Exploration of the decision-making processes, perceptions of risk and psychosocial experiences among young women undergoing bilateral prophylactic mastectomy

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Bachelor of Arts Honours

This thesis is presented for the degree of Doctor of Philosophy of The University of Western Australia

Medical School (Division of Surgery)
Faculty of Health and Medical Sciences

2018
THESIS DECLARATION

I, Rachael Wynne Glassey, certify that:

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The following approvals were obtained prior to commencing the relevant work described in this thesis: Royal Perth Hospital (REF:15-095 (RPH)), St John Of God Hospital, Subiaco (REF:866) (SJOG)) and kConFab (HREC # 97_27).

This thesis contains published work and/or work prepared for publication, some of which has been co-authored.

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Date: 20\textsuperscript{th} February 2018
ACKNOWLEDGEMENTS

I dedicate this thesis to my Dad, Mike who is my number one fan and continuously demonstrates his pride in my achievements and support of my university studies.

First and foremost I would like to express my gratitude to my principal supervisor Christobel Saunders for her support of this project since its inception and her endless encouragement. I would also like to thank my co-supervisors Angela Ives, Moira O’Connor and Sarah Hardcastle for their continuous guidance and support throughout the development of this thesis.

I would like to thank the women who participated in this study, Genetic Services of Western Australia, Register4 and kConFab for their help in recruitment.

I would also like to thank The University of Western Australia who awarded a Scholarship for this research to be undertaken. This research is supported by an Australian Government Research Training Program Scholarship.

I would like to acknowledge and thank Heather Thorne, Sarah O’Sullivan and Toni Musiello for their guidance and assistance with the publication of some of the manuscripts in this thesis.

Last but not least I would like to sincerely thank my husband, Steven for his never ending support throughout the last 3 years, and my daughter, Summer for being the best kid a PhD Mum could ask for.
LIST OF CONFERENCE PRESENTATIONS

1. **Glassey, R.,** O’Connor, M., Ives, A., kConFab Investigators, Hardcastle S. J., Saunders, C. The need for a multidisciplinary approach to the management of younger women at high risk of developing breast cancer considering bilateral prophylactic mastectomy (BPM). 11th Scientific Meeting Quandaries and Controversies for the Multidisciplinary Team, Gold Coast, QLD, 6th October 2017 (poster presentation, Appendix 1).


4. **Glassey, R.** Information needs and experiences of young women considering, or who have undergone, preventative mastectomy. WA BRCA Day, Perth 28th May 2016.
LIST OF PUBLICATIONS


This thesis contains work that has been published and prepared for publication.

**Details of the work:**

**Location in thesis:**
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**AUTHORSHIP DECLARATION: CO-AUTHORED PUBLICATIONS**

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**Location in thesis:**
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<td>Dr Sarah Hardcastle 29/01/2018</td>
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AUTHORSHIP DECLARATION: CO-AUTHORED PUBLICATIONS

Details of the work:
Glassey, R., Saunders, C., & Hardcastle, S. Commentary: Bilateral risk-reducing mastectomy is the safest strategy in BRCA1 carriers. Frontiers in psychology. 2017:8:1-3

Location in thesis:
Appendix 3

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<td>Transport Layer Security</td>
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ABSTRACT

Introduction. Breast cancer (BC) is the most common malignancy in women. Although the aetiology is largely unknown, a strong family history of cancer, in particular an inherited predisposing gene mutation, such as BRCA1 or 2, increases the lifetime risk of developing the disease from around 12 up to 80%. Bilateral prophylactic mastectomy (BPM) reduces this risk to almost zero. In Australia it is thought around ~21% of high risk women undertake this option. Having a BPM before age 40 years has the greatest benefit for risk reduction. However, the literature focusing on younger women in relation to BPM is scarce.

Aim. The overarching aim of this study was to explore the perceptions and experiences of younger women (<35 years) at high risk of developing BC who are considering, or have undergone, BPM. This information will be used to improve the outcomes for women at high risk of developing BC.

Methods. This study adopted a mixed methods approach with qualitative (semi-structured interviews) and quantitative (questionnaire) components. Forty-six women <35 years from Australia and New Zealand were recruited between November 2015 and July 2016, if they had undergone BPM (n=26) or were seeking medical advice about BPM (n=20). Their mean age was 30.4 years (31 years BPM group, 29.5 years considering group). Thirty-six were BRCA carriers and for ten BRCA status was unknown. Interviews focused on information received, risk perceptions, decision-making, cancer-related worry, body image and sexuality. Interviews with the BPM group included questions about surgery. Interviews were analysed using principles of interpretative phenomenological analysis. Participants completed an online questionnaire including demographics, family history, genetic testing and five validated questionnaires (Depression, Anxiety, Stress Scales Short Form, body image, Impact of Events, Sexual Activity Questionnaire and risk perception).

Results. The qualitative component identified a number of themes, including decision-making, heightened risk perception, the importance of psychological consultation, dimensions associated with body image and sexuality satisfaction, and barriers to accessing information.

The decision to undergo BPM was multifaceted but appeared underpinned by fear and anxiety. Women had heightened, and sometimes inaccurate, perceptions of their BC risk. Those who had undergone BPM seemed more anxious about their BC risk than those considering surgery. Anxiety did not always appear to reduce for those who underwent BPM. Some women’s risk perception and subsequent decision-making appeared influenced by worst case scenario
examples provided by clinicians. Participants who saw a psychologist pre-BPM appeared to have improved psychological well-being and satisfaction with body image and intimacy post-surgery. Satisfaction with breasts before surgery, outcome expectations, type of mastectomy, and open communication appeared to influence satisfaction with reconstructed breasts post-BPM. Barriers to accessing information appeared widespread and included a lack of integrated services that contributed to inconsistent information. Women’s preferences for information included clearly defined pathways to access information after confirmation of familial BC risk.

The quantitative findings indicated those who had undergone BPM had significantly more cancer-related worry than those considering BPM. In contrast to the qualitative findings, neither group had negative feelings towards body image or intimacy. Three-quarters of women did not accurately recall the lifetime BC risk to any woman in the general population and overestimated their own BC risk.

**Conclusions.** Overall, these findings present a comprehensive body of work and give insight into the experiences of undergoing or considering a BPM for women younger than 35 years. An important finding was clinicians appeared to influence younger women’s decision-making and risk perception. The way younger women perceive information given to them should be taken into account when discussing risk. Furthermore, prophylactic surgery did not always relieve anxiety in younger women. If the risk reduction BPM offers is not reflected in women’s perception of their own risk, this poses a problem for clinical practice. Emphasise should be placed on communicating accurate BC risk pre and post-BPM.

The findings identified a number of important influences to satisfaction with body image, intimacy and psychological well-being. Of particular importance, it appeared beneficial for women to seek psychological support prior to BPM and these findings support the recommendation for all women considering BPM to undergo psychological consultation. A further important finding was the lack of integrated services and inconsistent information that women reported. A multi-disciplinary team could assist these barriers to accessing information.
Chapter 1. Introduction

1.1 Chapter Overview
This chapter provides background about why younger women (defined as women aged less than 35 years) may be faced with the decision to undergo a bilateral prophylactic mastectomy (BPM). It begins with an overview of breast cancer (BC), including hereditary BC. The chapter also provides an overview of genetic testing and discusses the risk management options for those at high risk of developing BC, such as undergoing a BPM. There is a dearth of research relating to younger women who undergo BPM and this chapter presents a detailed justification of why it is important to understand the needs and experiences of younger women who consider BPM. The aims and objectives of this study are included in this chapter. A detailed discussion of the rationale and the significance of the overall study are included. This chapter concludes by outlining the remaining structure of this thesis.

1.2 Breast Cancer
Breast cancer (BC) is the most common type of cancer among women in Australia (1) and New Zealand (NZ) (2). The average lifetime risk of developing BC is one in eight by age 85 years, however, it is eight times greater than this for BRCA1/2 carriers (3). In 2014, BC was the 4th leading cause of death in Australia (4). The number of people developing BC in Australia doubled between 1982-1987 and 2006-2010, however, the survival rate has increased by 17% (5). In 2017, it was estimated that there will be 17,730 new cases of BC diagnosed in Australia (4).

Risk factors for the development of BC include: age, family history, exposure to endogenous and exogenous oestrogen, and lifestyle choices such as diet, exercise, and alcohol (6). BC can be an unpredictable disease; and some people are exposed to all the known risk factors but do not develop the disease (7). About twelve percent of the general population will develop BC at some point in their life (5, 8), but having one first degree relative diagnosed with BC doubles a woman’s lifetime risk of developing the disease (9). If a woman is a BRCA1/2 gene mutation carrier this can translate to an 80% lifetime risk of developing BC (10).

Breast cancer starts with a mutated cell (an abnormal cell) that grows and divides to eventually produce a tumour (1). Once a BC has acquired enough mutations to become invasive it can spread to other areas in the body via a process called metastasis, either via lymphatics or blood. The most common areas where BC metastasises to are the lymph nodes, liver, bones, lung or brain (11).
1.3 Hereditary Breast Cancer

Despite family history being a risk factor for developing BC only about five percent of BC is attributed to a known inheritable genetic cause (12). A number of genetic mutations have been identified that increase susceptibility to BC, such as BRCA1 or 2, TP53, CDH1, PTEN, PALB2 and STK11 (13). The most commonly identified are pathological mutations in the BRCA1/2 genes which account for 1-2% of all BC (14). The BRCA1 gene mutation was identified in 1990 on the long arm of chromosome 17 (15). After the discovery of BRCA1, studies found that it was the mutation responsible in most families who had multiple early onset BC and ovarian cancer (including 45% of families with BC only). However, it was not responsible for families with both female and male BC (16). This finding led to the discovery of the BRCA2 gene mutation on chromosome 13q12-13 in 1994 (16).

1.4 Genetic Testing

Following the discovery of the BRCA1 and BRCA2 genes, testing became available to identify mutation carriers. Traditional genetic testing via Sanger sequencing usually begins with a living relative who has had BC or ovarian cancer. Ponder detailed this for three reasons: 1 – a mutation is more likely to be found in an affected person (personal history of BC) than an unaffected person (no personal history of BC); 2 – a mutation found in an affected person is assumed a significant one, however, one found in an unaffected person may not be; and 3 – there are thousands of different mutations and when one is found in an affected person the testing of other family members can focus on that mutation, rather than each possible scenario (17). In the Australian public healthcare system, genetic testing is usually unavailable to individuals who have not been diagnosed with cancer, unless a gene fault has already been identified in an affected family member.

More recently, next generation sequencing (NGS) has become available. NGS enables a panel of genes to be analysed simultaneously, at reduced cost and a quick turnaround time (compared with Sanger sequencing) (18). While it remains ideal to begin a family’s genetic testing with a relative who has been diagnosed with cancer, this is not always possible (for example, the relative is deceased or declines genetic testing); NGS allows more accessible testing of unaffected relatives who wish to clarify their risks.

In Australia, the demand for genetic testing continues to grow and public healthcare resources remain limited. This situation, coupled with the availability of NGS testing options, has helped to enable the establishment of private genetic clinics. This new model of clinical genetics gives
patients the option of receiving genetic counselling services that they are ineligible to receive through the public healthcare system.

Genetic testing is not without limitations. This is particularly true of panel testing, which may include more recently described genes for which data (including cancer risks and risk management) are currently limited. Panel testing also increases the likelihood of identifying a variant of uncertain significance (19). The results of any genetic testing are only meaningful and useful to patients when they can be interpreted correctly, hence genetic counselling remains an important component of the genetic testing process in both the public and private healthcare systems.

1.5 Risk Management

There are currently four main risk management strategies for those at high risk of developing BC. They are; risk-reducing lifestyle measures, surveillance, medication and surgery.

1.5.1 Risk-reducing lifestyle measures

There are a number of lifestyle measures that can reduce a woman’s risk of developing BC. Some measures have conflicting results and/or the risk reduction is not conclusive (7). However, there is evidence to suggest that BC risk is reduced for women who have at least one full term pregnancy and breastfeed; it is possible that the younger the woman is at her first pregnancy is also a protective factor against developing BC. Other lifestyle measures such as, avoiding obesity, maintaining a low fat diet, exercise and reducing alcohol and smoking intake are said to lower ones risk of developing BC (7).

1.5.2 Surveillance

Early detection is a key to improving survival following a BC diagnosis. There are a number of different methods used to screen women for BC, including mammogram, MRI and ultrasound. Mammogram is not usually an adequate screening tool in younger women because they have dense breast tissue which makes BC more difficult to detect and can lead to false positives or false negatives (20). For women with a family history of BC, it is recommended they begin surveillance by self-examination from the age of 18 years and then begin annual breast examination by a health professional from the age of 25-30 years (21). However, women should see their health professional to tailor a screening program to the individual, taking into account their age and family history (20). Screening by imaging for mutation carriers usually starts at about 30 years of age. Women of this age have an annual MRI, until the age of 50
years when they are usually recommended to have annual mammograms and sometimes ultrasound.

1.5.3 **Risk-reducing medication**
Risk-reducing medication is an option for those at higher than average risk of developing BC. There is, however, a lack of evidence for the effectiveness of risk-reducing medication for those with BRCA1/2 mutations (22). There are currently two types of risk-reducing medication. For pre-menopausal women, tamoxifen, and for post-menopausal women Raloxifene or an aromatase inhibitor, which reduce the risk of BC associated with oestrogen receptor positive BC’s. There is no evidence they reduce the risk of BC associated with oestrogen receptor negative tumours. Tamoxifen and Raloxifene have a number of risks and side effects, notably an increased risk of endometrial cancer after menopause and thromboembolic side effects.

