for each outcome variable (i.e., decisional conflict and regret). Whether or not a woman underwent contralateral or bilateral mastectomy for risk reducing purposes was significantly related to both decision regret and conflict and was also entered as a covariate. No other demographic or medical variables were significantly related to outcome variables.

4.4 Results

Sample characteristics are the same as those reported in Chapter 3 Table 1, shown below.

Table 1. *Sample Demographic Characteristics*

Variable	Percentage	Number (n)	Mean	SD
Age	-	-	47.73	8.64
Marital Status			-	-
No partner	20.00	16		
Married or partnership	80.00	64		
Country of Birth			-	-
Australia	65.00	52		
New Zealand	3.75	3		
UK/Ireland	16.25	13		
Asia	6.25	5		
Europe	5.00	4		
Africa	3.75	3		
Education			-	-
Less than 12 years	23.80	19		
12 years	7.50	6		
Vocational Training	30.00	24		
Some university	2.50	2		
Bachelor's degree or above	36.30	29		
Family history of breast cancer	36.30	29	-	-
Underwent prior breast surgery	28.70	23	-	-
Diagnosed with breast cancer	93.80	75	-	-
Time since diagnosis			-	-
Less than 1 year	31.25	25		
1-2 years	40.00	32		
2-3 years	13.75	11		
3-4 years	3.75	3		
5 or more years	11.25	9		
Type of treatment received*			-	-
Chemotherapy	60.00	48		
Radiation	21.30	17		
Hormonal treatment	50.00	40		
Type of mastectomy			-	-
Single (one breast)	52.50	42		
Double (both breasts)	47.50	38		
Type of reconstruction			-	-
NSM + implants	90.00	72		
NSM + flap	8.80	7		

*Participant may have received more than one type of treatment.

Correlations between the variables of interest and means and standard deviations are presented in Table 2 below. Relationships between key variables were in the expected direction. While the decisional conflict mean scores (*M* = 17.85, SD = 18.76; range: 0.00 – 89.06) fell within the normal range, the magnitude of the standard deviation and range indicated high levels of decisional conflict in approximately 15% of the current sample (i.e., scores above 37.50, scale range 0.00 – 100). Decision regret mean scores indicated low levels of decision regret in the majority of the sample (*M* = 13.75, SD = 17.98; range: 0.00 – 75.00). Approximately 47.5% of the current sample experienced no regret, 32.5% experienced mild regret (scores between 1 and 25), and the remaining 20% experienced moderate to strong regret (score of 26 or higher (Sheehan et al., 2007)).

Table 2. *Correlations between variables of interest*

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. Age												
2. Education^	–0.36**											
3. Reconstruction Type^	0.07	0.06										
4. Risk-Reducing Mastectomy^	– 0.21	0.16	– 0.14									
5. Time since diagnosis (months)												
6. Decisional Conflict	0.06	0.17	0.30*	0.05								
7. Decision Regret												
8. Partner Reaction	0.01	0.02	0.12	– 0.42**	0.01							
9. Care About Partner Reaction	0.12	– 0.04	0.04	– 0.30**	0.12	0.69**						
10. Satisfaction with Breasts	– 0.10	0.09	0.10	0.12	– 0.03	– 0.33**	– 0.34**					
11. Physical Well-being	– 0.16	– 0.06	0.05	– 0.06	– 0.05	0.20	0.02	– 0.05				
12. Sexual Well-being	– 0.16	0.02	– 0.08	0.41**	– 0.10	– 0.51**	– 0.62**	0.38**	– 0.12			
	0.07	– 0.03	0.27*	0.11	0.20	– 0.24*	– 0.30**	0.12	– 0.09	0.33**		
	0.09	– 0.09	0.08	0.24*	– 0.05	– 0.45**	– 0.46**	0.31*	– 0.25	0.55**	0.37**	
Mean	47.72	-	-	-	24.00	17.85	13.75	4.05	3.18	61.96	73.44	51.20
SD	8.64	-	-	-	21.60	18.76	17.98	1.02	1.04	16.30	13.78	19.23

N = 80 for full sample, for Partner questionnaires *n*=68. ^Spearman's correlations used for ordinal variables.
** Correlation is significant at the 0.01 level (two-tailed).
* Correlation is significant at the 0.05 level (two-tailed).

Linear regression analysis for decisional conflict indicated that the overall model was significant, $R^2 = 0.39$, $F(8, 58) = 4.60$, $p = 0.0005$, with only the extent to which a woman cared about her partner's reaction to her reconstructed breasts being significantly associated with decisional conflict (see Table 3 below). The more a woman cared about her partner's reaction to her reconstructed breasts, the more decisional conflict she experienced.

Linear regression analysis for decisional regret yielded a significant overall model, $R^2 = 0.49$, $F(8, 58) = 6.96$, $p = 0.0005$ (see Table 4). Total satisfaction with breasts was significantly associated with decisional regret, and the association of physical well-being with decisional regret approached significance. The more satisfaction a woman experienced with her reconstructed breasts and the better her physical well-being, the less regret she experienced.

Table 3. *Simple linear regression summary table for Decisional Conflict*

Variable	**B**	**SE**	***B***	***T***	**df**	***p***
Risk-Reducing mastectomy	– 8.96	4.47	– 0.23	– 2.01	8	0.050*
Education	1.76	1.21	0.16	1.45	8	0.152
Reconstruction Type	1.96	3.73	0.06	0.53	8	0.601
Satisfaction with breasts	– 0.18	0.17	– 0.14	– 1.05	8	0.297
Physical Well-being	– 0.18	0.17	– 0.13	– 1.06	8	0.293
Sexual Well-being	– 0.14	0.14	– 0.13	– 0.97	8	0.338
Partner Reaction	– 2.81	2.33	– 0.15	– 1.21	8	0.233
Care about Partner Reaction	4.64	2.05	0.24	2.26	8	0.028*

Table 4. *Simple linear regression summary table for Decision Regret*

Variable	**B**	**SE**	***B***	***T***	**df**	***p***
Risk-Reducing mastectomy	– 0.58	3.91	– 0.02	– 0.15	8	0.883
Education	– 0.29	1.06	– 0.03	– 0.27	8	0.788
Reconstruction Type	3.59	3.26	0.11	1.10	8	0.276
Satisfaction with breasts	– 0.62	0.15	– 0.50	– 4.07	8	0.0005**
Physical Well-Being	– 0.29	0.15	– 0.22	– 1.95	8	0.056
Sexual Well-Being	– 0.15	0.12	– 0.15	– 1.21	8	0.230
Partner Reaction	– 0.15	2.04	– 0.01	– 0.08	8	0.940
Care about Partner Reaction	– 2073	1.80	– 1.52	– 1.52	8	0.134

N = 80 for full sample, for Partner questionnaires *n*=68.
** Significant at the 0.01 level.
* Significant at the 0.05 level.

4.5 Discussion

This study investigated levels of decisional conflict and regret in women undergoing NSM+IBR, and whether factors such as satisfaction with reconstructed breasts, sexual and physical well-being, partner reactions to reconstructed breasts and the importance placed on this reaction, are associated with these decisional process outcomes. NSM+IBR surgery offers the potential for better cosmetic outcomes following breast reconstruction compared with traditional non-nipple sparing approaches (Al-Ghazal et al., 2000), which may result in greater concordance with patient preferences, higher satisfaction with NSM+IBR, and consequently, lower levels of decisional conflict and post-decision regret. The innovative procedure of a single-step surgical process, and being able to retain one's own skin and nipple areola complex may also contribute to greater post-surgery physical and sexual well-being in women, again reducing the experience of decisional conflict and post-decision regret.

The mean score of decisional conflict in the current study fell within the normal range (M = 17.85, SD = 18.76). Notably, the current mean score was comparable with previous reports from samples in which low levels of decisional conflict would typically be expected, such as women who did not have breast cancer but accepted a breast screening invitation (M = 16.50, SD = 3.60; O'Connor, 2012), women who were diagnosed with ductal carcinoma in situ (DCIS) but not invasive breast cancer (M = 20.5, SD = 15.60; De Morgan, Redman, D'Este, & Rogers, 2011), and women with breast cancer who were given a decision aid to assist with decision-making for breast cancer surgery, before the decision was made (M = 15.80, SD = 15.50; Lam et al., 2013). It has been shown that women who use decision aids to assist with their medical decision-making typically experience lower decisional conflict, compared with women who did not use decision aids (Lam et al., 2013; Obeidat et al., 2011; Sheehan & Sherman, 2012).

Interestingly, approximately 15% of the current sample experienced high levels of decisional conflict, compared with 47% of women reported in the DCIS study (De Morgan et al., 2011). This difference could be attributed to the lack of knowledge in the DCIS sample, where confusion or lack of knowledge about DCIS was significantly associated with dissatisfaction with information and worries about dying, respectively. This further highlights the importance of information and education in reducing decisional conflict, and also presents NSM+IBR as a surgical option in which the majority of women experienced low levels of decisional conflict.

The mean score of decision regret in the current sample (M = 13.75, SD = 17.98) was also comparable to that reported in previous studies (e.g., Brehaut et al., 2003; Sheehan et al., 2007, 2008). Specifically, the women in the current study experienced levels of regret similar to a study of 100 women with breast reconstruction in which the majority of women underwent delayed procedures using autologous tissue methods (M = 9.30, SD = 17.20; Zhong et al., 2013), a study in which 101 women had been given decision aids to assist with the decision for breast surgery (M = 21.40, SD = 17.20; Lam et al., 2013), and a study of 123 women with breast cancer who underwent mastectomy with immediate (58% of sample) or delayed (42% of sample) breast reconstruction (Sheehan et al., 2008). Approximately half the current sample (52.5%) experienced some level of regret (classified as mild, moderate or strong (Brehaut et al., 2003), with 20% experiencing moderate to strong regret, comparable to (Sheehan et al., 2008). Thus, although the mean level of regret is comparable to previous research, a proportion of women in the current sample experienced high levels of regret.

The women in the current sample were generally satisfied with the outcome of their surgery (M = 61.96, SD = 16.30) and reported relatively high levels of physical well-being (M = 73.44, SD = 13.78). Although seemingly low levels of sexual well-being

were reported (*M* = 51.20, SD = 19.23), this is comparable to recent studies investigating single-stage implant reconstruction and two-stage expander reconstruction (e.g., Susarla et al., 2015). This perhaps demonstrates the need to improve sexual well-being outcomes after breast surgery in general. While no normative data are available for the partner reaction scales, the mean scores indicated that most women felt their partners were accepting of and comfortable with their bodies post-reconstruction (*M* = 4.05, SD = 1.02), and placed a moderately high level of importance on their partners' reaction to their reconstructed breasts (*M* = 3.18, SD = 1.04).

All correlations among main variables of interest were in the expected direction. Decisional conflict and decisional regret were significantly and positively correlated with each other, suggesting that the experiences of decisional conflict and post-decision regret are very much related. Both decisional conflict and regret were significantly and negatively associated with satisfaction with reconstructed breasts, physical and sexual well-being, and perceived partner reaction to reconstructed breasts. This suggests that women who felt more satisfied after their surgery (in terms of aesthetic outcome, physical and sexual well-being) and perceived a more favourable partner reaction, felt less conflicted and regretful about their decision.

Regression analyses indicated that only the extent to which a woman cared about her partner's reaction to her reconstructed breasts was a significant predictor of decisional conflict. This is consistent with previous research that found women's medical decisions and subsequent psychological well-being are influenced by marital status and perceived partner support and reactions (Talley et al., 2010; Voti et al., 2006; Wimberly et al., 2005). These findings also suggest that how much a woman cares about her partner's reaction to her reconstructed breasts may help explain feeling conflicted about the decision made, over and above her own satisfaction and physical and sexual well-

being. It is possible that for women who place a high level of importance on their partners' reactions to their reconstructed breasts, partner reactions may mean more to a woman post-surgery than her own satisfaction with her reconstructed breasts. A favourable perceived partner reaction to her reconstructed breasts may help to reduce her experience of decisional conflict after the decision has been made (Emilee et al., 2010; Ming, 2002; Wimberly et al., 2005). These findings further underscore the importance of including a woman's partner in the decision-making process to help clarify values, reactions and potentially reduce decisional conflict. The present findings extend this further by not only assessing perceived partner reactions, but the importance placed on these reactions.

The regression analyses for decision regret indicated that only the extent to which a woman was satisfied with her reconstructed breasts remained significant in the final model, along with a non-significant trend for physical wellbeing. These findings are consistent with previous cancer research that demonstrates post-decision regret is associated with unfavourable aesthetic and physical outcomes and negative appraisal of treatment decisions (e.g., Ashraf et al., 2013; Bride et al., 2013; O'Connor, 2012; Payne et al., 2000; Sheehan et al., 2007; Zhong et al., 2013). Unexpectedly, sexual well-being, perception of partner reactions and the importance placed on this reaction did not uniquely contribute to a woman's experience of regret. This perhaps suggests that regret, compared with decisional conflict, is of a more personal nature. Unexpected findings such as these with regard to regret in NSM+IBR may point to the need for further consideration to be given to the time point at which decision appraisal, and therefore regret, is assessed, as previous research has shown that decision regret may be affected by reflecting and reframing treatment decisions over time (Fernandes-Taylor & Bloom, 2011; Hitz et al., 2013). Time since diagnosis was not significantly associated with

decisional conflict or regret in the current cross-sectional study. However, the current study assessed women at a range of time points since diagnosis and surgery, from less than 12 months to more than five years since diagnosis. Thus it may have been difficult to capture the more subtle changes that may occur in decisional conflict and post-decision regret over the period from diagnosis to treatment and beyond.

Implications for Clinical Practice

The current study supports NSM+IBR as an acceptable surgical option for women with breast cancer, given that the majority of women in the current sample experienced levels of decisional conflict and post-decision regret that were within the normal ranges, after having undergone NSM+IBR. Mean physical well-being scores were relatively high, which further supports NSM+IBR as overcoming the physical and practical challenges of non-nipple sparing mastectomy and reconstruction.

The current levels of satisfaction with reconstructed breasts demonstrate scope for further improvement, with other studies reporting mean satisfaction scores ranging from high seventies to low eighties (e.g., Liu et al., 2014; Sugrue, MacGregor, Sugrue, Curran, & Murphy, 2013). When outlining NSM+IBR as a potential surgical option, surgeons could further educate women on the expected outcomes of breast surgery, including aspects such as anticipated aesthetic outcome and potential impact of adjuvant therapy on reconstructed breasts (Peled et al., 2014). Further education such as this could improve the concordance between women's expectations and actual outcome, thereby improving satisfaction with reconstructed breasts and reducing post-decision regret. Routinely involving partners in the consultation and decision-making process may also help reduce decisional conflict. This may help women feel more supported by their partners in the decision-making process and thereby reduce decisional conflict,

particularly for those women who place a greater emphasis on their partner's reaction to their reconstructed breasts.

Strengths and Limitations

This is one of the first studies to assess decisional conflict and post-decision regret in women who have undergone NSM+IBR, contributing to the sparse literature on decisional conflict and post-decision regret in cancer generally, and specifically in NSM+IBR in women with breast cancer. The current study also investigated the impact of factors such as perception and importance of partner reactions on decisional conflict and regret, extending the sparse research on partner involvement/support in breast cancer.

The current study is limited by the relatively small sample size, but one that represents more than 60% of the available pool of individuals (limited to two oncoplastic surgeons at two cancer institutions who underwent the procedure in a five-year period) undergoing this emerging surgical technique. Given the current cross-sectional approach, it is also difficult to infer causal relationships between the variables. The exclusion of women with known psychological difficulties at the recruitment stage of the study may have biased the sample, consequently, conclusions regarding the potential benefits of NSM+IBR on psychological adjustment post-surgery should be made and interpreted with caution.