New research is emerging that a drug known as Denosumab used to treat osteoporosis may help to prevent BC in BRCA1 and BRCA2 carriers (23). Researchers have recently identified a molecule known as RANK which is prevalent in BRCA1/2 carriers and appears to be an important regulator in the cell growth of BC. Denosumab is able to inhibit RANK delaying and preventing BC tumour growth (24). Researchers have so far evidenced this in mouse models and a pilot study of six BRCA1 carriers both showing promising results (25). An international trial of the use of Denosumab in BRCA1/2 carriers is planned (25).

1.5.4 **Surgical**
Rather than rely on early detection through surveillance or risk-reducing medication, which only offers a 50% risk reduction and has potential side effects, some women opt for risk-reducing surgery, usually bilateral prophylactic mastectomy (BPM) +/- reconstruction. A BPM is the surgical procedure to remove a woman’s breasts as a precaution to later developing BC. For women with a strong family history of BC or a BRCA1/2 mutation, BPM can reduce the risk that BC will develop by up to 95% (26).

There are three main types of mastectomies that can be performed (27): 1- total mastectomy, which removes as much breast and skin tissue that was covering the breast as possible, as well as the nipple/areola complex, 2- skin-sparing mastectomy removes as much breast tissue as possible, as well as the nipple, but leaves the skin that was covering the breast, this is to assist with reconstruction of the breast and 3- subcutaneous mastectomy or nipple-sparing mastectomy (NSM) which removes as much breast tissue as possible but leaves the nipple and the skin covering the breast. A NSM often provides the best cosmetic outcome for
reconstruction. Leaving the nipple will leave some ducts with a potential risk of cancer developing in these (27).

There are also a number of different types of breast reconstruction available following a BPM. These are usually either with breast implants or using the patient’s own tissue as an autologous flap reconstruction. Breast implants are usually completed as a two stage procedure with a tissue expander (Figure 1) (28) inserted first and often covered with a material to act as an internal sling, such as human acellular dermis, often either FlexHD or AlloDerm (Figure 2) (29). There are a number of other options that use a woman’s own tissue to build new breasts, these include latissimus dorsi (LD) flap (Figure 3) which removes tissue from the LD muscle on the back, usually with a tissue expander/implant as well, transverse rectus abdominus myocutaneous (TRAM) flap and a deep inferior epigastric perforator (DIEP) flap (Figure 4), which both remove tissue from the abdominal wall; there are also other flap options available (28).

![Figure 1. Tissue expander and breast implant sitting behind the muscle (30).](image-url)
Figure 2. Implant reconstruction with use of AlloDerm (31).

Figure 3. Where they take and position the muscle from a LD reconstruction (32).

Uptake of BPM in Australia appears to be relatively low with older data showing only 21% of BRCA1/2 women undergo BPM (33). However, this is the only study to date in Australia...
estimating the uptake of BPM and may need to be updated, particularly following the ‘Angelina effect’ (34). Worldwide it has been suggested that uptake of BPM is associated with younger age (35, 36). However, research looking at younger women with a genetic predisposition to BC is relatively new (37-42) and there is a dearth of research focusing specifically on younger women who undergo a BPM as a preventative measure (43).

Figure 4. The different areas muscle can be taken from to reconstruct breasts (44).

1.6 Aims and rationale
The overall aim of this study was to explore the perceptions and experiences of younger women (less than 35 years) at high risk of developing BC and who are considering, or have undergone BPM surgery. There are seven objectives and each objective represents a different chapter in this thesis in the following order:

1. A review of the literature to review the psychological and psychosocial outcomes in women who choose to undergo a BPM. This review aims to synthesise current knowledge in the area with a particular focus on psychological wellbeing, and where applicable, detail the experiences of younger women.
2. Explore the influences on decision-making for younger women (<35 years) living in Australia and New Zealand at high risk of developing BC who are undergoing or considering BPM.

3. Explore the influences of how younger women (<35 years) perceive their personal risk of BC and whether these influences differ in women who have undergone BPM compared to those who are considering BPM. A secondary aim was to explore whether risk perception differed between women who had a proven BRCA1/2 mutation and those with a strong family history without a known familial mutation.

4. Explore whether prior psychological consultation provides psychosocial benefit to younger women (<35 years) after BPM, in comparison to those who had no such support.

5. Explore the influences on satisfaction with reconstructed breasts and intimacy in younger women (<35 years) with a strong family history of BC following BPM.

6. Explore the barriers to and experiences of accessing information for women who have received genetic risk information and when considering BPM, and explore participants’ preferences concerning information and support needs.

7. Investigate the factors affecting the psychological well-being of younger women (<35 years) at high risk of BC who are considering, or have undergone BPM.

1.7 Rationale and significance
Women in their 20’s and 30’s are underrepresented in the BPM literature (43). This study is unique in that the experiences of younger women (<35 years) with a family history of BC who undergo a BPM has not previously been researched. In the last five years focusing on younger women at high risk of developing BC has become more common. There are six studies to date (37-42) involving/including younger women, however, the majority focus on the experiences of being in a high risk bracket and not specifically undergoing BPM. All of the current studies include younger women with BRCA mutations and exclude those who have a strong family history of BC without a known mutation. All but one study about younger women (<36 years), are limited to the United States. Younger women are reportedly undergoing BPM more frequently (36, 45, 46) and guidelines recommend women undergo this procedure by the age 40 years (47). It is of utmost importance to ensure younger women are informed about any short and long-term issues that can be experienced following a BPM (48).

Younger women with a strong family history of BC have unique medical and psychosocial challenges. Alongside making decisions about their risk of developing BC (42) younger women
(<40 years) are often facing multiple responsibilities and life events (49), such as exploring new relationships, getting married or having children (50). They may also be less comfortable with their body image, in comparison to an older (>40 years) woman (51). Younger age is defined in the literature as being <40 years (52), however for the current study younger age refers to women <35 years. Any other age bracket reference throughout this thesis is with respect to the sample of a specific study being referred to.

Younger women with strong family history of BC are also required to make difficult medical decisions about their risk reduction (41). They often feel pressured to make decisions sooner than they would have, had they not been at high risk of developing BC (53). Due to their age they may have a relative lack of life experience in decision-making, in comparison to older women (41). Consequently they may be ill prepared to consider or understand both the short and long-term consequences of their decision-making. Women need to be cognitively and emotionally ready to make such decisions and this presents a challenge for health professionals (41). It is therefore important to understand the experiences and needs of younger women undergoing BPM to tailor care and interventions.

Research suggests younger women may be more distressed than their older counterparts (41). Younger women have limited experience with health related decision-making. It is unknown how younger women’s decisions will emotionally affect them. The experiences and information needs of younger women have not been scientifically evaluated, separate from the more commonly researched group of older women. Robust evidence about the after effects of a BPM are not being routinely communicated to younger women (37, 38) and therefore these women are not able to make an informed decision about whether or not to undergo a BPM. Younger women need consistent and reliable information and they often want a better understanding of their options (41). It is important to further inform clinical practice about the needs of younger women to ensure they receive accurate and relevant information that they understand. This research will assist in providing clinical practice evidenced based findings on the needs of younger women and identify areas in which they need more support. Younger women who are better informed will be less likely to experience negative psychological and emotional issues. This research has the potential to alter the way information is communicated to this group of women.

This study will contribute to the body of literature on BPM by including the experiences of younger women. To the knowledge of the researcher this study has not been undertaken in
Australia, NZ or internationally. The findings could lead to further research by international researchers as it will be the only study of its kind. The research will be a basis for a prospective study as women will be asked to consent to be contacted about future research. The results have the potential to improve outcomes for younger women at high risk of developing BC and identify ways clinical practice could amend their services to incorporate the needs of younger women choosing BPM. This research will also build on the Australian research reputation. The proposal to use the experiences of this younger cohort to inform clinical practice within BPM is a new area and may significantly affect the way in which decision-making information is portrayed to younger women in the future. This research also has the potential to affect national and worldwide practice by delivering knowledge on the experiences of younger women undergoing a BPM. The findings will provide important data on the psychological, emotional and physical impact of a BPM and the impact of providing this information to young women.

1.8 **Structure of the thesis**

The current chapter, Chapter One provided a background to why younger women are faced with having to decide about BPM, including BC, hereditary BC and genetic testing. The chapter has given an overview of the risk management options to a woman at high risk of developing BC, including, lifestyle measures, surveillance, risk-reducing medication (including emerging research using a new medication) and risk-reducing surgery. The aims of the current research have also been identified.

Chapter Two is a published review of the literature. It encompasses the psychosocial aspects that are important for those undergoing BPM and details the previous literature on the topic. Where applicable the literature review highlights where there is information available for younger women. It provides a detailed explanation of why it is important to do this research with younger women and describes how current BPM literature does not encompass this. The literature review also includes justification for the methodology of this research project, including the limitations of previous methodologies and justification for the age range being younger women less than 35 years of age.

Chapter Three consists of the qualitative methodology and methods, and provides a detailed explanation of the theory behind the qualitative component of this study. It also provides a detailed description of participant recruitment, data collection and analysis, as well as further justification for the methodology utilised.
Chapter Four is a published paper which discusses the influences to decision-making for younger women undergoing and considering a BPM and any differences between the groups.

Chapter Five is a published paper which explores the influences of how younger women perceive their personal risk of BC and whether these influences differ in women who have undergone BPM compared to those who are considering BPM. This paper also explores whether risk perception differed between women who had a proven BRCA1/2 mutation and those with a strong family history without a known familial mutation.

Chapter Six is a published paper which explores the value of prior psychological consultation and whether this provides psychosocial benefit to younger women (<35 years) after BPM. This paper also makes comparisons where viable between those who underwent psychological consultation and those who received no such support.

Chapter Seven is a published paper which focuses on the influencers to satisfaction with reconstructed breasts and intimacy in younger women (<35 years) with a strong family history of BC following BPM.

Chapter Eight is a published paper that’s aim is to explore the barriers to and experiences of accessing information for women who have received genetic risk information and when considering BPM, and explore participants’ preferences concerning information and support needs.

Chapter Nine consists of the quantitative component of this study – an online questionnaire investigating the factors affecting the psychological well-being of younger women (<35 years) at high risk of BC who are considering, or have undergone BPM. It provides details of the quantitative methodology, the results and a discussion of the important findings.

Chapter Ten concludes with an overall discussion combining the main findings from chapters 1-10. Interactions between main findings are discussed and compared. The contribution of this study to the literature and to improving the outcomes for younger women considering BPM is discussed. This chapter also includes, limitations and strengths of the study as a whole, clinical implications, and recommendations for future research.
Chapter 2. Decision making, psychological wellbeing and psychosocial outcomes for high risk women who choose to undergo bilateral prophylactic mastectomy – A review of the literature.

2.1 Chapter overview

This chapter presents a published literature review. It begins with a foreword discussing literature missed in the review and literature published since this review was published. The literature review provides a justification for the overarching study, including gaps in the literature and why further research is warranted. Permission to include this publication in this thesis can be found in Appendix 4 and a copy of the front page of this publication in Appendix 5.


2.2 Foreword

Unfortunately there was one article that was missed in the literature search. Hoskins et al. (39) investigated risk perception in younger women (the mean age was 29.6 years) that had a BRCA1/2 mutation. It is the only other study (aside from that which has been published from this study) that specifically investigates risk perception in younger women (<36 years). It was a qualitative study of 60 women and 17 (28%) had undergone a BPM. They found that visits to health professionals increased participants’ risk perception, as it was a constant reminder of their high risk. Women felt their risk perception heightened when considering the adverse effects a diagnosis of BC could have on their children (39). Communication of risk information and how women assimilated this differed for individuals. Those who understood the genetic information provided by genetic counsellors or physicians found the experience less stressful, in comparison to those who did not understand the information. Hoskins et al. (39) concluded that younger (<36 years) BRCA positive women’s perception of risk differed to that of older women. Childrearing was a major consideration in decision-making and this contributed to heightened risk perception. Many women were burdened by the decision to have BPM before or after having children. Hoskins et al’s. (39) study provides a basis for understanding
perceived risk for younger women (<36 years). More research, however, is needed to explore further factors influencing perception of risk in younger women undergoing BPM.

Evans et al. (41) have made available the results of a new study since this literature review was published. This was a qualitative study of 12 women whose mean age was 22 years old. Four women had tested positive for one of the BRCA mutations. No women in this study had undergone a BPM. They found that younger women with a strong family history of BC face difficult and challenging medical decisions about their risk reduction, presenting unique psychosocial challenges for young women. They must take into account the short and long-term psychosocial and health consequences. Young women need to be cognitively and emotionally ready to make such decisions and this presents a challenge for health professionals. The women in Evans et al. (41) study needed consistent and reliable information and reported receiving conflicting recommendations. They also wanted a better understanding of their risk.

Younger women have a relative lack of life experience in decision-making, in comparison to older women (41). They may be ill prepared to consider or understand the long-term consequences of their decision-making. Many women followed the example of family without considering what they would prefer themselves. Their limited experience with health related decision-making, and understanding the consequences of how their decisions will emotionally affect them, have not been fully thought through. Many studies have been with older women, and therefore, it is unlikely the needs of this younger population have been given full consideration.