Additionally, a wide temporal period post-surgery was assessed, making it difficult to capture subtle changes in decisional conflict and regret over time. That most women in the current sample were approximately one to two years post-breast cancer diagnosis may also be a confounding factor when considering the level of decisional conflict and regret post-surgery in the current sample.

Another limitation of the current study is the lack of control or comparison group with other types of surgery (i.e. breast cancer surgery patients who did not undergo NSM+IBR). This lack of comparison group further limits the conclusions that may be drawn about the effects of NSM+IBR on decisional conflict and regret.

Future Research

It may be beneficial for future research to assess post-decision regret at specific time points after surgery to more accurately assess regret and factors contributing to this. This may be particularly useful given that post-decision regret has been shown to manifest even five years post-surgery, and may involve reflecting and reframing over this time (Fernandes-Taylor & Bloom, 2011; Hitz et al., 2013). It may also be of interest to assess regret of inaction (not having had NSM+IBR or any other type of breast reconstruction), compared with regret of action, as it has been suggested that there is a tendency for people to regret actions in the short-term but to regret inactions over the longer-term (Fernandes-Taylor & Bloom, 2011). This may be a particularly important factor to consider for women who are considered to be longer-term breast cancer survivors (e.g., five years after diagnosis and treatment).

Moreover, given the increased recognition of the discrepancy between a woman's perceived and actual level of involvement in shared decision-making, it would be important to further investigate this issue. For example, women's perceived involvement in the decision-making process may be compared with their actual involvement and level of desired involvement. The impact of the discrepancy between perceived versus desired level of involvement on a woman's overall satisfaction with surgery, and thereby decisional conflict and regret, also warrants further investigation.

Conclusion

The current study extends the limited research on decisional conflict and regret in breast cancer and reconstruction, particularly in a new procedure, NSM+IBR, and factors that may contribute to these outcomes. Understanding the factors associated with decisional conflict and post-treatment regret will contribute to the process of medical decision-making and women's appraisals of treatment decisions made.

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Conflict of Interest

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Chapter 5. General Discussion and Conclusions

5.1 Summary of Thesis Aims and Current Findings

The current thesis aimed to contribute to the oncology literature by investigating the following aims in two empirical studies. First, to investigate levels of body image disturbance, psychological distress, decisional conflict and post-decision decision regret in women who have undergone nipple sparing mastectomy with immediate breast reconstruction (NSM+IBR). Second, to determine if self-compassion exhibits a unique indirect (mediating) effect on the relationship between body image disturbance and psychological distress, and whether appearance investment exerts a moderating role on this relationship. A third aim was to identify a range of factors that may account for variations in decisional conflict and regret, such as the woman's level of satisfaction with her reconstructed breasts, her post-surgical physical and sexual well-being, and factors relating to her partner including her perceptions of her partner's reactions to her body after breast reconstruction and the importance the woman places on this reaction.

As NSM+IBR allows restoration of the breast shape and preservation of a woman's own skin and nipple areola complex (Boneti et al., 2011; Moyer et al., 2012), it was hypothesised that levels of body image disturbance, psychological distress, decisional conflict and post-decision regret would be within the normal ranges for women who have undergone NSM+IBR, reflecting fewer negative outcomes compared with other surgery, such as mastectomy, alone. Based on previous studies in the breast cancer context, it was further hypothesised that self-compassion would exhibit a significant mediating effect on the body image-distress relationship (Przezdziecki et al., 2013), and that appearance investment would have a significant moderating effect on this relationship (Moreira et al., 2010). A final hypothesis was that factors such as,

satisfaction with reconstructed breasts, post-surgery physical and sexual well-being, perceived partner reactions to a woman's body after reconstruction and the importance placed on this reaction, would contribute uniquely to a woman's experience of decisional conflict or post-decision regret, as previous research has indicated that these factors influence a woman's appraisal of treatment decisions made (e.g., Duggal et al., 2013; Lam et al., 2013;. Lam et al., 2012; Neto et al., 2013; Zhong et al., 2013).

Levels of body image disturbance and psychological distress reported by women in the current NSM+IBR sample were lower than those reported in previous studies of women undergoing non-nipple sparing mastectomy, using similar measures of body image disturbance and psychological distress (e.g., Begovic-Juhant et al., 2012; Boquiren et al., 2013; Falk Dahl et al., 2010; Przezdziecki et al., 2013; Sheehan et al., 2007). Levels of decisional conflict and post-decision regret in the current sample were comparable to those previously reported in a study of non-nipple sparing mastectomy with no breast reconstruction or delayed breast reconstruction (Lam et al., 2013). These findings support the first hypothesis.

The second hypothesis was confirmed by results that indicated the significant mediating and moderating effects of self-compassion and appearance investment, respectively, through a moderated mediation model. Specifically, self-compassion was found to exhibit unique indirect (mediating) effects on the relationship between body image and depression, anxiety and stress, at high levels of appearance investment. This significant moderated mediation effect was found only for the self-evaluative salience component of appearance investment and not the motivational salience component.

The final hypothesis was partially supported. A woman's satisfaction with her reconstructed breasts, post-surgery physical and sexual well-being, perceived partner reactions to her body after reconstruction and the importance placed on this reaction, all

accounted for 39% and 49% of variance in decisional conflict and post-decision regret, respectively. How much a woman cared about her partner's reaction to her reconstructed breasts contributed uniquely to her experience of decisional conflict, while satisfaction with reconstructed breasts contributed uniquely to her experience of post-decision regret. No other factors were significantly associated with decisional conflict and post-decision regret.

5.2 The Current Findings Presented within the Existing Literature

As mentioned previously, issues of long-term survivorship in breast cancer have become increasingly important in recent times as long-term (10 years) survival rates improve with advances in diagnosis and treatment (Alfano et al., 2012; Australian Institute of Health and Welfare, 2012; Coleman et al., 2011; Fallbjörk et al., 2013; Gao & Dizon, 2013; Moreira & Canavarro, 2010). Such issues include body image disturbance and associated psychological distress arising from the effects of breast surgery and adjuvant treatment, as well as treatment decision-making difficulties during the decision-making process (i.e., decisional conflict), and post-decision regret after the treatment decision has been made, particularly if an unfavourable outcome was experienced (Ashraf et al., 2013; Bride et al., 2013; O'Connor, 2012; Payne et al., 2000; Sheehan et al., 2007, 2008; Zhong et al., 2013). For the majority of women with breast cancer, these psychosocial difficulties may be most apparent in the 12 months following breast cancer diagnosis and treatment, but for approximately one-third of women, these difficulties may persist for up to six or seven years post-treatment (Fang et al., 2014; Helms et al., 2008; Lam et al., 2012; Przezdziecki et al., 2013; Sackey et al., 2010). It is, therefore, important for oncology clinicians and researchers to be able to identify women who would be most vulnerable to poorer psychological adjustment in the initial 12-

month period of diagnosis and treatment, as well as being able to identify women who continue to experience these difficulties beyond 12 months.