2.3 Abstract
A bilateral prophylactic, or preventative, mastectomy (BPM) for women at high risk of developing breast cancer (BC) can reduce their risk of developing the disease by up to 90% (relative risk reduction). An increasing number of women, including young women, are taking up this option. However, there is a dearth of information for younger women (under 40 years) choosing preventative mastectomy. In fact, no studies to date have specifically focused on younger women’s experiences of a BPM and investigated their informational needs.

The purpose of this review is to report on the current literature surrounding the psychological experience of a BPM and the informational needs for women at high risk of developing BC with a particular emphasis on younger women.

Research has highlighted a range of psychological outcomes linked to preventative mastectomy, including positives such as reduced anxiety and negatives including impaired
body image and sexuality. The literature strongly suggests women want more information surrounding BPM, particularly related to the after effects of the surgery, and the impact on their psychological wellbeing. Research method limitations and reporting has resulted in conflicting conclusions, making it difficult for women to be well informed. In particular, there has been little focus on the experiences and needs of younger women opting for BPM. Due to the unique needs of younger women and an increase in BPM rates for younger women, it is imperative that the needs of this group are addressed. Together these findings provide justification and recommendation for further research in this area.

2.4 Introduction

The removal of ‘healthy’ breasts is often seen as a ‘drastic’ or ‘radical’ procedure undertaken on the basis of fear (54, 55). A bilateral prophylactic or preventative mastectomy (BPM) is the surgical procedure to remove a woman’s breasts as a precaution to later developing breast cancer (BC). For women with a significant family history of BC, such as two or more first or second degree relatives on the same side of the family diagnosed with a breast or ovarian cancer, or a BRCA1/2 mutation, a BPM can reduce the relative risk that BC will develop by over 90% (56, 57). Guidelines for BRCA1/2 carriers suggest breast screening should start between the ages of 25-30 years (47, 58, 59). The recommendation for undergoing a BPM is that it has the greatest benefit in risk reduction for women before age 40 years (47). Uptake of BPM has reportedly differed per country. In an Australian study BPM has been found to be relatively low with only 21% of BRCA1/2 carriers undergoing BPM (n=325) (33). However, in two European studies, from England (n=211) and Denmark (n= 306), the uptake of BPM for high risk women was estimated to be between 40-50% (35, 36). In both European studies higher uptake of BPM was significantly associated with younger women, with the average age being <35 years and <40 years respectively. These studies suggest that in recent years younger women are undergoing BPM more frequently. However, to date there appears to be no studies detailing the specific experiences of younger women (<40 years) who undergo a BPM.

Older and younger women differ in the various roles they adopt at certain points in their life and consequently have different priorities and responsibilities (60). Erickson defined young adulthood to be between ages 18 and 40 years (52). Young adults face many new challenges such as independence from parents, educational and career choices, exploring relationships, and making decisions about children and lifestyle (49). Young women with a family history of BC are trying to balance these multiple emerging roles and significant life events while having to make decisions surrounding their increased BC risk (42). In comparison, older women (>40
years) are more likely to be more securely settled, married or in a long-term relationship, have school age or older children, have an established career (60), and may be more comfortable with their body image (51). As women further age their roles change again and they may focus more on independence, retirement, widowhood, constrained finances and physical/mental function decline (61). Based on these life stage role differences younger women are likely to have different experiences and perceptions when considering their increased BC risk and undergoing a BPM.

2.5 Aims of the Study
The primary aim of this literature review is to review the psychological and psychosocial outcomes in women who choose to undergo a BPM. This review aims to synthesise current knowledge in the area with a particular focus on psychological wellbeing, and where applicable, detail the experiences of younger women.

2.6 Methods
This literature search was carried out between July 2014 and July 2015 using the databases PsychInfo, PubMed, and ProQuest, utilising a combination of the following keywords “bilateral prophylactic mastectomy”, “preventative mastectomy”, “prophylactic surgery”, and “risk-reducing mastectomy”. These keywords alone were found to be too broad as the majority of papers were medically or surgically focused rather than psychosocial/psychological. Therefore, the words “psychosocial”, “psychological” and “body image” were used to further refine the search. There was no restriction on date of publication. To ensure papers were relating to BPM rather than contralateral prophylactic mastectomy (CPM), the word “contralateral” was excluded. However many papers include both women who have undergone BPM and CPM and therefore were included. Papers were included if they were original (we excluded review papers) and in peer reviewed journals, they were in English, the full text was available, the participants had a strong family history of BC and the paper’s focus was psychological/psychosocial elements of BPM. A total of 729 papers were found; many were unrelated to the focus of this literature review and were excluded on title inspection as being surgically/medically focused or describing treatment focused genetic testing (TFGT) in women with BC. Of the remaining 264 papers the abstracts were reviewed and 25 were found to be relevant. The remaining 239 were again either surgically or medically focused, or about TFGT. To cross check the literature search we reviewed the reference lists of relevant papers and found a further 10 (Appendix 6). The electronic literature search, inclusion/exclusion of papers and identification of themes was conducted by the first author and cross checked by one other
person. Results from the literature search focused on particular themes; decision making, genetic testing, risk perception, psychological wellbeing, anxiety, cancer related worry, sexuality, body image, age, and information received. These themes were found to all be common elements of psychological studies on BPM with the exception of age, specifically younger women, where the literature only includes four papers relating to younger age.

2.7 Decision Making

Some researchers have suggested that the decision to undergo a BPM is driven by irrational fear (62). However, decisions are not based on fear alone, they also take into account an individual’s personal history, family history and personality. Consequently a number of indicators for choosing BPM were identified in the literature. These include: psychological distress from a close family member’s BC or ovarian cancer death (63); a strong family history of BC (64); and/or a desire to live longer for children or other family members (65). A diagnosis of BC in the family that has caused significant distress may be a deciding factor for undergoing a BPM, however, this may also contribute to exaggerated perceptions about one’s own risk (63).

Actual (or absolute) age based risk estimates are not always a strong influencer for BPM. Rather the age at which a women’s family member was diagnosed with BC and/or died can motivate women to choose BPM (65). The closer a women comes to this age the more urgency she feels to undergo BPM (40). In a qualitative study by Hoskins et al. (40) young women (21-36 years) were interviewed about their decision to undergo a BPM. One woman (25 years) reported that she felt as though she was “treading on thin ice” because she was the same age at which her mother was diagnosed with BC. Another woman aged 24 years described how she felt it was inevitable she would develop BC sooner rather than later and felt that she had to “act very quickly”. They describe three further factors influencing decision making for younger women: 1 - encouragement from a loved one; 2 - screening fatigue; and 3 - a desire to put high risk status in the past.

Family is also important when deciding to undergo a BPM. In a qualitative study (n=10) by Lloyd et al. (65) one woman described wanting to protect her father from any more loss in his late life. Another woman detailed the difficult experience of losing her mother in her twenties and felt she could not put her young children through that. Similarly young women have described the loss of their mother to BC when they were young as a powerful influencer to undergo BPM (42).
Women’s confidence in screening methods may also influence their decision to undergo a BPM. Lloyd et al. (65) found several women expressed concern that if a BC were to develop it would not be detected by current screening methods. In a study on the process of deciding about prophylactic surgery, women reported mixed findings. Some felt health professionals were too directive and came across as insensitive, while others felt disappointed they were not more directive (66). It is unknown whether this is clinician-dependent or due to different personality characteristics of the women.

A retrospective study (n=19) found that the initiation of discussion about BPM could also influence decision making (67). Women who had regrets about their BPM reported that the BPM discussion was initiated by a health professional(s) rather than the woman herself. Whilst a small retrospective study, their findings suggested a health professional initiated discussion about BPM predicted regret. These women described issues relating to screening, such as breasts were hard to examine, or anxiety associated with benign biopsies that contributed to the professional initiating discussion about BPM (67).

2.8 Genetic Testing

Increasing numbers of younger women are undergoing testing for BRCA1/2 (62). However due to the limitations in genetic testing younger women also undergo BPM in the absence of a positive BRCA1/2 mutation (33, 68). In countries such as Australia (69), UK (59), and the USA (58) genetic testing known as a ‘mutation search’ is first offered to an affected individual (i.e. an individual with a personal history of breast or ovarian cancer). If a mutation is identified predictive testing can be offered to other family members. However, if the mutation search is inconclusive no further testing is usually offered to relatives (70). If results are inconclusive the individual and family are still treated as potentially high risk, and many of these women still choose to undergo BPM (71-73). A mutation search can be problematic if there are no living or willing family members. It is rare for an unaffected individual to be tested for BRCA1/2 (74). In certain circumstances when there is at least a 10% probability that a mutation will be found an unaffected individual can be tested (59). However, if geneticists do not know what they are looking for (i.e. an identified BRCA1/2 mutation in a family member) the results of this type of genetic testing can be difficult to interpret. There are thousands of variations of BRCA1/2, some still unidentified (13).

Metcalfe et al. (75) analysed the absolute BC risk in 1,492 women with a family history of BC and an inconclusive family BRCA1/2 result; 65 women developed BC compared to 15.2
expected cases. BC risk was calculated by the actual observed risk compared with the expected risk in the cancer registry. These women had a fourfold (40%) lifetime risk of developing BC compared to the general population. Those under 40 years had the greatest risk elevation compared to the general (age based) population (75). Kauff et al.’s (76) research supported these results, although they had a far smaller sample size (n=165). The women in Kauff’s study were affected individuals who had an inconclusive BRCA1/2 result and also included their family members. Nineteen women developed BC but only 6.07 cases were expected. Domchek et al. (77) analysed a sample of those whose predictive BRCA1/2 testing resulted in a true negative result. Of the 375 women they observed they found two cases of in situ and two cases of invasive BC, versus the expected 0.9 and four cases respectively. They found no increased risk of invasive BC. Whilst those who have a true negative BRCA1/2 predictive test result may not be at increased risk of developing BC (77), those whose family mutation search result is inconclusive are still at a potentially high risk of BC (75, 76).

2.9 Risk Perception

No research studies to date have explored risk perception solely for younger women who have undergone BPM. However Hoskins et al. (40) found young women who were deciding about BPM reported very high levels of risk perception to the extent they believed it was certain they would develop BC. Other research has shown that women undergoing BPM often overestimate their risk of developing BC. Bebbington-Hatcher et al. (54) reported in 143 women at high risk that those who underwent a BPM had a significantly higher perception of their BC risk (94%) compared to those who opted for screening (74%). Heiniger et al. (71) found that risk perception was higher prior to surgery for those who had a BPM compared with age and risk matched controls. This study, however, is limited by small sample size (n=17). In women who had undergone BPM Metcalfe et al. (78) compared women’s perception of developing BC to actual computed estimates of their risk based on self-reported family history. They found that women estimated their lifetime risk of developing BC to be 76% compared to computer generated estimates of 59% for BRCA carriers and 17% for those with only a family history of BC. Women may not only overestimate their risk of developing BC before a BPM but also after undergoing their BPM (67).

2.10 Psychological wellbeing, anxiety and cancer related worry

Psychological wellbeing, anxiety and cancer related worry have not been investigated specifically in younger women. Research suggests that many women reported anxiety prior to a BPM, and this anxiety focused on cancer related worry about whether they would develop
BC. In a qualitative study (n=20) some women’s cancer related worry was so extreme the researcher described they were “unable to plan for the future because they believed they didn’t have one.” (63). This study reported that distress and anxiety experienced before surgery decreased after a BPM. This was attributed mostly to women no longer living with the fear of a BC diagnosis (63). Moreover, this finding was shown to be consistent over time (6-12 months) (64, 73). Whilst anxiety can decrease after a BPM, some research has suggested it may be higher in women who undergo BPM compared to women who opt for regular screening (64, 71, 78). However, this finding has been challenged. Bebbington Hatcher et al. (54) found women who opted for regular screening had greater anxiety (78%) than those who opted for a BPM (56%). Those who declined BPM believed that screening could help detect BC early. However, for those who had a BPM they believed it was inevitable they would develop BC (63). In women who chose to undergo a BPM, poor cosmetic outcomes, complications from surgery and/or reconstruction were associated with greater psychological distress (8, 63). Some women believed they were personally responsible for complications and they attributed this to their own failures; these women especially need more support (65). Even though most women suffered some degree of pain and discomfort after surgery the majority still thought it was the right decision (63). Bresser et al. (64) found support for this indicating that women who undergo BPM and experience no complications from surgery report minimal levels of psychological and emotional distress.

Whilst it is routine for women undergoing genetic testing to first be seen by a genetic counsellor (35, 79), psychological consultation before any woman at risk undergoes a BPM is not standard practice. Patenaude et al. (80) explored the use of psychological consultation in 108 women who were considering BPM and CPM. More than 50% of the women who had surgery felt a psychological consultation before surgery would have been helpful, and two thirds thought a consultation post-surgery was also needed. Of the 37 women still considering BPM or CPM all (100%) believed a consultation would assist them in decision making and preparing for surgery. This is important given the struggles and issues women face with respect to decision making, risk perception, body image, sexuality and psychological wellbeing. The majority of women do not regret their decision to undergo BPM, however, do report that making decisions on undergoing surgery to reduce their risk of BC was stressful and emotional. Women reported that would have liked to have been offered some additional support to assist them in making these decisions, and processing the outcomes of BPM (40, 63, 80).
2.11 **Sexuality and body image**

Sexuality and body image have not been exclusively researched for younger women undergoing a BPM. However, research irrespective of age suggests BPM can impact on women’s self-esteem, body image, and sexuality (8, 73). Maintaining femininity is an important factor for women who try to maintain this after surgery (65). A woman’s perception of her body can change as a result of BPM, and this can contribute to women feeling less feminine. In particular, some women report their reconstructed breasts look and feel unnatural which makes them feel less attractive (8, 73, 81). They report their breasts feel different, hard, and cold and they do not like to look at their naked reflection in the mirror (72). This can have a negative impact on a woman’s sexuality; with the lack of sensation in the reconstructed breasts particularly impacting on women’s’ sex lives (8). Some women described sexual problems as a couple. However, when questioned further they reported that the problem remained with themselves and their self-perception, rather than a problem with their husband/partner (65). One year post-surgery women still reported being less sexually active and having low sexual pleasure (63). This has been found to increase psychological and emotional distress (8, 63). Other research suggests that the negative beliefs women hold about their body image are attributed to outcomes including poor reconstruction and surgical complications. One year following BPM women still report problems with body image including being self-conscious (73). Only two studies report women’s negative concerns relating to surgical scars (72, 81). However, it is unclear from other studies whether this was an important concern for women or whether they were not asked questions about surgical scars.

Despite the negative feelings toward body image felt by some, others have focused on the positives. Lloyd et al. (65) reported women felt visible improvements to their breasts, such as a change in breast shape and size which reflected their ideal shape and size. Many women spoke about their breasts in a positive manner such that they were firmer and some felt they had a more youthful figure, meaning they could wear sexier clothing (72). Women who disliked their breasts before their BPM reported more positive feelings towards their reconstructed breasts compared to those who liked their breasts pre-BPM surgery (65).

2.12 **Information received**

Information based on the experiences of others is necessary to support all women who choose to undergo a BPM to make fully informed treatment decisions, both from a physical and psychological perspective (54). Extensive literature supports this (63, 81, 82), with women undergoing BPM reporting that they want more information (8, 72, 81). Some women have
suggested that had they been given enough information they would have reconsidered their decision to undergo a BPM (67). It appears that whilst women are aware of the potential sequelae they feel they are not informed about the reality of what post-BPM may physically feel like or the emotional impact of the surgery. In addition, women have reported that they wanted more information about scars, pain, numbness and implants (83).

Another study found women felt they were not knowledgeable enough to determine what questions they should ask of health professionals (63). Women struggled to understand information about their risk of developing BC, reporting that they felt emotionally blocked (83). Hoskins et al. (38) found that BRCA positive young women (<25 years) wanted more clarity and information surrounding screening and prevention. They also requested ongoing contact with health professionals to better inform their decision making (38). Similarly young adult daughters (aged 21-25 years) whose mothers were BRCA1/2 positive felt they did not have adequate information regarding their own genetic susceptibility to BC. They felt their knowledge had gaps and misconceptions and one third of these women reported high cancer related distress (37). There are a number of misconceptions regarding BPM surgery. For example, Payne et al. (67) reported findings from a quantitative study of women’s regrets after a BPM; they found that women feared that reconstructive surgery would impair cancer detection.

Asking women what they wish they had known before their BPM is uncommon, however, Rolnick et al. (81) carried out a retrospective study asking this particular question. A strong theme emerged in their findings, with women reporting that they wished more information had been provided to their partners. These women felt as though they were relatively well prepared for their surgery, however, their significant others were not. Photographs of BPM reconstruction were something women would have liked to have seen more of before surgery (81). In another study one woman expressed shock at the complete loss of feeling to her reconstructed breasts as she believed this possibility had not been discussed with her prior to the procedure (65).

2.13 Younger women

Many studies do not report age data in subgroups. Of the 35 papers included in this review only 12 included sub age groups. The sub groups reported were never the same between papers and identifying actual numbers of younger women was difficult. In 12 studies (n=3,540) 25% were under 45 years. In six of these studies (n=1,265), only 18% were under 30 years. Younger
women may be at an age where their risk of BC is low (75, 84), (Figure 5), however, research suggests that increasing numbers of younger women are still undergoing BPM (33, 36). These women are currently underrepresented in BPM research. Due to the differing life stages, roles and experiences it would be highly useful for research to explore the decision making and psychological impact of both younger and older women who are undergoing BPM. This in turn could help to provide data to assist women to make informed decisions about undergoing such treatment to reduce their BC risk.

Only four studies have focused specifically on younger women aged less than 39 years with a family history of BC (37, 38, 40, 42). Two of these studies focused on decision making (40, 42) and two on informational needs (37, 40). All four studies only included women who had a positive BRCA mutation. Women with a confirmed BRCA gene mutation are only a small proportion of women at increased risk of developing BC (75). All four papers highlighted the importance of understanding the unique experiences of younger women who are considering BPM. Based on the definition of age provided by Erikson and these studies on younger women, it is reasonable to conclude that women under 40 years be considered ‘younger women’.

![Figure 5. Shows the absolute age based risk of developing BC for BRCA1/2 positive and inconclusive and the general population](image)

2.14 Limitations of published research

Previous research examining BPM may not adequately represent women’s experiences due to limitations in design and method (8). Research in the area of BPM has mostly been quantitative and the general consensus is that women are satisfied with the outcomes of BPM (64, 73, 81). However, qualitative studies have found the situation is more complex and many women are not satisfied or happy with the physical changes caused by surgery (67, 72, 85). For example
one study (8) found 70% of women who responded with negative comments to open ended questions actually reported satisfaction when asked the same question in a closed format. In a quantitative study Metcalfe et al. (86) found that 97% of their sample (n=60) were overall satisfied with their surgery, however, they found that younger women <50 years old reported less satisfaction. These findings suggest women’s true experiences are not being captured by quantitative methods. Of the qualitative studies only one was a prospective study (63), finding that women want more information prior to surgery and need further emotional support. The lack of prospective studies is problematic as recall bias is a known limitation of retrospective studies. Lloyd et al. (65) expressed a limitation of their study was not including those who were waiting for surgery or in the decision making phase of considering a BPM.

In addition, the lack of information that women receive before their surgery suggests women are not well informed prior to making a decision about BPM (63, 81, 82). Moreover, the age of the women in the samples does not reflect the experiences of younger women (63-65) and previous studies often do not report age sub groups to better make comparisons between younger and older women. Many studies are not adequately powered and have small sample sizes (38, 42, 65, 67) limiting generalisability.

2.15 Conclusion/ Justification for further research
BPM reduces the relative risk of developing BC by over 90% for those with a strong family history of the disease, however, the surgery is not without issues or complications. Decisions to undergo a BPM are often related to family commitments including being around for children and parents. A strong influencer of BPM timing is the age in which a family member was diagnosed with BC or died from BC. Limitations in genetic testing mean many women are undergoing a BPM in the absence of a positive mutation being found. Those with a negative result may not be at increased risk but those who are unable to be tested or have an inconclusive result are still at potentially high risk of developing BC. Many women overestimate their risk of developing BC and particularly young women report very high levels of risk perception. Psychological wellbeing can be negatively affected by BPM. Anxiety focused on cancer related worry is often high however decreases after BPM. However previous research shows conflicting and contradictory findings as to whether anxiety is higher in women who opt for BPM compared with those who have screening. Perception of body image can change after a BPM and can impact negatively on a woman’s sex life. Women report their breasts look or feel unnatural and they are hard and cold. However some women report positives such as ideal shape and size. Research strongly suggests women want more information. They understand
the practicalities of the surgery but not how they will feel emotionally post-surgery. Younger women in particular have reported they want and need more information. Psychological consultation before and after surgery appears helpful in preparing women for BPM and assisting them in dealing emotionally with the outcomes.

There are limitations to previous research methods and designs in BPM research, notably the lack of qualitative studies. Research does not often report age in sub group and many studies lack power due to small sample size. The studies in this review estimate small percentages of women under 39 years are being included in research despite uptake of BPM being higher in younger women. The literature to date has included some younger women but it has not focused specifically on younger women’s experiences of BPM nor have their informational and other needs been investigated. Younger women have different priorities, roles and responsibilities and may have different psychological and emotional needs to that of older women. Despite women in their twenties and early thirties not yet being at a significant risk of developing BC they are still undergoing BPM. Research focusing specifically on this group of women in the literature will address any age-related concerns, provide other younger women with more information and allow for greater awareness and support from professionals.

We suggest future research could focus on women younger than 35 years, targeting both those women with a known germline mutation and those who have a strong family history of BC. Research should utilise qualitative and quantitative components, ideally in a prospective study to control for the limitation of recall bias.
Chapter 3. Methodology and methods

3.1 Chapter Overview

This chapter describes the research methodology and methods used for the qualitative component of this study. The chapter begins by explaining the theoretical framework underpinning the research. This is followed by researcher reflexivity, recruitment processes, including the various Human Research Ethics Committee (HREC) approvals, data collection measures and analysis and participant selection. A detailed description of the data management, confidentially and communication, and how this was handled throughout the recruitment and storage of data can be found in Appendix 7.

3.2 Methodology

3.2.1 Theoretical framework

After careful consideration and review of the literature Interpretative Phenomenological Analysis (IPA) was deemed the most appropriate theoretical framework to guide the qualitative element of this study (87). IPA was chosen in comparison to other theoretical frameworks as the aims of this study were not to build theories from data (grounded theory), understand cultures (ethnography) or analyse linguistic expression (discourse analysis). There are small numbers of women undergoing BPM in Western Australia (in Australia wide it is estimated that approximately 21% of high risk women undergo BPM). Therefore, this study aimed to recruit widely, including across Australia and New Zealand (NZ); and as such, any observational methodological approach would not have been viable. The aim was to hear women’s experiences and it was not necessary to observe participants in their surroundings or understand their actions and daily practices. IPA is widely used in psychology and healthcare research (88) and it has been used to understand the experiences of those at high risk of developing BC (89).

Jonathan Smith developed IPA. The epistemological stance proposes that through interpretation IPA enables researchers to explore individuals’ ideographic experiences (88). In brief, the theoretical roots of IPA are in phenomenology and symbolic interactionism. Phenomenology explores how participants make sense of and understand their experiences. Phenomenology delivers individuals’ own descriptions and accounts of their lived experience, and an interpretation of the meaning of the experience for the individual (90). Symbolic interactionism, was influenced by phenomenology in an era where positive psychology was being rejected (87). Symbolic interactionism theorists believe that it is in fact the meaning of
events that should be of prime importance; more specifically the meaning ascribed to events. This meaning derives through a process of interpretation.

IPA follows the premise of identifying the experience, describing it and then understanding it. There are three guiding principles to IPA that align with the aims of this research: 1. IPA focuses on the lived experience and the meaning of that experience; 2. it aims to bracket knowledge by not having any prior presumptions influencing data collection; and 3. it views research as a reflective process by acknowledging the researchers influence on data collection and interpretation (91). For example, regardless of the use of open-ended questions participant’s response will be influenced by the question topic (i.e. if you ask about body image they will respond with their experience regarding body image). IPA acknowledges that the reflectivity between the researcher and participant is an important part of the research process. The nature of phenomenological traditions is to put aside or bracket preconceptions or presumptions the researcher may have, so the true experience is revealed (92).

The essential component in IPA is not the object but what the object means to a person (93). In the case of women with a family history of BC, it is not their breasts, but what their breasts mean to them that is important. IPA through its roots in phenomenology allows for accounts of two people who have the same ‘condition’ to categorise them differently based on their own perception, interpretation and meaning (87). For example, two women who have both undergone BPM may have different perceptions and accounts of doing so. IPA is appropriate for exploring novel issues because it holds no prior preconceptions (i.e. hypotheses) (89). Due to the lack of research in this area it was important to gain an understanding of the experiences of younger women undergoing BPM without any prior theoretical presumptions. Using IPA as a theoretical guide for this research allowed for an in-depth perspective of what it means to a woman to be at high risk of developing BC and exploring undergoing BPM surgery as a preventative measure (87).

3.3 Research team and reflexivity

Reflexivity in qualitative research is a process of reflection on the researcher’s influence of the research context. Researcher characteristics and prior knowledge are taken into account in the data collection and data analysis of the research (94).

The researcher (the PhD student) who is an experienced interviewer conducted all of the interviews with participants. Prior to the interview there had been no relationship between the interviewer and the interviewees. The researcher is female and her sole occupation at the time
of the interviews was a student. Her qualifications are a Bachelor of Arts (honours). The participants did not know any personal details about the researchers.

The interviewer has a personal history of BC in her family. From the theoretical standpoint of IPA and the intention to understand the participants experience from their perspective, it was decided not to share the researcher’s own personal background on the topic with participants. The researcher decided not to share her personal narrative to ensure that the interviewee responses were not affected by the researcher’s similarities to their personal situation.

The researcher has not undergone BPM, nor is currently considering the procedure for herself. Her opinions on the procedure are neutral; that it is a personal decision made by each individual. The researcher has a large amount of academic knowledge on the research topic. This can be useful, however, also requires constant reflection on values, assumptions and opinions. The researcher engaged in bracketing (laying aside any preconceptions or personal experiences) throughout the interviewers and analysing of the data.

In qualitative research, bracketing, which has roots in phenomenology, is a method used to set aside any preconceptions, personal experiences, assumptions, biases or theories the researcher may hold, in an attempt to ensure the research findings are not tainted by this prior knowledge or experience (95). Researchers engage in bracketing during data analysis, whereby a process of deep reflection and awareness of one’s own preconceptions is undertaken, to ensure the themes found reveal participants lived experience and not researcher’s preconceptions. The concepts and methods of bracketing have a lack of uniformity and have been described as ambiguous; as such some have argued that it is not possible for one to set aside preconceptions (95), however, for this research, the researcher felt it was important to engage in bracketing.