The overall low levels of body image disturbance and associated psychological distress demonstrated in the current NSM+IBR sample may be a reflection of the nipple-sparing surgical approach, whereby a woman's skin and nipple areola complex are preserved in the breast reconstruction process (Moyer et al., 2012; Serletti et al., 2011). The current findings support previous reports that retaining one's own skin and nipple areola complex may result in less body image disturbance, and therefore, less psychological distress following the NSM+IBR procedure (Al-Ghazal et al., 2000; Didier et al., 2009; Yueh et al., 2009). Levels of decisional conflict and post-decision regret in the current sample also fell within the normal ranges. These results could be due to NSM+IBR being more aligned with patient preferences of retaining one's own skin and nipple areola complex, resulting in higher satisfaction with reconstructed breasts and overall surgery outcome, (Djohan et al., 2010), and thereby decreasing decisional conflict and regret. This adds to emerging reports that women undergoing NSM+IBR generally experience high levels of satisfaction with the surgery (Didier et al., 2009; Djohan et al., 2010; Peled et al., 2014; Sackey et al., 2010; Susarla et al., 2015; Yueh et al., 2009; Yueh et al., 2010). Additionally, given that most women in the current study were between one to two years post-diagnosis, the generally low levels of body image disturbance, psychological distress, decisional conflict and post-decision regret are not surprising, as previous reports indicate that by 12 months post-diagnosis, distress generally diminishes to pre-diagnosis levels (e.g., Al-Ghazal et al., 2000; Al-Ghazal et al., 2000; Elder et al., 2005; Fobair et al., 2006; Montazeri et al., 2008; Peled et al., 2014). Contrary to previous research, length of time since diagnosis in the current research was not associated with body image disturbance or psychological distress. However, a similar

finding has been noted in a recent study, whereby the relationship between time since surgery and similar outcome variables was not significant (Fang et al., 2014). In spite of this, that women in the current study were assessed approximately one to years following surgery, when psychological distress is expected to have returned to pre-diagnosis levels (Peled et al., 2014), may also affect the interpretation of current results about the effects of NSM+IBR.

Despite generally low levels of body image disturbance and psychological distress, a significant negative relationship was found between age and body image disturbance. This supports previous research that younger women, comprising approximately 60% of the current sample, may experience greater body image disturbance (Fobair et al., 2006; Rosenberg et al., 2013).

Consistent with prior studies of women with breast cancer (Leary et al., 2007; Moreira & Canavarro, 2010, 2012; Moreira et al., 2010; Neff et al., 2007), body image disturbance was found to be significantly related to self-compassion and appearance investment, such that greater self-compassion and lower self-evaluative salience were associated with less body image disturbance. The demonstrated mediating effect of self-compassion on the relationship between body image disturbance and psychological distress in the current research contributes to the literature on self-compassion as a construct positively related to psychological well-being and negatively related to psychological distress (Leary et al., 2007; Neff et al., 2007; Przezdziecki et al., 2013; Raes et al., 2011). These findings support previous research that suggests if women are able to respond with self-kindness and acceptance of bodily changes and body image disturbances as part of their cancer experience, this may ease their experience of psychological distress (Przezdziecki et al., 2013). The current research further demonstrated that the mediating effect of self-compassion on the body image-distress

relationship was evident only at high levels of appearance investment, suggesting that women whose personal appearance weighs heavily on how they view themselves are likely to respond in a less self-compassionate and more critical way to their experience of body image disturbance. These findings extend prior research in the breast cancer context on the mediating role of self-compassion and the moderating role of appearance investment (Cash et al., 2004; Moreira & Canavarro, 2010, 2012; Moreira et al., 2010; White, 2000). While it is possible that NSM+IBR was an attractive surgical option for women high in appearance investment, thereby self-selecting into the study and biasing the current sample, this is not indicated by the mean levels of appearance investment in the current study, which were comparable to those of the normative sample.

Consistent with previous research on decisional conflict and post-decision regret in women with breast cancer, factors such as a woman's satisfaction with her reconstructed breasts, post-surgery physical and sexual well-being, perceived partner reactions to her body after reconstruction and the importance placed on this reaction, were all significantly associated with decisional conflict and post-decision regret. The unique contribution of the importance placed by a woman on her perceived partner's reaction to her reconstructed breasts to decisional conflict adds to research on the influence of partner reactions in a woman's decision-making process and her appraisal of the decision made (Falk Dahl et al., 2010; Talley et al., 2010; Voti et al., 2006; Wimberly et al., 2005). The unique contribution of satisfaction with reconstructed breasts to a woman's experience of post-decision regret was consistent with previous research that high patient satisfaction with reconstructed breasts is typically associated with low post-decision regret (Djohan et al., 2010), and that adverse outcomes are typically associated with higher regret (Payne et al., 2000). Unexpectedly, physical and sexual well-being, perception of partner reactions and the importance placed on this

reaction did not uniquely contribute to a woman's experience of decisional conflict and post-decision regret. Unexpected findings such as these with regard to regret in NSM+IBR may point to the need for further consideration to be given to the time point at which decision appraisal, and therefore, decisional conflict and post-decision regret, are assessed, as previous research has shown that these processes may be affected by reflecting and reframing treatment decisions over time (Fernandes-Taylor & Bloom, 2011; Hitz et al., 2013).

5.3 Implications for Clinical Practice

The current program of research supports NSM+IBR as an acceptable surgical option for women with breast cancer that may help overcome the physical and practical challenges of non-nipple sparing mastectomy and reconstruction, with potential for added psychological benefits for body image and distress. As the majority of women in the current sample experienced levels of decisional conflict and post-decision regret that were within the normal ranges after having undergone NSM+IBR, this further supports NSM+IBR as overcoming the physical and practical challenges of non-nipple sparing mastectomy and reconstruction. The current results suggest that NSM+IBR should be made available to women who are considering their options for breast surgery, with the potential benefits explained and balanced with an individual's breast cancer stage and adjuvant treatment required.

However, NSM+IBR is not an available option for all women undergoing mastectomy, and clinically, being able to identify women pre-surgery with higher levels of self-evaluative salience and lower levels of self-compassion may aid in identifying women who are more likely to experience higher levels of distress, or are at greater risk for poorer psychological adjustment in the 12-months post-surgery and beyond. The

findings of this study may, therefore, be of particular relevance for clinicians engaged in psychological interventions dedicated to women who have undergone breast surgery by: i) highlighting the need to provide more support to women identified as at risk for greater distress, and, ii) assisting clinicians in modifying existing breast surgery body image interventions (e.g., by providing psycho-education on the roles of self-compassion and appearance investment in adjustment to bodily changes post-surgery, as well as practical strategies to increase self-compassion and reduce appearance investment). Indeed, enhancing self-compassion may be a key factor in designing or modifying effective body image interventions for women with breast cancer post-treatment (e.g., Przezdziecki et al., 2013).

During the decision-making stage of treatment, when outlining NSM+IBR as a potential surgical option, surgeons could further educate women on the expected outcomes of breast surgery in order to improve satisfaction with reconstructed breasts and reduce post-decision regret, including aspects such as anticipated aesthetic outcome (Peled et al., 2014), as well as potential impact to physical and sexual well-being and relationship with partners. Routinely involving partners in these consultations may also mean that women are better able to consult with their partners about treatment options, thereby increasing perceived partner support and reducing decisional conflict (Emilee et al., 2010; Ming, 2002; Wimberly et al., 2005). This may also help improve satisfaction and confidence with treatment decision made, possibly reducing the experience of post-decision regret.

5.4 Strengths and Limitation of the Current Research

The current program of research both supports and extends previous literature by investigating body image disturbance, psychological distress, decisional conflict and post-decision regret in women with breast cancer, and particularly, the growing body of literature on NSM+IBR. This is the first study in Australia to investigate psychological outcomes in women who have undergone NSM+IBR. The current thesis also contributes to the literature on the mediating role of self-compassion and the moderating role of appearance investment in women with breast cancer, as well as further investigating specific factors that are associated with decisional conflict and post-decision regret.

However, the current research is limited by the relatively small sample size, but one that represents more than 60% of the available pool of individuals (limited to two oncoplastic surgeons at two cancer institutions in a five-year period) undergoing this emerging surgical technique. Given the current cross-sectional approach and lack of pre-surgery assessment of variables under study, it is also difficult to infer causal relationships between the variables, which may be clinically and practically useful in identifying women who are likely to experience significant distress post-surgery, as well as variables that may function as protective factors. The lack of inclusion of a more general measure of body image in the current study may also be viewed as a limitation, as it is possible that the effect of breast surgery may be apparent only when measured using cancer-specific, rather than general, measures of body image.

The exclusion of women with known psychological difficulties at the recruitment stage of the study may have biased the sample, consequently, conclusions regarding the potential benefits of NSM+IBR on psychological adjustment post-surgery should be made and interpreted with caution. That most women in the current sample were approximately one to two years post-breast cancer diagnosis may also be a confounding factor when considering the level of psychological adjustment post-

surgery in the current sample. The wide temporal period post-surgery assessed, may also make it difficult to capture the more subtle changes in decisional conflict and regret over time.Another limitation of the current study is the lack of control or comparison group with other types of surgery (i.e. breast cancer surgery patients who did not undergo NSM+IBR). This lack of comparison group further limits the conclusions that may be drawn about the benefits of NSM+IBR.

5.5 Suggestions for Future Research

Future studies with a continued focus on NSM+IBR, and the roles of self-compassion and appearance investment, with larger sample sizes are warranted. As the pool of women who undergo NSM+IBR increases, researchers could compare levels of psychological distress and body image disturbance between women who have undergone NSM+IBR and women who have undergone traditional non-nipple sparing mastectomy. It would also be of interest to compare the psychological outcomes (i.e., body image disturbance, psychological distress, decisional conflict and regret) of different types of immediate breast reconstruction with NSM+IBR. The use of both cancer-specific and more general measures of body image may also provide further elaboration on the effect of breast cancer surgery on body image, as well as the factors that influence this.

It would also be of interest to assess self-compassion, appearance investment body image and decisional conflict pre-surgery, post-surgery (immediately to one week following surgery) and at various time points following surgery. This may further clarify the relationships between these variables, and allow for more definitive conclusions to be drawn regarding the specific effect of NSM+IBR on these variables.

Additionally, it may be beneficial for future research to assess post-decision regret at specific time points after surgery to more accurately assess regret and factors

contributing to this. This may be particularly useful given that post-decision regret has been shown to manifest even five years post-surgery, and may involve reflecting and reframing over this time (Fernandes-Taylor & Bloom, 2011; Hitz et al., 2013). It may also be of interest to assess regret of inaction (i.e., not having had NSM+IBR or any other type of breast reconstruction) compared with regret of action, as it has been suggested that there is a tendency for people to regret actions in the short-term but to regret inactions over the longer-term (Fernandes-Taylor & Bloom, 2011). This may be a particularly important factor to consider for women who are considered to be longer-term breast cancer survivors (e.g., five years after diagnosis and treatment). Moreover, given the increased recognition of the discrepancy between a woman's perceived and actual level of involvement in shared decision-making, it would be important to further investigate this issue. For example, women's perceived involvement in the decision-making process may be compared with their actual involvement and level of desired involvement. The impact of the discrepancy between perceived versus desired level of involvement on a woman's overall satisfaction with surgery, and thereby decisional conflict and regret, also warrants further investigation.

5.6 Conclusions

The current study found that, for the majority of women undergoing NSM+IBR, body image disturbance, psychological distress, decisional conflict and post-decision regret are typically within normal limits. Self-compassion was found to have a significant mediating effect on the body-image distress relationship, at high levels of appearance investment. How much a woman cared about her partner's reaction to her reconstructed breasts uniquely contributed to her experience of decisional conflict, and her satisfaction with her reconstructed breasts uniquely contributed to her experience of post-decision

regret. Consequently, these are factors which require further research, and may have useful clinical implications when helping women adjust to bodily changes following breast cancer diagnosis and treatment.

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Appendix A. Ethics Approval from The Cancer Institute of New South Wales, Australia.

Dr Kerry Sherman,
Department of Psychology
Macquarie University
North Ryde
NSW 2109

7 October 2011

Dear Dr Kerry Sherman,

NSW Population & Health Services Research Ethics Committee

AU RED Reference: HREC/11/CIPHS/45

Cancer Institute NSW reference number: 2011/07/340

Project Title: Evaluating a New Breast Reconstruction Technique, Nipple Sparing Mastectomy: Physical and Psychological Outcomes

Thank you for your correspondence dated 31 August 2011, 29 September 2011 and 5 October 2011 responding to a request for further information/clarification of the above referenced study, submitted to the NSW Population & Health Services Research Ethics Committee for single ethical and scientific review. The Committee reviewed your response at its meeting held on 7 October 2011 and I am pleased to inform you that full ethical approval has been granted.

The following documents were reviewed during the Committee's deliberation of the study:

- National Ethics Application Form version 2, submission code AU/1/50A9011, dated 20 June 2011
- Research Protocol Sherman, dated 16 June 2011
- Information and Consent form, Phase 1, Version 1, dated 16 June 2011
- Information and Consent form, Phase 2 Study, Version 1, dated 16 June 2011
- Invitation letter from Westmead Breast Cancer Institute (for women who have undergone a nipple sparing mastectomy and immediate reconstruction), Version 1, dated 16 June 2011
- Invitation letter from The Poche Centre (for women who have undergone a nipple sparing mastectomy and immediate reconstruction), Version 1, dated 16 June 2011
- Invitation letter from Westmead Breast Cancer Institute (for women who are about to undergo mastectomy), Version 1, dated 16 June 2011
- Invitation letter from The Poche Centre (for women who are about to undergo mastectomy), Version 1, dated 16 June 2011
- Retrospective Study – Questionnaire, Women's Views of Nipple Sparing Mastectomy Questionnaire, Version 1, dated 16 June 2011
- Phase 2 – Baseline, Attitudes and Responses to Breast Surgery, Questionnaire 1, Version 1, dated 16 June 2011

- Attitudes and Responses to Breast Surgery, Questionnaire 2, 3, 4, Version 1, dated 16 June 2011
- Evaluating Nipple Sparing Mastectomy: Physical and Psychological Outcomes, Surgeon-Rated Outcomes, Version 1, dated 16 June 2011
- Email dated 31 August 2011 responding to the committees comments
- Cover Letter dated 29 September 2011
- Amended Protocol dated 5 October 2011

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.

The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* and relevant legislation and guidelines.

Please note that ethical approval is valid for **5 years**, conditional on the following:

- Principal investigators will immediately report anything which might warrant a review of ethical approval of the research, including unforeseen events that might affect continued ethical acceptability.
- Proposed amendments to the research proposal or conduct of the research which may affect the ethical acceptability of the research are to be provided to the NSW Population & Health Services Research Ethics Committee for review.
- The NSW Population & Health Services Research Ethics Committee will be notified giving reasons, if the research is discontinued before the expected date of completion.
- The Principal Investigator will provide an annual progress report to the NSW Population & Health Services Research Ethics Committee and at the completion of the study.

For further information about the NSW Population & Health Services Research Ethics Committee, please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal, please contact Kate Lowrie, Admin Support Officer – Ethics on 02 8374 5616 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Kimberly Strong, PhD
Ethics Coordinator
Cancer Institute NSW
NSW Population & Health Services Research Ethics Committee

Appendix B. Ethics Approval from Macquarie University Human Research Ethics Committee

MACQUARIE University

Samantha Woon <samantha.woon@mq.edu.au>

External Approval Noted- Sherman (5201100876 D)

Ethics Secretariat <ethics.secretariat@mq.edu.au> Tue, Nov 8, 2011 at 11:25 AM
To: Dr Kerry Sherman <kerry.sherman@mq.edu.au>
Cc: Miss Samantha Woon <samantha.woon@mq.edu.au>

Dear Dr Sherman

Re: "Evaluating a new breast reconstruction technique, nipple sparing mastectomy, physical and psychological outcomes"

The above application was considered by the Executive of the Human Research Ethics Committee. In accordance with section 5.5 of the National Statement on Ethical Conduct in Human Research (2007) the Executive noted the final approval from the Cancer Institute NSW and your right to proceed under their authority.

Please do not hesitate to contact the Ethics Secretariat if you have any questions or concerns.

Please do not hesitate to contact the Ethics Secretariat at the address below, if you require a hard copy letter of the above notification.

Please retain a copy of this email as this is your official notification of external approval being noted.