Due to the researcher’s personal history and knowledge of this topic it was decided that a second researcher with no prior knowledge or personal history of the topic would be sought to analyse the data. Dr Sarah Hardcastle assisted in analysing the data and had no prior knowledge on the topic of BPM. Dr Hardcastle has extensive interviewing experience and is an expert in qualitative research. Her background is in the psychology of health behaviour change, particularly in relation to physical activity. Her occupation at the time of analysing the data was a Senior Research Fellow within the Department of Psychology at Curtin University.
3.4 Method

3.4.1 Design

This study used a retrospective mixed methodology design, encompassing both qualitative and quantitative (discussed in Chapter Nine) elements. Previous research examining BPM may not adequately represent women’s experiences due to limitations in design and method (8). Research in the area of BPM has mostly been quantitative and the general consensus from published studies is that women are satisfied with the outcomes of BPM (64, 73, 81). However, qualitative studies have found that the situation is more complex and many women are not satisfied, or happy, with the physical changes caused by surgery (67, 72, 85). For example, one study (8) found 70% of women who responded with negative comments to open-ended questions actually reported satisfaction when asked the same question in a closed format. In a quantitative study Metcalfe et al. (86) found that 97% of their sample (n=60) were overall satisfied with their surgery, however, they found younger women (<50 years old) reported less satisfaction. These findings suggest women’s experiences may not be entirely captured by quantitative methods. Of the qualitative studies only one was a prospective study (63), which found that women want more information prior to surgery and need further emotional support. The lack of prospective studies is problematic as recall bias is a known limitation of retrospective studies.

3.4.2 Participants and recruitment

Ethical approval was sought from Royal Perth Hospital (REF:15-095 (RPH)), St John Of God Hospital, Subiaco (REF:866 (SJOG)) and The University of Western Australia (UWA) (REF: RA/4/1/7836). This study recruited two groups of high risk young women (aged <35 years). Group one included women who had undergone BPM, and group two included women who were considering a BPM and were currently seeking medical advice to inform their decision. Women from both Australia and NZ were recruited. Recruitment to the study was through organisations that support women at high risk of developing BC, including KConFab, and Register4. Register 4 is an Australian online database. They currently have 41,514 members, 97% are female. Their participants’ age ranges from 18-89 years old. Members do not have to have had cancer, anyone can join as a member. To date Register4 invites current members to “invite a friend” through their quarterly ENews, they also promote Register4 at events and previously BreastScreen mail outs have invited participants to join. KConFab recruit only high risk families, those with a strong family history of breast or ovarian cancer (about 10% of the general population). They currently have 1,796 families enrolled in kConFab, this comprises
of 13,906 individuals for which they have a blood sample from and 68% are female. Women were also recruited online using a Facebook post to support groups. In Western Australia (WA) participants were recruited through Genetic Services WA, the high risk breast cancer clinic at Fiona Stanley Hospital (FSH), and a surgical clinic at SJOG Subiaco who had women undergoing or seeking advice on BPM. As women in regional areas must come to Perth to see a surgeon or attend the high risk breast clinic it was assumed that women in these areas would be represented in this study; and could potentially include Aboriginal and Torres Strait Islander women and culturally and linguistically diverse women.

3.4.3 Inclusion criteria

3.4.3.1 Risk of BC

This study used the National Breast and Ovarian Cancer Centre classification for women who are at high risk of developing BC due to a family history of the disease (12). That is:

- Women who have a genetic mutation associated with an inherited predisposition to breast or ovarian cancer (i.e. positive BRCA1/2 result or have a family member with a positive result).

OR

- Women who have at least two first degree (parent, sibling, children) or second degree relatives (grandparent, aunt, uncle, niece, nephew, cousin) on the same side of the family diagnosed with breast or ovarian cancer plus one or more of the following on the same side of the family:
  - Other family members with breast or ovarian cancer
  - Breast and ovarian cancer in the same woman
  - BC before age 40 years
  - Bilateral BC
  - BC in a male family member
  - Jewish ancestry

OR

- One first degree or second degree relative diagnosed with BC before the age of 45 years plus another first or second degree relative diagnosed with a sarcoma before age 45 years
3.4.3.2 BPM women

Women who had a family history of BC (defined by the above classification), were under 35 years and had undergone a BPM or had their BPM when under the age of 35 years (up to age 40 years at time of recruitment) were included in the study. Women needed to be more than eight weeks post-surgery. It was unknown for how long women who had undergone BPM deliberated before making their decision to undergo BPM.

3.4.3.3 Considering group

Women who had a family history of BC (defined by the above classification), were under 35 years of age and were considering a BPM were recruited if they had sought any information about BPM and/or had seen a medical practitioner regarding a BPM. These women self-reported seeking information from health professionals about their high risk of BC and exploring BPM as a management option (e.g. geneticist, breast physician, surgeon, high risk clinic). None of the women in the considering group had considered BPM and chosen not to pursue this option at the time of the interview. The women in the considering group were all at a similar stage of decision making, they were actively exploring undertaking BPM as a risk management option and seeking information to inform their decision.

3.4.4 Exclusion criteria

Women were excluded from the comparison group if they were aged 35 years and over and from the BPM group if they underwent their BPM when aged 35 years or over. If they had a previous diagnosis of BC, a contralateral prophylactic mastectomy, were receiving treatment for other cancers and/or had any other significant co-morbidities they were excluded. If the women were not fluent in written and spoken English they were also excluded.

3.4.5 Participant Selection

Participants were selected for three main reasons. Previous research with women at high risk of developing BC undergoing or considering BPM has solely (if at all) included women who are; 1. Considering BPM; 2. Women who are younger than 35 years old; and 3. Women with a strong family history of BC without an identified genetic mutation. The importance of the inclusion of these populations is detailed below.

Lloyd et al. (65) reported a limitation of their study to be the lack of including those who were waiting for surgery or in the decision-making phase of considering a BPM. Hoskins et al. (39) included women who had already undergone BPM, as well as those who planned to, and found many young women underwent BPM as an alternative to living with the fear of developing
BC; however, the two groups were not compared. There is a lack of prospective studies reported in the BPM literature (43) and it is possible that retrospective study findings could be flawed due to recall bias. Based on these limitations, for the current study a group consisting of women at comparable high risk of developing BC who were considering a BPM are included to explore the influences to considering BPM.

The age of the women in prior samples does not reflect the experiences of younger women (63-65). Previous studies have often not reported age subgroups to better make comparisons between younger and older women. Many studies are also not adequately powered and have small sample sizes (38, 42, 65, 67) limiting generalisability. Of the 35 papers included in the literature review (Chapter Two) only 12 included age as a subgroup. The age subgroups reported were never the same between papers and identifying actual numbers of younger women was difficult. In 12 studies (n=3,540) 25% were under 45 years of age. In six of these studies (n=1,265), only 18% were aged under 30 years. Younger women may be at an age where their risk of BC is low (75, 84), however, research suggests that increasing numbers of younger women are undergoing BPM (33, 36). Younger women are underrepresented in BPM research. Due to the differing life stages, roles and experiences, it is important for research to explore the decision-making and psychological impact on younger women undergoing BPM.

This data would assist women to make informed decisions about undergoing such treatment to reduce their BC risk. The population of younger women and their unique development needs, have not been taken into full consideration in BPM research (41).

Limitations in genetic testing (i.e. mutation testing in unaffected individuals is difficult to interpret and often not available in the public health system) mean younger women are undergoing BPM in the absence of a positive mutation (33, 68), however, previous studies have only included those with positive BRCA1/2 mutations (39, 40, 42). It is important to understand whether women’s experiences differ if they have or do not have a confirmed genetic mutation. Therefore, the present study included both women who have a BRCA1/2 mutation and those with a strong family history of BC (defined by the National Breast and Ovarian Cancer Centre) (12).

3.5 Procedure
Recruitment took place between November 2015 and June 2016. Online and social media were the main sources of recruitment (Table 1). The information about the study and the researchers contact details (email and phone) were posted online (see Appendix 8 for social media post)
for potential participants to flag their interest. For those recruited through Genetic Services WA, surgical clinics and high risk clinics in WA, kConFab and Register4, participant contact details were given to the researcher if they were interested in participating. Their BC family history was validated by self-report (except for those recruited through kConFab, who provided this information) prior to being invited to participate in the study.

All eligible women were formally invited to participate by email. The email included a Participant Information Form (PIF) and Participant Consent Form (PCF) (Appendices 9 and 10 respectively). Those who did not reply to the first email were sent a reminder email two weeks later to follow up on their participation. Upon return of the PCF, participants were phoned and a suitable time was made to conduct the interview. Following the interview women were asked to complete the online questionnaire and were sent the link and a unique code via email. An email thanking participants for their participation was emailed to women after completing the interview and online questionnaire. Once the data analysis was completed, participants were sent a summary of the findings.

Table 1. Recruitment Source

<table>
<thead>
<tr>
<th>Recruitment Source</th>
<th>Total (n=46)</th>
<th>BPM (n=26)</th>
<th>Considering (n=20)</th>
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<tbody>
<tr>
<td>Register4</td>
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<td>7</td>
<td>8</td>
</tr>
<tr>
<td>kConFab research consortium</td>
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<td>5</td>
<td>0</td>
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<tr>
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</tr>
<tr>
<td>Genetic Services WA</td>
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</tr>
</tbody>
</table>

3.6 Data Collection Measures

3.6.1 Semi structured interviews

Consistent with IPA, and for participants to share their story the PhD student conducted semi-structured interviews with participants. Both face-to-face (n=2) and telephone interviews (n=44) were conducted, and at a time most convenient to the participants. This study was undertaken in Perth (where the researcher resides) and throughout Australia and NZ. It was not viable to travel interstate or internationally to interview participants face-to-face, however, it was acknowledged that some participants residing in Perth may wish to attend an interview in person. Additionally, all participants (irrespective of location) were given the choice of either telephone interview or face-to-face interview to encourage them to share their experiences in a
way they felt most comfortable. It was not necessary to understand facial cues or hand gestures or any other non-verbal form of communication, in which case telephone interviews were an acceptable method of data collection. Studies suggest little difference between face-to-face and telephone interviews (96-98).

To ensure confidentiality all face-to-face interviews took place in a private room at one of two sites; either The School of Surgery, UWA at the QE11 Medical Centre or The School of Surgery, UWA at the Harry Perkins Institute of Medical Research South building on the FSH site. Participants were given the option to come to one of the above sites (which were identified in the PIF). If they wished their interview be via telephone the researcher conducted the interviews in the same private interview rooms used for face-to-face interviews. The interviews were guided by a schedule of open-ended questions (Appendices 11 and 12), formulated from the findings of previous research. The schedule included questions about information received, risk perception, decision-making, cancer related worry, body image, sexuality and family. Interviews with the BPM group also included questions concerning their BPM and reconstruction surgery. Following the path of semi-structured interviews bound by IPA, the interview followed the participants experience as they wished to share it and the question schedule was a guide. Occasional prompts were used to encourage participants to elaborate. The interviews lasted between 30-60 minutes and were audio recorded and transcribed verbatim.

3.6.2 Online questionnaire

Please see Chapter Nine for a detailed discussion of the quantitative methodology. This was an online questionnaire consisting of six sections, including demographics and five validated measures.

3.7 Data Analysis

Data were analysed independently by two researchers (one was the PhD student), consistent with IPA and involving five steps. Step one included reading each transcript in its entirety to familiarise with the account as a whole. Comments were made in the left margins of the transcript (exploratory coding) (87). Such comments were content related, linguistic or conceptual. In step two transcripts were read again and coding conducted. This involved transforming initial notes into concise phrases (coding, in the right margin) capturing meaning. Each code referred to a different idea, for example, confidence, relationship, support (87). Some codes clustered together to form an overarching theme. Step three involved further
interpretation whereby coding between transcripts was connected and made sense of (99). Step four involved looking for repeating patterns across cases and ensuring important dimensions were not missed. Similarities and differences were identified to connect participants experiences and finalise themes (91, 99). Step five involved both researchers meeting to discuss and compare themes identified independently and the evidence (quotes) for each theme. For greater clarity of interpretation they agreed that one of the researchers (the PhD student) would conduct second interviews with several (n=3) participants to gain further understanding. Following this both researchers again discussed and agreed the extra data was sufficient. Cross-checking for overlap and consensus was reached (91).

This study offers a credible interpretation of the data by continuing data collection until data saturation, having two researchers independently analysing the data and reaching theme consensus (100). Data saturation is defined as the point where no new relevant knowledge is being obtained (101). The researcher identified data saturation had been met when interviews ceased identifying new data relevant to the aims of the study. Consistent with IPA researchers using inductive inference in the interpretation of data, there were no predetermined themes. Having two researchers independently coding data contributed to rigorous interpretation, credibility through reflection upon, and exploration of alternative explanations and interpretations of the data. Collecting further data enabled a greater understanding of participants’ perceptions and experiences, thus enhancing the credibility and rigour of our interpretations (92). As with all qualitative research this interpretation is one interpretation and other interpretations are possible.
Chapter 4. Influences on decision-making for young women undergoing bilateral prophylactic mastectomy

4.1 Chapter Overview

This chapter presents a published paper discussing the influences on decision-making for younger women undergoing a BPM. Permission to include this publication in this thesis can be found in Appendix 13 and a copy of the front page of this publication in Appendix 14.


4.2 Abstract

Objective: The objective of this study was to explore the influences on decision-making of younger women (<35) undergoing or considering bilateral prophylactic mastectomy (BPM).

Methods: Qualitative interviews guided by interpretative phenomenological analysis (IPA) were conducted with forty-six women who had a strong family history of breast cancer (BC) who had either undergone (n=26) or were considering (n=20) BPM. Participants were recruited from Australia and New Zealand (NZ) via hospitals, a genetics clinic, a research cohort, a registry and online.

Results: Four themes underpinning the influences on decision-making were identified: fear and anxiety, children, personal experiences with BC, health professional’s influence.

Conclusions: The decision to undergo BPM for younger women (<35) was multifaceted, however, it appeared that fear and anxiety were the main influence. Younger women appear more anxious than previous research with older women. There appears to be few differences between those with confirmed BRCA1/2 mutations and those with no known mutation and this is clinically significant.

Practice Implications: These findings have important practice implications, particularly improving communication of risk statistics, especially to those with no known mutation. Health professionals need to take into account the way younger women perceive information given to them when discussing risk.
4.3 Introduction

Bilateral prophylactic mastectomy (BPM) is an option for women at high risk of developing breast cancer (BC) (54) reducing the risk by up to 95% (26). The greatest risk reduction occurs if BPM is undertaken before age 40 (47). Uptake of BPM differs worldwide; in Australia and the United States (US), it has been low (21% and 23% respectively) (33, 102). In England and Denmark, uptake is between 40-50% (35, 36). BPM uptake and intention has been associated with younger age (<35 years and <40 years respectively) (35, 36, 46), however, the literature focusing on younger women (<40) and BPM is scarce (43).

Research with older women (>40 years) has found a number of indicators for choosing BPM; including a close family member’s cancer death (63), strong family history of BC (64), desire to live longer for family (65) and heightened BC risk perception (103, 104). Women’s confidence in screening methods may influence their decision to undergo BPM. Lloyd et al. (65) found women expressed concern that if BC developed it would not be detected by screening methods. The initiation of discussion about BPM could influence decision-making (67). Women with regrets about their surgery reported that a health professional(s) initiated discussion of BPM, rather than the woman herself.

Few studies have reported on BPM decision-making in younger women (<40). Findings from these studies are similar to research with older women (>40), such as, not wanting children to experience their mother’s treatment for BC (38) and the possibility of children losing their mother (42). Screening fatigue, encouragement from family, age a relative developed BC, inevitability of a BC diagnosis and fear of developing BC also contribute to BPM decision-making in younger women (<40) (40, 42).

Women in their 20’s and 30’s are underrepresented in the BPM literature (43). Younger adults face new challenges, such as, career choices, exploring relationships, and family planning (49, 50). In comparison, older women (>40) are frequently more settled, in a long-term relationship, have school age or older children, an established career (60), and may be more comfortable with their body image (51). Younger women with a family history of BC are balancing multiple emerging roles and significant life events while making decisions about their increased BC risk (42). Subsequently their decision-making processes may differ to older women’s.

Existing research provides a basis to understanding influences on decision-making for this age group. Further research exploring BPM decision-making to assist specialists and counsellors when dealing with younger women is needed. Existing research has not compared the decision-
making of those who have undergone BPM with those still considering the surgery, which has been reported as a limitation of previous research (65). It is important to explore what influences timing of undergoing BPM for younger women and how this affects them (40) i.e. why some women rush the decision (62) and others wait. These studies have only included women with BRCA1/2 mutations, however, younger women are undergoing BPM in the absence of a known mutation (33, 68). It is important to understand what influences women with a strong family history of BC to choose BPM, and whether their decision-making processes differ to those with a confirmed mutation. Existing research is limited to the US. Women receive different information, genetic services vary by country and research is needed specific to the national setting.

The aim of this study was to explore the influences on decision-making for younger women (<35) living in Australia and NZ at high risk of developing BC who are undergoing or considering BPM.

4.4 Methods

4.4.1 Design

The qualitative design for this study was based on Interpretative Phenomenological Analysis (IPA) (87). IPA allowed in-depth explorations of what contributes to decision-making for younger women undergoing or considering BPM (89).

4.4.2 Participant recruitment

Ethical approval was gained from Royal Perth Hospital (REF:15-095), St John Of God Hospital, Subiaco (REF:866) and The University of Western Australia (REF: RA/4/1/7836). To increase the likelihood of reaching data saturation we recruited widely, including participants from throughout Australia and NZ via five different routes: 1) two Perth hospitals (one public, one private) where women were invited to participate by their specialist; 2) Register4 (a registry for BC research) via written invitation to participate; 3) through kConFab (a national familial cancer research consortium) via written invitation to participate (HREC # 97_27); 4) online via Facebook post to two private groups for those with family histories of BC, where participants contacted the researcher directly, 5) Genetic Services WA where women at follow-up were invited to participate. The guideline recommendations for BPM are the same in Australia and NZ.

Participants were eligible if they had a family history of BC per the National Breast and Ovarian Cancer Centre classification for women who are at high risk of developing BC (12), had
undergone BPM <35 years old or were considering BPM and were <35 years. Women who self-reported seeking information from health professionals (e.g. geneticist, breast physician, surgeon, high risk clinic) about their high risk of BC and exploring BPM as a management option were recruited to the considering group. Women considering BPM were included as a reference group to interpret decision-making prior to undergoing BPM.

Exclusion criteria included a previous diagnosis of BC, insufficient fluency in written/spoken English and older than 40 years old at recruitment. Participants provided written informed consent before the interview.

4.4.3 Data collection
Semi-structured interviews were used to explore influencers to decision-making. Participants were asked questions concerning risk perceptions, decision-making, cancer related worry and psychological well-being. An experienced interviewer (RG) conducted interviews between November 2015 and July 2016. Interviews took place at the researcher’s office, and continued for up to 60 minutes. Interviews were guided by an interview schedule, were digitally audio-recorded and transcribed verbatim. Data collection continued until data saturation was reached (101). Demographic information (including genetic status) was collected from participants by self-report, via an online survey.

4.4.4 Data Analysis
Data were analysed independently by two researchers (RG, SH), consistent with IPA. Transcripts were read and initial coding conducted. Transcripts were read a second time by both researchers and themes identified. Once all transcripts had been read, analysed and themes identified the researcher looked for patterns between participants to connect themes (91). The researchers discussed themes, cross checked for overlap and reached consensus.

As with all qualitative research, our interpretation of the data is subjective and we acknowledge other interpretations are possible. One of the researchers (SH) had no prior knowledge of the literature, which enabled a more open analysis of findings. We offer a credible interpretation of the data by continuing data collection until data saturation, having two researchers independently analysing the data, and by using direct quotes providing thick description allowing reader interpretation of the findings (100).

4.5 Results
Forty-six women participated in the study. Twenty-six had undergone BPM and twenty were considering BPM (Table 2). The mean age of the sample at participation was 30.4 years. Thirty-
six women were BRCA carriers and ten had no known mutation (three had a family member inconclusive and seven were not tested for BRCA). Participants were knowledgeable concerning their genetic status and were quickly able to identify whether they were BRCA1/2 positive, or had not undertaken genetic testing. There were no women from BRCA positive families who were negative for the family mutation. Three women underwent BPM with no known mutation. The women in the BPM group were between one and six years post-surgery. Influences on decision-making were identified by four themes: fear and anxiety, children, personal experiences with BC, and health professionals’ influence. Each quote is followed by pseudonym (used to report participants’ views), age and BPM status (those who had undergone BPM reported as ‘M’ and those considering BPM as ‘C’).

Table 2. Demographics

<table>
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<th>Total n=46</th>
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<th>Considering n=20</th>
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<td>29.5</td>
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4.5.1 Fear and anxiety

For many women who had undergone BPM it appeared heightened risk perception influenced their decision to undergo BPM. They often felt developing BC was inevitable: “I thought there’s no way I am going to wait for that [BC] to happen to me” (Rebecca, 26, M). They felt they had no choice but to undergo BPM: “I thought my chances are so high and seeing both of them [Mum and Aunt] go through it [BC] I would be crazy not to go through with it [BPM], I felt like I had no choice” (Adele, 28, M). They frequently made bold statements about their anxiety: “it wasn’t the anxiety of getting the boobs off it was the anxiety of living with the boobs” (Shawney, 38, M).

Some women appeared to rush the decision to undergo BPM driven by fear: “I had said already that I was having it [BPM], I didn’t care if they found it [BRCA mutation]” (Shelly, 34, M).

It appeared that individual differences between participants affected how they dealt with uncertainty surrounding their increased risk of BC. When asked about the reason for having surgery at a young age (21 years old) Jessica said: “I think it was my personality, already with the ovarian side I have nightmares and am always worried, I think I wanted to get rid of them [breasts] and stop worrying” (Jessica, 25, M). In comparison, women considering BPM appeared not as driven by fear to undergo surgery: “It’s definitely in the back of your mind because you’re being presented with these facts but it hasn’t changed how I go about my daily life” (Katherine, 28, C).

Some women who underwent BPM thought developing BC meant they would die, and this fear of dying was a main driver to undergo BPM:

“I always felt like there was a time bomb, I was just waiting; a couple of years after my Mum died I found a letter she wrote to herself that said exactly that, she was just waiting to turn 30 and then she was going to die” (Shelly, 34, M).

One woman said “I didn’t want to die from cancer” (Michelle, 33, M) when asked what made her consider BPM. Women driven most by fear appeared to be those with a confirmed BRCA1 mutation.

Those still considering BPM were less certain they would die should they develop BC: “I am less attached to the fact that it is an inevitability, the screening is still good, I do my self-examinations, so maybe I don’t need to [undergo BPM]” (Ashleigh, 32, C).
Many women who had undergone BPM recalled intense anxiety when undergoing screening and this contributed to their decision to undergo BPM: “I remember lying in the MRI thinking ‘I am not doing this every 12 months….I had to wait two weeks for the results…I couldn’t sleep’” (Sian, 34, M). Several women had experienced a cancer scare soon after beginning screening which heightened their anxiety about developing BC. They quickly decided screening was too risky and opted for BPM:

“I went to my first MRI, then I had to have an ultrasound, it was just a cyst but that scared me enough, I don’t want to go through this every 6 months, so that’s what sent me on my way” (Heather, 30, M).

4.5.2 Children

It appeared timing of BPM was important to women in relation to having children. Half of the women still considering BPM reported their reason for waiting was they wanted to have children and the opportunity to breastfeed: “I would like to start a family before I have that sort of surgery….I would love to breast feed” (Olivia, 26, C) and “we don’t know if we want to have more children...so am definitely thinking after I have finished having children and breastfeeding” (Yvette, 34, C).

This differed from those who had undergone BPM. Several women had children and then underwent BPM, however many had not yet had children. Decision-making was similar for all women who had undergone BPM, regardless of whether they had children or were yet to have children. Many believed their children would suffer if they were diagnosed with BC and this could put added pressure on their families. Rachel who already had children said: “I just didn’t want the kids to see me go through anything if I got it [BC]....that was my biggest fear” (Rachel, 32, M). In comparison, Jipsy who did not have children felt:

“I would rather not be able to breastfeed my children than have them grow up without a mother....I didn’t want that much pressure on my family and my husband, I didn’t think it was fair and it worried me, I didn’t want to be anxious my entire life” (Jipsy, 26, M).

Some women initially decided to undergo screening before considering BPM so they could have children and the opportunity to breastfeed, however, changed their mind due to intense anxiety: “I was only 23/24, thinking I had a bit of time, I decided to wait till after kids and then at the start of last year I started getting really anxious, I was doing breast checks in the shower every second day” (Pat, 28, M).
A few women decided to have BPM due to the lack of screening while pregnant and breastfeeding and the delays it meant for their BPM: "I wanted to have children and if I waited then I’ll just be running the risk of not having screening through pregnancy and lactating” (Fiona, 32, M) and "I had this feeling I would have developed BC within the 3 year period of having that third child and breastfeeding... so breastfeed [second baby] for 6 months, get pregnant again, go through a 10 month pregnancy and then breastfeed for another 12 months, that would have put me 2-3 years behind where I was at and I just had an overwhelming sense that I couldn’t wait” (Mary, 31, M).

4.5.3 Personal experiences with breast cancer
For many women, watching a close family member go through BC treatment was sufficient to influence their decision to undergo BPM: “I’d seen my Mum go through treatment and 7 years later she is having terrible physical trouble from the chemo” (Nicola, 28, M). Watching a first degree relative die was recalled as a motivator to undergo BPM: “Seeing what my Mum went through, I wanted to reduce my risk as low as possible” (Jane, 34, M). Whilst experiencing a first degree relative die was a factor in the decision to undergo BPM for some women, it did not appear to be the driving factor. Women who chose to wait in the considering group had equal numbers of first degree relatives die from cancer as those who had BPM: “I lost my mum to BC, she was 52 when she passed away” (Kayla, 33, C).

4.5.4 Health professionals’ influence
Almost a quarter of women who underwent BPM acknowledged health professionals influenced their decision. There were instances where women reported feeling ‘scared’ by their health professional, which influenced their decision to undergo BPM:

“I think at the time I was pregnant and there was a comment made to me that really hit me to the core, he told me that if you want to see your children grow up you should have this surgery” (Jaimee, 32, M).

One participant recalled a clinician telling her further investigation was needed following a routine screen and inferred she had cancer and may need to cancel her honeymoon. Some years later the same clinician influenced her decision to undergo BPM before having her third child:

"we were going to try for a third baby and the breast surgeon told us they had just lost a 31 year old with the BRCA mutation who had a baby, got cancer in the third trimester
and died by the time the baby was one....my husband and I thought we need to do this for the sake of our family and the decision was made there and then" (Angela, 32, M).