Yours sincerely

Dr Karolyn White
Director of Research Ethics
Chair, Human Research Ethics Committee

Appendix C. Participant Information and Consent Form

PARTICIPANT INFORMATION

TITLE: **Women's Views of Nipple Sparing Mastectomy**

INVESTIGATOR: **Dr Kerry Sherman**

You are invited to participate in a research study investigating breast reconstruction physical and psychological outcomes using nipple sparing mastectomy in female breast cancer patients.

The study is being conducted by:

- Dr Kerry Sherman, Department of Psychology Macquarie University (Principal Investigator)
- Dr James French, Breast Surgeon, Westmead Breast Cancer Institute, Westmead Hospital (Co-Investigator)
- Dr Elisabeth Edstrom Elder, Breast Surgeon, Westmead Breast Cancer Institute, Westmead Hospital (Co-Investigator)
- Ms Louise Koelmeyer, Occupational Therapist, Westmead Breast Cancer Institute, Westmead Hospital (Co-Investigator)
- Dr Paul Brown, University of California, Merced (Co-Investigator)
- Dr Meagan Brennan, Poche Centre and Westmead Breast Cancer Institute, Westmead Hospital
- Dr Thomas Lam, Westmead Breast Cancer Institute
- Ms Samantha Woon, Doctoral Student, Macquarie University

Study Recruitment Sites

- Westmead Breast Cancer Institute
- Poche Centre
- Norwest Hospital
- Breast Cancer Network of Australia

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree participate in this study, you will be asked to indicate your consent on the form on the following screen.

1. 'What is the purpose of this study?'

The purpose is to assess the outcomes of nipple sparring mastectomy. We are interested in how women like yourself, who have had any type of mastectomy with immediate reconstruction, feel about their breast surgery and the way it looks.

2. 'Why have I been invited to participate in this study?'

You are eligible to participate in this study because you have had a mastectomy with immediate reconstruction.

3. 'What if I don't want to take part in this study or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the care you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Withdrawing from this study will not affect your relationship with your doctors or any standard treatment you may be receiving.

4. 'What does this study involve?'

Information for this study will be collected for a period of approximately ten to twelve months.
If you agree to participate in this trial, you will then be asked to undergo the following procedures:

- Fill-in and submit the consent form and demographic details online. Use the website address to access the study webpage.
- Following your consent, a questionnaire will be made available online for you to complete, which will take approximately 30-35 minutes' time. You will be asked to read each question and, unless otherwise specified, to give your considered answer based on your thoughts and feelings at that present moment. Items in the questionnaire will assess your level of satisfaction with your breast surgery including physical, emotional and economic outcomes. A code number will be used to identify the questionnaires. Data from the questionnaires will be sent electronically to a password-protected file on a secure server.
- Following the completion of your questionnaire, you will then be given the option of providing your contact details to take part in an in depth telephone interview with the research assistant, discussing more fully your reactions to your breast surgery. The interview will take approximately 45 minutes' time.

5. 'Are there risks to me in taking part in this study?'

There is very little risk associated with participating in this study. It is possible that consideration of breast reconstruction options in relation to breast cancer may cause some degree of anxiety. In such an event you are encouraged to inform the research staff for this study, who can refer you to the clinic counsellor as required.
Alternatively the Cancer Council Helpline is a free and confidential telephone information and support service, with experienced cancer health professionals and counsellors. The Cancer Council Helpline number is 13 11 20. Also, in the event that you feel anxious, worried or uncomfortable about any of the questions, you can choose not to answer those questions.

6. 'Will I benefit from the study?'

This study aims to facilitate recommendations being made to improve the provision of breast surgery and possible options for reconstruction. It cannot be guaranteed that you

will receive any direct benefit from participating in this study. The information collected from this study may help other people who need to make decisions associated with breast surgery and reconstruction in the future.

7. 'Will taking part in this study cost me anything, and will I be paid?

All questionnaires and information you will receive related to this study will be provided to you at no cost. You will not be paid for your participation in this study.

8. 'How will my confidentiality be protected?'

Of the people caring for you, only the researcher, Dr Kerry Sherman, and the study research assistant will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at the Westmead Breast Cancer Institute.

A code number will be used to identify the questionnaires which will be held securely at the Westmead Breast Cancer Institute, and data from the questionnaires will be entered and stored in a password-protected computer file to which only Dr Sherman and the research assistant will have access. Information containing your personal details will be kept in a password-protected file, separate to the information collected from your questionnaires.

9. 'What happens with the results?'

The results of this study may be published in psychological journals, presented to the research staff at the four nominated hospitals, or presented at a relevant conference or other professional forums. In any information which is presented, you will not be identified. Further, the results will not be included in medical records.

10. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, if you have any questions or enquiries, please don't hesitate to contact the researchers via email at kerry.sherman@mq.edu.au, or via phone on 02-97625301.

11. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved the Cancer Institute NSW Clinical Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Coordinator, who is the person nominated to receive complaints from research participants. You should contact them on 02 8374 5600.

The ethical aspects of this study have also 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 Research Ethics Officer (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

If you have any concerns about the conduct of the study, or your rights as a study participant, you may also contact:

- Westmead Hospital Patient Representative, Ms Jillian Gwynne Lewis, Telephone No 9845 7014 or email jillian.lewis@swahs.health.nsw.gov.au.

You are also free to discuss any concerns about this trial, not only with your medical team, but also your family, friends, other health care professionals or legal advisors.

Thank you for taking the time to consider this study.
If you have read the above information and you wish to take part in it, please click 'next' and you will be taken to the online consent form and asked to provide your personal details. A copy of the information provided on this page will be sent to you via email once you have submitted your personal details.

Next

PARTICIPANT INFORMATION SHEET AND CONSENT

Women's Views of Mastectomy and Immediate Breast Reconstruction

You are invited to participate in a research study regarding the operation you underwent for your breast reconstruction. We are interested in your thoughts and feelings about the outcomes of your operation.

The study is being conducted by a team of cancer specialists and researchers from the Westmead Breast Cancer Institute and the Poche Centre, and a Doctoral student from Macquarie University. The investigators are:

- Dr Kerry Sherman, Health Psychologist
- Dr James French, Breast Surgeon
- Dr Elisabeth Edstrom Elder, Breast Surgeon
- Prof Paul Brown, Health Economist
- Ms Louise Koelmeyer, Occupational Therapist
- Dr Meagan Brennan, Breast Physician
- Dr Thomas Lam, Plastic and Reconstructive Surgeon
- Ms Samantha Woon, Doctoral student

I have read and understood the Participant Information Sheet. The nature and purpose of the research study has been explained to me.

I have had the chance to ask questions, and understand the answers I have been given. I understand that I may ask questions at any time during the study.

I understand that I may not directly benefit from taking part in the study.

I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

I have had the opportunity to discuss taking part in this investigation with a family member or friend.

I understand that any refusal to participate in the research will not prejudice my future care in any way.

I understand that I am free to leave this study at any time, and doing so will not prevent me from receiving any future treatment.

If you are willing to participate in the following study, please indicate your consent by clicking the 'I agree to participate' button below.

I Agree to Participate

Please note: by clicking this link you will be taken to the next page, which will require you to submit your personal contact information. After doing this you will be sent a copy of the participant information and this consent form.

If you do not wish to participate in this study, please click on the "I do not wish to participate" button below and you will be returned to the study home page

I Do Not Wish to Participate

Appendix D. Poster Presentation of Study 1[1]

[1] Poster presented at the 2014 International Congress of Behavioural Medicine, Grongingen, The Netherlands, and the 2015 Australasian Society for Behavioural Health and Medicine, Perth, Australia.

MACQUARIE UNIVERSITY

BODY IMAGE AND PSYCHOLOGICAL DISTRESS IN NIPPLE-SPARING MASTECTOMY: MEDIATING ROLES OF SELF-COMPASSION AND APPEARANCE INVESTMENT

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BACKGROUND

Women with breast cancer face threats to body image following surgery. Nipple-sparing mastectomy with immediate breast reconstruction (NSM+IBR) may minimise impacts on body image as this preserves the woman's skin and areola complex. Psychological factors, such as self-compassion and investment in appearance, may also mediate body image disturbance. This study assessed body image disturbance and psychological distress in women undergoing NSM+IBR, and determined whether self-compassion and appearance investment mediated the relationship between body image and distress.

Objective: To investigate the levels of body image disturbance, general and cancer-specific psychological distress in women who have undergone NSM+IBR and explore the mediating roles of self-compassion and appearance investment.

METHODS

Women diagnosed with breast cancer (N=80) who had previously undergone NSM+IBR completed online or hard copy questionnaires:

- **Demographic Details**
- **Body Image Scale** (α = .91)
- **Depression, Anxiety & Stress Scales** (α = .92)
- **Impact of Events Scale** (α = .92)
- **Self-Compassion Scale** (short form; α = .91)
- **Appearance Schemas Inventory – Revised** (self-evaluative salience, α = .85 motivational salience, α = .88)

Table 1: **Sample Characteristics (*N* = 80)**

VARIABLES	MEAN (SD) or *n* (%)
Age	47.73 (8.64)
Chemotherapy	48 (60.0%)
Radiation	17 (21.3%)
Hormonal treatment	40 (50.0%)
Time since diagnosis	
<1 year	25 (31.25%)
1-2 years	32 (40.0%)
2-3 years	11 (13.75%)
3-4 years	3 (3.75%)
≥ 5 years	9 (11.25%)

RESULTS

- **Mean general and cancer-specific psychological distress were within normal ranges and body image disturbance was relatively low.**
- **Body image was positively correlated with Depression, Stress, Impact of Event scale scores and appearance investment, and negatively correlated with self-compassion.**
- **Bootstrap analyses indicated a mediating effect of self-compassion (depression, anxiety, stress) and appearance investment (depression, stress, cancer-specific distress).**

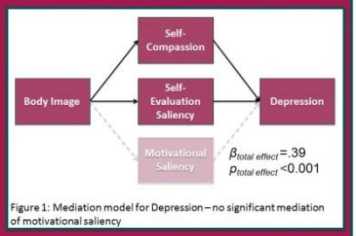

Figure 1: Mediation model for Depression – no significant mediation of motivational saliency

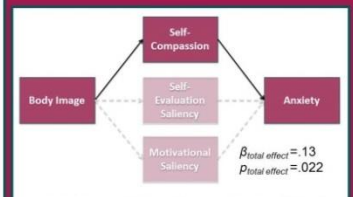

Figure 2: Mediation model for Anxiety – no significant mediation of self-evaluation saliency or motivational saliency

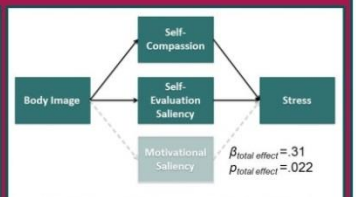

Figure 3: Mediation model for Stress – no significant mediation of motivational saliency

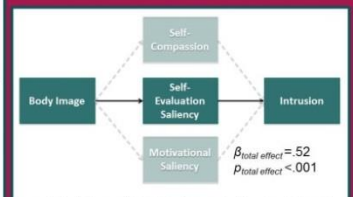

Figure 4: Mediation model for Intrusion - no significant mediation of self-compassion or motivational saliency

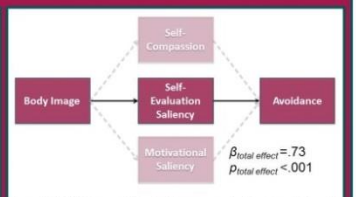

Figure 5: Mediation model for Avoidance – no significant mediation of self-compassion or motivational saliency

CONCLUSIONS

Relatively low levels of psychological distress and body image disturbance in the current study suggest that NSM+IBR may minimise the adverse psychological impacts of mastectomy. As predicted, greater levels of body image disturbance was associated with greater levels of general and cancer-specific psychological distress. It was also found that the body image-distress relationship was mediated by self-compassion and self-evaluative salience, with self-compassion appearing to function as a protective factor against experiencing higher levels of psychological distress, and self-evaluative salience appearing to be a vulnerability factor for distress. This suggests a potential role for these individual characteristics as the focus of psychological interventions to minimise the negative impacts of mastectomy.

Clinically, being able to identify women pre-surgery with higher levels of self-evaluative salience may aid in identifying women following surgery who are more likely to experience higher levels of distress, or are at greater risk for poorer psychological adjustment. Conversely, interventions aimed at enhancing self-compassion may be beneficial for women undergoing breast surgery.

BCI westmead breast cancer institute

FURTHER INFORMATION:

Contact Samantha Woon

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PHONE: +61 422 961 510

References:

Cash, T., *Brief manual for the Appearance Schemas Inventory–Revised.* Body Image Research Consulting. Virginia, 2003.

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Appendix E. Depression, Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995)

Author Note: Formatting for all questionnaires was conducted through online survey using Qualtrics. Questionnaires shown here are for demonstration purposes only.

DASS21

Please read each statement and circle a number 0, 1, 2 or 3 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.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	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)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

Appendix F. Impact of Event Scale (Horowitz et. al., 1979)

Impact of Event Scale

DIRECTIONS: Below is a list of comments made by people during various life events. We are interested in knowing how you feel in relation to your decision about breast surgery.

Please tick the box corresponding to the statement that indicates how frequently each comment was true for you in the past week regarding your decision. If any of these responses do not occur, mark the "not at all" column with an X.

How I felt in relation to my decision about breast surgery in the past week…	***Not at all***	**Rarely**	***Some-times***	**Often**
1. I thought about it when I didn't mean to.				
2. I avoided letting myself get upset when I thought about it or was reminded of it.				
3. I tried to remove it from memory.				
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind.				
5. I had waves of strong feelings about it.				
6. I had dreams about it.				
7. I stayed away from reminders of it.				
8. I felt as if it hadn't happened or it wasn't real.				
9. I tried not to talk about it.				
10. Pictures about it popped into my mind.				
11. Other things kept making me think about it.				
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13. I tried not to think about it.				
14. Any reminder brought back feelings about it.				
15. My feelings about it were kind of numb.				

Appendix G. Body Image Scale (Hopwood et. al., 2001)

PSYCHOLOGICAL OUTCOMES OF NIPPLE SPARING MASTECTOMY

Body Image Scale

DIRECTIONS: In this questionnaire 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 place a tick in the box alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

How I have been feeling about my appearance during the past week:	***Not at all***	**A little**	***Quite a bit***	**Very much**
1. Have you been feeling self-conscious about your appearance?				
2. Have you felt less physically attractive as a result of your decision?				
3. Have you been dissatisfied with your appearance when dressed?				
4. Have you been feeling less feminine as a result of your decision?				
5. Do you find it difficult to look at yourself naked?				
6. Have you been feeling less sexually attractive as a result of your decision?				
7. Did you avoid people because of the way you felt about your appearance.				
8. Have you been feeling the treatment has left your body less whole?				
9. Have you felt dissatisfied with your body?				
10. Have you been dissatisfied with the appearance of your scar(s)?				

Appendix H. Self-Compassion Scale (Short Form; Raes et al., 2011)

Self-Compassion Scale – Short Form

DIRECTIONS: Please read each statement carefully before answering, then indicate which response best applies to you by circling the appropriate response.