The researchers interpreted health professionals exaggerating outcomes to some women after two women recalled: "my private surgeon said to me if I got the one [BC] my Mum had you can’t survive, she said if you get that I can prolong your life but I can’t save your life” (Colleen, 34, M) and “one of the specialists I saw said to me it’s not a matter of if, it’s a matter of when” (Lorraine, 36, M).

On some occasions, women perceived health professionals influenced them not to have BPM:

“I saw the geneticist…I felt he was against having a mastectomy, I didn’t feel like it was unbiased, my sister saw him too and maybe that was one of the factors in her not having the surgery [sister developed BC]” (Charlotte, 34, M).

Several women talked about being told very high risk statistics by health professionals: “when I went to the breast clinic, they said I have an 80% chance of getting BC” (Natasha, 31, C) and “I felt like the risk was 100%.....they didn’t tell me 100% I think they quoted me 87%, but it felt like 100%” (Lorraine, 36, M). There also seemed to be confusion around accurate risk statistics: “I wasn’t guaranteed [to get BC] but anywhere between 45% and 87%” (Nicola, 28, M).

4.6 Discussion

The decision to undergo BPM for younger women (<35) was multifaceted. Participants reported feeling intense fear often believing it was inevitable they would develop BC. This was driven by screening, wanting to be around for their children and personal BC experiences. An important and novel finding was information recalled by participants suggested some health professionals may reinforce these fears. There was a lack of apparent differences between those who had a BRCA1/2 mutation and those with no known mutation but a strong family history of BC. Those who expressed concern about dying appeared to be associated with BRCA1 carriers, however no other differences were found. This is the first study with younger women to include those at high risk of developing BC with and without a known BRCA mutation with both groups experiencing similar feelings. This is a novel and clinically significant finding.

The findings of this study with younger women have some similarities to decision-making in older women (>40); distress from a family member’s cancer diagnosis (63) and desire to live longer for children (65). The findings also support previous research with younger women that
screening, fear of developing BC and heightened risk perceptions (38-40) contribute to BPM decision-making (63, 65). Many women in this study seemed driven by fear and felt they had no choice but to undergo BPM. Our findings support previous research suggesting that strong feelings of fear and inaccurate risk perceptions often result in a rushed decision to undergo BPM (38, 40).

Our findings potentially identify a difference between younger (<35) and older women (>40); younger women appear to be more anxious and have higher perceptions of BC risk. Previous research supports this finding (105, 106). Individual differences (such as personality, a tendency to be more anxious or due to life events, such as caring for young children with their own mortality in mind) and how women cope with uncertainty concerning their risk of developing BC could account for younger women appearing to be more anxious and having higher perceptions of risk. Individual differences could play a role in heightening fear and anxiety and decision-making. While exploring fear and anxiety reduction following BPM was beyond our scope, recent research has found some younger women are still concerned about their risk of developing BC following BPM (107). This is important for decision-making in clinical practice.

Those who underwent BPM recalled greater fear than those still considering surgery and this often influenced the timing of BPM. Those who had BPM were often convinced they would get BC or die from the disease if they did not have BPM immediately. Those who had undergone BPM and those still considering BPM differed with respect to when they wished to have children. Many women in the BPM group choose to have BPM before having children and those in the considering group were choosing to wait for surgery until they had children. Losing a first degree relative to BC was a motivator to undergo BPM for some women, but not all. The loss of first degree relatives in each group was equal. To the knowledge of the researchers this is the first study to compare younger women who underwent BPM to those who are considering the surgery, however, more research is needed to explore the differences between the groups.

It has been suggested that health professionals initiating discussion about BPM influenced older women’s (>40) decision to undergo surgery (67). In our study some participants perceived health professionals influenced their decision to undergo BPM by highlighting worst case scenarios. At times, these comments appeared to evoke fear and prompted participants to undergo BPM. The influence of recalled information from health professionals on decision-
making in this context is a novel finding and has not been reported in the BPM literature. Potential harms of BPM appeared to be rarely discussed, in comparison to the benefits. Our results suggest it is possible clinician biases (for example, personality traits, previous experience, professional opinion) (108) could influence their perception of women’s risk, the benefits and harms of undergoing BPM and subsequent decision-making. Given that there is currently no research on how clinician factors influence BPM decision-making; future research could focus on this issue.

4.6.1 Limitations
Limitations include the possibility of recall or confirmation bias for those who have already undergone BPM. The findings are based on participant’s reports and interpretations. There is the potential for inaccurate recollections and distortions. Sampling bias is another possible limitation with a self-selected sample of women who were willing to share their stories. It is possible that the difference in sample size for those who did not have a confirmed mutation (n=10) and those who did (n=36) could have skewed the findings. However, saturation was apparent in both groups, and differences and similarities between groups were clear. The rigour of this analysis is evidenced by the multiple methods of recruitment from across Australia and NZ resulting in a diverse sample. We reached data saturation and provide salient examples of influences on decision-making for younger women undergoing BPM.

4.6.2 Conclusion
The decision to undergo BPM for younger women (<35) was multifaceted, however, it appeared that fear was the main influence driven by screening, decisions about children and personal experiences of BC. There appeared to be few differences between those with a confirmed BRCA mutation and those with no known mutation; this is a clinically significant finding. Health professionals appeared to influence BPM by contributing to risk perception. Implications for practice include providing improved risk estimates, and the identification of those who need additional support. Additionally, health professionals need to be aware of their influencing over decision-making.

4.6.3 Practice Implications
These findings have important practice implications, particularly communication of improved risk statistics. It is important to identify why a woman wants to undergo BPM. This is key given the fear younger women who undergo BPM recount. The lack of apparent differences between BRCA1/2 carriers and those with no proven mutation is a novel finding backed up by
recent research that suggests both groups may experience similar perceptions of BC risk (107).

Communicating improved and consistent risk statistics in clinical practice is important for patients to make informed decisions about their BC risk management. Those who have inaccurate perceptions of BC risk may be at increased risk of undergoing BPM unnecessarily. Clinicians should assess whether younger women’s perceptions of risk are justified, particularly those with no known mutation. Also, clinicians need to take into account the way younger women perceive information given to them when discussing risk. The development of a BPM protocol could assist clinicians to cover all the benefits and harms of BPM with their patients to aid in informed decision-making and limit clinician biases. Routine psychological consultation for all women considering BPM could assist to ensure women’s understanding of risk and BPM is accurate and realistic (109). These findings could help identify those who need psychological support, particularly those who seem to be rushing the decision to undergo BPM.
Chapter 5. Heightened perception of breast cancer risk in young women at risk of familial breast cancer

5.1 Chapter Overview

This chapter presents a published paper discussing heightened perception of breast cancer risk in young women who are undergoing or considering a BPM. Permission to include this publication in this thesis can be found in Appendix 15 and a copy of the front page of this publication in Appendix 16.


5.2 Abstract

Objective: The objective of this study was to explore the factors that influence perceived personal risk of developing breast cancer (BC) in younger women (<35) who are considering or have undergone bilateral prophylactic mastectomy (BPM).

Methods: Qualitative interviews guided by interpretative phenomenological analysis (IPA) were conducted with forty-six women who had a strong family history of BC and had either undergone (n=26) or were considering (n=20) BPM. Participants were recruited from Australia and New Zealand via hospitals, a genetics clinic, a research cohort, a registry and online.

Results: Three main themes were identified: information that increases fear of BC and death, underlying anxiety and fear and screening anxiety. A further two themes: relief following surgery and confusion about residual risk following surgery were identified. Younger women (<35) appeared to have heightened and sometimes inaccurate perceptions of their BC risk. They appeared less relieved of anxiety and fear of developing BC by BPM surgery, in comparison to previous research with older women (>40). Those who had undergone BPM seemed more anxious about their risk of developing BC than those who were still considering surgery.

Conclusions: This research has important implications for practice, particularly improving communication of accurate risk statistics. Future research should examine why some women interpret information differently and explore the benefits of psychological consultation for very anxious women.
5.3 Introduction

A woman’s lifetime risk of developing breast cancer (BC) may be doubled if she has a first degree relative diagnosed with a BC (9). If a woman has a known mutation in one of the most common cancer pre-disposition genes BRCA1 or BRCA2, her BC risk to age 70 is approximately 60% (BRCA1) and 55% (BRCA2) (110). Some women choose risk-reducing surgery to prevent BC, rather than relying on early detection through surveillance.

Bilateral prophylactic mastectomy (BPM) is a surgical option for those at high risk of developing BC that can reduce a woman’s risk by up to 95% (26). Uptake of BPM differs worldwide and has reportedly been as low as 21% and as high as 50% (33, 35, 36, 102). Undertaking BPM before age 40 has the greatest benefit in risk reduction (47) and it has been suggested that younger women have a higher intention to undergo BPM (46). However, there is a dearth of literature focusing on younger women (<40) in relation to BPM (43).

The way women perceive their risk of developing BC could have a strong influence on the decision to undergo BPM. Many women overestimate their risk of developing BC (111, 112) and their fear of this risk is often a deciding factor to undergo BPM (54, 62, 103). Previous research with women about the age of 40 at high risk of developing BC has found that they often overestimate their risk of developing BC (54, 71, 78, 103) and this decreases following BPM (48, 73, 113). However, one study suggested women (>40) may continue to overestimate their risk following BPM (67). This has not been further investigated.

Only one study has investigated risk perception specifically in younger women (<36) at high risk of developing BC but not necessarily undergoing BPM (39). They found visits to health professionals increased participants’ risk perception because it was a constant reminder of their high risk. Women felt their risk perception was heightened when considering the adverse effects a diagnosis of BC could have on their children (39). Communication of risk information and how women assimilated this differed for individuals. Those who understood the genetic information they were given by genetic counsellors or physicians found the experience less stressful, in comparison to those who did not understand the information. Hoskins et al. (39) concluded that younger (<36) BRCA positive women’s perception of risk differed to that of older women. Childrearing was a major consideration in decision-making and this contributed to heightened risk perception. Many young women were burdened by the decision to have BPM before or after having children.
Hoskins et al’s. (39) study provides a basis for understanding perceived risk for younger women (<36). More research, however, is needed to explore further factors influencing perception of risk in younger women undergoing BPM. Alongside making decisions about their risk of developing BC (42) younger women (<40) are often facing multiple responsibilities and life events (49), such as getting married or having children (50). They may feel pressured to make these decisions sooner than they would have, had they not been at high risk of developing BC (53). As such they may have a different perception of risk compared to older women (>40).

A BPM is not without physical and emotional complications (48, 72) and it is important to understand whether younger women’s perceptions of risk are justified. Research has shown that women undergoing BPM often overestimate their risk of developing BC in comparison to those who opt for screening (54) and age and risk matched controls (71). No research, however, has investigated the perception of risk in women considering BPM but who are yet to make a definitive decision about the procedure or women who wish to undergo BPM but are delaying the procedure (e.g. women who want to have children before undergoing BPM). Fear or perception of risk can lead to a rushed decision to undergo BPM (62) and it is important to explore how women who are yet to undergo the procedure perceive their risk of developing BC and if this influences their decision to delay surgery. A limitation of previous research was not including women who were considering BPM (65). Also risk perception has not been investigated post-BPM in younger women (<40). It is important to know if younger women understand residual risk following BPM and identify those who suffer from continued concern over BC risk post-procedure.

Existing research on younger women (<36) and risk perception is limited to the United States (39). Globally women may receive different information, and genetic services vary, therefore risk perceptions may differ depending upon the national setting. Younger women are undergoing BPM in the absence of a positive mutation (33, 68), however, the one study (39) investigating risk perception in younger women only included those with a known BRCA1/2 mutation. It is important to understand whether women’s risk perceptions differ if they have or do not have a confirmed genetic mutation.

The aim of this study was to explore the factors that influence how younger women (<35 years) perceive their personal risk of developing BC in relation to BPM and whether these influences differ in women who have undergone BPM compared to those who are still considering BPM.
or choosing to wait for the procedure. A secondary aim was to explore whether risk perception differed between women with a known BRCA1/2 mutation, compared to those without a known BRCA mutation.

5.4 Method

5.4.1 Design
This study was a qualitative design based on Interpretative Phenomenological Analysis (IPA) (87). IPA allows for a thorough examination of what it means to a woman to be living with high risk of developing BC and an exploration of their risk perceptions (89).

5.4.2 Participant recruitment
Ethical approval was sought from The University of Western Australia (REF: RA/4/1/7836), St John Of God Hospital, Subiaco (REF:866) (SJOB) and Royal Perth Hospital (REF:15-095 (RPH)). Participants were recruited from Australia and New Zealand in one of five ways: 1) through Genetic Services of Western Australia where women contacted for follow up were invited to participate; 2) online recruitment via two private Facebook groups, whereby interested participants could contact the researcher directly; 3) through Register4 (an online registry for BC research) via a written invitation to participate; 4) through kConFab (a national familial cancer research consortium (HREC # 97_27) via written invitation to participate; and 5) from two Perth hospitals (one public, one private) where women were invited to participate by their specialist. Participants provided written informed consent before the interview.