How I typically act towards myself in difficult times:

	Almost Never				Almost Always
1. When I fail at something important to me I become consumed by feelings of inadequacy.	1	2	3	4	5
2. I try to be understanding and patient towards those aspects of my personality I don't like.	1	2	3	4	5
3. When something painful happens I try to take a balanced view of the situation.	1	2	3	4	5
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1	2	3	4	5
5. I try to see my failings as part of the human condition.	1	2	3	4	5
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	1	2	3	4	5
7. When something upsets me I try to keep my emotions in balance.	1	2	3	4	5
8. When I fail at something that's important to me, I tend to feel alone in my failure.	1	2	3	4	5
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1	2	3	4	5
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1	2	3	4	5
11. I'm disapproving and judgmental about my own flaws and inadequacies.	1	2	3	4	5
12. I'm intolerant and impatient towards those aspects of my personality I don't like.	1	2	3	4	5

Appendix I. Appearance Schemas Inventory – Revised (ASI-R; Cash, 2003)

Appearance Schemas Inventory – Revised

DIRECTIONS: 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 and circle a number from 1 to 5 in the space appropriately. 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
1. I spend little time on my physical appearance.	1	2	3	4	5
2. When I see good-looking people, I wonder about how my own looks measure up.	1	2	3	4	5
3. I try to be as physically attractive as I can be.	1	2	3	4	5
4. I have never paid much attention to what I look like.	1	2	3	4	5
5. I seldom compare my appearance to that of other people I see.	1	2	3	4	5
6. I often check my appearance in a mirror just to make sure I look okay.	1	2	3	4	5
7. When something makes me feel good or bad about my looks, I tend to dwell on it.	1	2	3	4	5
8. If I like how I look on a given day, it's easy to feel happy about other things.	1	2	3	4	5
9. If somebody had a negative reaction to what I look like, it wouldn't bother me.	1	2	3	4	5
10. When it comes to my physical appearance, I have high standards.	1	2	3	4	5

11. My physical appearance has had little influence on my life.	1	2	3	4	5
12. Dressing well is not a priority for me.	1	2	3	4	5
13. When I meet people for the first time, I wonder what they think about how I look.	1	2	3	4	5
14. In my everyday life, lots of things happen that make me think about what I look like.	1	2	3	4	5
15. If I dislike how I look on a given day, it's hard to feel happy about other things.	1	2	3	4	5
16. I fantasise about what it would be like to be better looking than I am.	1	2	3	4	5
17. Before going out, I make sure that I look as good as I possibly can.	1	2	3	4	5
18. What I look like is an important part of who I am.	1	2	3	4	5
19. By controlling my appearance, I can control many of the social and emotional events in my life.	1	2	3	4	5
20. My appearance is responsible for much of what's happened to me in my life.	1	2	3	4	5

Appendix J. Decisional Conflict Scale (O'Connor, 2012)

Decisional Conflict Scale

<u>DIRECTIONS</u>: The following questions relate to how satisfied you feel about your decision regarding the type of breast surgery you chose. Please tick the option that describes how you feel.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1. I knew which options were available to me.					
2. I knew the benefits of each option.					
3. I knew the risks and side effects of each option.					
4. I was clear about which benefits mattered most to me.					
5. I was clear about which risks and side effects mattered most to me.					
6. I was clear about which was more important to me (the benefits or the risks and side effects).					
7. I had enough support from others to make a choice.					
8. I was choosing without pressure from others.					
9. I had enough advice to make a choice.					
10. I was clear about the best choice for me.					
11. I felt sure about what to choose.					
12. This decision was easy for me to make.					

13. I feel I have made an informed choice.					
14. My decision shows what is important to me.					
15. I expect to stick with my decision.					
16. I am satisfied with my decision.					

Appendix K. Decision Regret Scale (Brehaut et. al., 2003)

Decision Regret Scale

<u>DIRECTIONS:</u> Please reflect on the decision that you made about breast surgery with, or without, reconstruction, after talking with your breast surgeon.

Please show how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about your decision.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
1. It was the right decision.	1	2	3	4	5
2. I regret the choice that was made.	1	2	3	4	5
3. I would go for the same choice if I had to do it over again.	1	2	3	4	5
4. The choice did me a lot of harm.	1	2	3	4	5
5. The decision was a wise one.	1	2	3	4	5

Appendix L. BREAST-Q Satisfaction with Breasts Subscale

(Pusic et al., 2009)

BREAST-Q Satisfaction with Breast Subscale

The following questions are about your breasts and breast surgery. After reading each question, please circle the number in the box that best describes your situation. If you are unsure how to answer a question, choose the answer that comes closest to how you feel. Please answer all questions.

With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
1. How you look in the mirror clothed?	1	2	3	4
2. How comfortably your bras fit?	1	2	3	4
3. Being able to wear clothing that is more fitted?	1	2	3	4
4. How you look in the mirror unclothed?	1	2	3	4
5. The shape of your reconstructed breast(s) when you are wearing a bra?	1	2	3	4
6. How normal you feel in clothes?	1	2	3	4
7. The size of your reconstructed breast(s)	1	2	3	4
8. How your breasts are lined up in relation to each other?	1	2	3	4
9. The softness of your reconstructed breast(s)?	1	2	3	4
10. How equal in size your breasts are to each other?	1	2	3	4
11. How natural your reconstructed breast(s) looks?	1	2	3	4

12. How naturally your reconstructed breast(s) sits/hangs?	1	2	3	4
13. How your reconstructed breast(s) feels to the touch?	1	2	3	4
14. How much your reconstructed breast(s) feels like a natural part of your body?	1	2	3	4
15. How closely matched your breasts are to each other?	1	2	3	4
16. How your reconstructed breast(s) look now compared to before you had any surgery?	1	2	3	4

Appendix M. BREAST-Q Physical Well-Being: Chest and Upper Body Subscale

BREAST-Q Physical Well-Being: Chest and Upper Body Subscale

In the past 2 weeks, <u>how often</u> have you experienced:

	None of the time	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
1. Neck pain?	1	2	3	4	5
2. Upper back pain?	1	2	3	4	5
3. Shoulder pain?	1	2	3	4	5
4. Arm pain?	1	2	3	4	5
5. Rib pain?	1	2	3	4	5
6. Pain in the muscles of your chest?	1	2	3	4	5
7. Difficulty lifting or moving your arms?	1	2	3	4	5
8. Difficulty sleeping because of discomfort in your breast area?	1	2	3	4	5
9. Tightness in your breast area?	1	2	3	4	5
10. Pulling in your breast area?	1	2	3	4	5
11. Nagging feeling in your breast area?	1	2	3	4	5
12. Tenderness in your breast area?	1	2	3	4	5
13. Sharp pains in your breast area?	1	2	3	4	5
14. Shooting pains in your breast area?	1	2	3	4	5
	1	2	3	4	5

15. Aching feeling in your breast area?					
16. Throbbing feeling in your breast area?	1	2	3	4	5

Appendix N. BREAST-Q Sexual Well-Being Subscale

BREAST-Q Sexual Well-Being Subscale

Regardless of your current level of sexual activity, please answer the following question.

Thinking of your sexuality, since your breast surgery, <u>how often</u> do you generally feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Not Applicable
1. Sexually attractive in your clothes?	1	2	3	4	5	N/A
2. Comfortable/at ease during sexual activity?	1	2	3	4	5	N/A
3. Confident sexually?	1	2	3	4	5	N/A
4. Satisfied with your sex-life?	1	2	3	4	5	N/A
5. Confident sexually about how your breast(s) look when <u>unclothed</u>?	1	2	3	4	5	N/A
6. Sexually attractive when <u>unclothed</u>?	1	2	3	4	5	N/A

Appendix O. Partner Reaction Questionnaire (designed for current thesis)

Partner Reactions

DIRECTIONS: Please read each statement carefully before answering, then indicate which response best applies to you by circling the appropriate response.

	Not at all				Very much
1. How much do you feel your partner has accepted your changed body (i.e. your body following mastectomy/reconstruction)?	1	2	3	4	5
2. How comfortable do you think your partner is with feeling or touching your body now?	1	2	3	4	5
3. How much does it matter to you that your partner accepts your body after the surgery?	1	2	3	4	5
4. Does your partner's reaction to your body affect the way your dress now?	1	2	3	4	5
5. Does your partner's reaction to your body influence how you feel about your body now?	1	2	3	4	5