Participants were eligible to participate if they had a strong family history of BC as per the National Breast and Ovarian Cancer Centre classification (12) and underwent BPM before 35 years or were <35 years and considering BPM and had sought information about BPM (i.e. from a breast physician, familial cancer clinic, high risk clinic). Women considering BPM were used as a reference group to explore perceptions of risk prior to undergoing BPM as a way to minimise recall bias and to interpret if they thought undergoing BPM would reduce any anxiety or fear they may hold. Exclusion criteria included insufficient fluency in written and spoken English, previous diagnosis of BC, and being >40 years of age at time of recruitment.

5.4.3 Data collection
Semi-structured interviews were utilised to explore factors that influence younger women’s perceived personal risk of developing BC in relation to BPM. Participants were asked questions concerning risk perceptions, cancer-related worry and psychological well-being. Interviews were conducted by the first author, an experienced interviewer. Interviews took place between
November 2015 and July 2016 at the researcher’s office, in person or over the phone, depending on the woman’s preference. Interviews were guided by an interview schedule and were on average 45 minutes long. Interviews were digitally audio-recorded and transcribed verbatim. Data collection continued until data saturation was reached (101).

5.4.4 Data Analysis
Consistent with IPA data were analysed independently by two researchers (RG, SH). Transcripts were read and initial coding conducted. Transcripts were read a second time by both researchers and themes identified. Once all transcripts had been read, analysed and themes identified the researcher’s looked for patterns between participants to connect main themes (91). The researchers discussed themes, cross checked for overlap and reached consensus. IPA recognises the researcher’s influence on the research context, and it was acknowledged that researcher prior knowledge could influence theme development.

5.5 Results
Forty-six women participated in the study. Twenty-six had undergone BPM and twenty were considering BPM (Table 3). The mean age of the sample at participation was 30.4 years (31 years BPM group, 29.5 years considering group). Thirty-six women were BRCA carriers and for ten women BRCA status was unknown (seven were not tested for BRCA and three had a family member who had BRCA testing but a mutation was not identified). There were no women from BRCA positive families who had tested negative. The women in the BPM group were between one and six years post-surgery. Three main themes were identified: information that increases fear of BC and death, underlying anxiety and fear and screening anxiety. Two further themes were identified: relief following surgery and confusion about residual risk following surgery. Pseudonyms are used to report the views of participants. Each quote is followed by pseudonym, age and BPM status. Those who had undergone BPM are reported as ‘M’ and those considering BPM as ‘C’.
Table 3. Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total n=46</th>
<th>BPM n=26 (56.52%)</th>
<th>Considering n=20 (43.48%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age – years (mean)</td>
<td>30.4</td>
<td>31</td>
<td>29.5</td>
</tr>
<tr>
<td>SD</td>
<td>3.55</td>
<td>3.89</td>
<td>2.91</td>
</tr>
<tr>
<td>Minimum</td>
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<td>23</td>
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<td></td>
</tr>
<tr>
<td>Marital Status:</td>
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<td></td>
</tr>
<tr>
<td>Single</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Living with partner</td>
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<td>2</td>
<td>7</td>
</tr>
<tr>
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<td>29</td>
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<td>9</td>
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<tr>
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<td>0</td>
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<tr>
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<td>44</td>
<td>26</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
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<td>2</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>7</td>
<td>2</td>
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<tr>
<td>TAFE/Polytechnic</td>
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<td>2</td>
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<td>3</td>
<td>7</td>
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<tr>
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<td>19</td>
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</tr>
<tr>
<td>New Zealand</td>
<td>11</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Genetic testing:</td>
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<td></td>
<td></td>
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<tr>
<td>BRCA1 positive</td>
<td>21</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>BRCA2 positive</td>
<td>15</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Family member inconclusive</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Have not been tested for</td>
<td>8</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>BRCA</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.5.1 Information that increases fear of BC and death

Some women’s perception of risk appeared to be influenced by examples of worst case scenarios provided to them by surgeons or breast specialists:

“I think at the time I was pregnant and there was a comment made to me that really hit me to the core he [practitioner] told me that in other words if you want to see your children grow up you should have this surgery” (Jaimee, 32, M).

One woman recalled deciding to undergo BPM before she had planned to after her surgeon told her the experiences of another woman in a similar situation:

"we were going to try for a third baby and I was having routine scans which were all fine and the breast surgeon had told us they had just lost a 31 year old woman with the BRCA gene mutation who had gone for a subsequent baby, got a cancer diagnosis in
the third trimester and had passed away by the time the baby was one...I have a husband and two young children and I just thought I don’t even want to risk putting them in that position " (Angela, 32, M).

Health professionals’ comments were not the only source of information inducing fear. One woman described an analogy she read on an online organisation for hereditary breast and ovarian cancer soon after returning home from being diagnosed BRCA2 positive:

“I remember going home and jumping on this website and reading studies like if you knew you had an 80% chance of crashing your car one morning would you even get in the car and it was something like you didn’t know if you were doing to die you didn’t know if you were going to walk away from it completely fine but there was 60-80% (chance) of crashing your car would you still even drive and to that I automatically went well no” (Pat, 28, M).

5.5.2 Underlying anxiety and fear

Prior to their surgery women recalled being extremely anxious about their risk of developing BC: “I just always felt like there was a time bomb....I just grew up knowing it would be me next” (Shelly, 34, M). Some women strongly believed they would develop BC in the future: “when you’ve got this BRCA gene it feels like you’ve constantly got this ticking time bomb....I felt like the risk was 100%” (Lorraine, 36, M).

Individual differences between participants, such as attitude and expectation appeared to influence perceptions of risk and fear. For those who had already undergone BPM, the anxiety they recalled often appeared to be unrelated to actual risk estimates of developing BC: “it was inevitable, it was something that was going to happen” (Joanne, 33, M) and “I was pretty positive that I would get it [BC]...it wasn’t really a choice it was just something I had to do” (Helen, 28,M). In comparison, women still considering BPM felt: “on a day to day basis it probably doesn’t affect my thinking too much” (Olivia, 26, C).

Some women who had no known genetic pre-disposition to BC still believed it was inevitable that they would develop BC and were extremely anxious: “it was always on my mind, I was thinking when am I going to get it” (Colleen, 34, M) and “It’s not if it’s when [attitude towards developing BC]” (Ruby, 26, M).

Losing a close family member appeared to contribute to anxiety in some women who underwent BPM: “I suffered anxiety quite a bit after my mum died and I think part of that was
feeling that it was going to happen to me” (Jade, 23, M). This was also experienced by those who had not yet undergone BPM: “my mother passed away from BC when she was 40” (Meredith, 29, C).

A few women described how their breasts caused them distress: “I hated my boobs back then [before surgery] because of what they were going to be doing to me in the future” (Michelle, 33, M). The anxiety many of these women recalled was intense and had an impact on their lives:

“it was terrifying and I don’t think I realised how much it was weighing on my shoulders until I got the surgery, just all that anxiety just sort of disappeared….I really wanted to get it done because BC was just constantly on my mind” (Jade, 23, M).

A few women who were still considering BPM also displayed heightened anxiousness:

“I want to be able to live my life without thinking I’ve got a wrist watch and I’ve only got until 5 o’clock and I’m gone….before someone sits down and looks me in the face and said you have BC” (Christina, 26, C).

Overall, however, it appeared those still considering BPM were less anxious about the possibility of developing BC, compared to those who had undergone BPM: “I haven’t had any screening for ages so it’s obviously not causing me a lot of anxiety” (Robyn, 34, C) and

“I am becoming less attached to the fact that it is an inevitability now….at one stage I thought you have to have the surgery because it is going to happen but now I am a little bit more well the screening is still good” (Ashleigh, 32, C).

5.5.3 Screening anxiety

The majority of women considering BPM recounted strong feelings of screening anxiety in relation to their regular BC surveillance. The annual or six monthly screening undertaken by participants served as a constant reminder of their BC risk and heightened their risk perception:

“every 6 months I have to have that check-up….and then the doctor said okay you’re clear for 6 months but in 6 months that’s no time at all I sometimes think am I’m leaving it too late….I feel anxious when I think I’ve got an appointment to go and have an ultrasound….I always feel anxious when I go to the hospital because I worry that they are going to find something” (Christina, 26, C).
They appeared particularly anxious around the time leading up to screening and waiting for their results: “every time I am waiting for a result yes [feels anxious], but the rest of the time I kind of try not to think about it” (Amy, 27, C). They often thought an abnormality would be found:

“when I go and have mammograms and ultrasounds I’m absolutely petrified….it’s just lying there going oh god I hope they don’t find something and just being so nervous because you know your risk is greater so that part is really quite scary” (Shannel, 30, C).

Some of those who had already undergone surgery recalled experiencing screening anxiety prior to their surgery: “one thing I was looking forward to about having the surgery is to have that stress reduced….when that yearly scans came up or any of those sort of testing I found it a very stressful time” (Angela, 32, M). Others were driven by fear of developing BC and were not prepared to undertake screening as a preventive measure before deciding to undergo BPM: “I considered ongoing surveillance [after BRCA1 confirmation] and I decided that was too risky for me and would impact my life too much” (Fiona, 32, M).

Participants who had experienced screening before undergoing BPM described suffering screening fatigue (continued distress, tiredness and anxiety surrounding attendance for regular screening and awaiting the results) which became a deciding factor to undergo BPM: “the last time I went in they found a lump…I had a MRI and a biopsy but they weren’t able to find it, I couldn’t do the stress anymore” (Joanne, 33, M). In comparison, despite their screening anxiety women who were considering BPM did not recall experiencing screening fatigue as a result of their regular surveillance.

5.5.4 Relief following surgery

For those who underwent BPM the intense anxiety they recalled feeling before surgery often diminished following their BPM. Many described feeling as “a weight has been shifted off my chest” (Rebecca, 26, M) and their BC worry decreased: “I’m not worried at all now….I am just happier without my little ticking time bomb” (Shawney, 38, M).

No women appeared to have regrets about their surgery, despite some suffering complications. Whilst the majority of participants expressed relief from anxiety and fear following their BPM, some still had concerns about their risk of developing BC:
“I was a little bit mixed about it, I was relieved it was a weight off my shoulders but at the same time it was always in the back of my mind because both my Mum and Grandmother they had BC over and over even after they had their breasts removed so it still played on my mind a lot” (Shelly, 34, M).

Some reported that they felt the need to continue with surveillance: “I am aware that there is still a risk and that is something that I know eventually....I will be looking into how to monitor and surveillance” (Rebecca, 26, M) and

“I have seen that I have to still be vigilant...[heard of a woman who had developed BC after BPM] that really worries me and it just makes me think that this doesn’t keep me in the clear so I know I am going to have to keep up my screening” (Jane, 34, M).

Others displayed less fear about developing BC following their BPM, however, some women felt it was necessary to see their breast specialist and self-examine their reconstructed breasts: “I felt that that risk [following BPM] was manageable...I still have good doctors like I still see the plastic surgeon to this day which is not necessary” (Charlotte, 34, M) and “I still check my breasts and kind of think maybe there’s a chance because there’s always a chance” (Ruby, 26, M).

Those still considering BPM reported mixed feelings about whether the anxiety they were feeling would resolve following a BPM. Some women said they not did know how they would feel, however, they thought it would reduce some of their anxiety or worry:

“I don’t know, I think there will still always be a risk there, I know that you can’t necessarily go okay I’m alright now but I guess there will be a bit of relief that I’ve done something about it” (Robyn, 34, C).

Others thought “definitely” (Karla, 33, C) it would reduce their anxiety: “yeah I really do...I will feel so good just knowing that I have done everything I can” (Summer, 30, C).

Several women thought they would feel some relief but still held fears:

“I think it would be greatly reduced just because you have reduced the amount of tissue you have, you have reduced the chance of developing something but ultimately once you’ve had a reconstruction there’s always a chance that there’s a small amount of tissue left behind and it just becomes harder to detect” (Kathleen, 24 C).
5.5.5 Confusion about residual risk following surgery
Confusion surrounding residual risk of developing BC following BPM could explain why some women were still anxious:

“even the risk of BC after your surgery, you feel like you’re safe but there’s still this part of you that goes how much is my risk, am I really safe…..not understanding what your risk is…that’s quite confusing and that’s probably the only thing that still lingers with me now that I’ve had my surgery” (Jade, 23, M).

Some women recalled being given percentage estimates of their BC risk following BPM, however, these were not consistent: “I guess they don’t know but I have had quotes anywhere from 2-8% at the moment…but even the perception of other health professionals I guess who aren’t well informed, they see me as having no risk” (Lorraine, 36, M) and “I sort of just went it will be 1-2% I won’t have to worry about it anymore” (Nicola, 28, M).

5.6 Discussion
Underlying anxiety and fear, individual participant differences, screening and information from health professionals or organisations that induced fear, were all factors influencing how younger women (<35) perceive their risk of developing BC. An important and novel finding was some women appear less reassured of anxiety and fear following BPM than previous research has suggested (48, 73). Those who had undergone BPM recalled more anxiety than those who were still considering the procedure. The younger women in our study appeared more anxious than previous qualitative research with older women (>40) has suggested (63, 65) and this supports findings that younger women at risk of developing BC tend to have higher perceptions of risk and anxiety (105, 106). We found no apparent difference in risk perception for those with BRCA1/2 mutations or no identified mutation. This is the first study with younger women to include those without a known BRCA mutation and the lack of differences appear to suggest both groups experience similar perceptions of risk. This is a novel and clinically significant finding. These findings suggest it is possible that heightened risk perception could be related to a tendency to be more anxious (for example, those who had already undergone BPM and those who had no known mutation) and/or the way women interpret the information they are told. This could represent individual participant differences which previous research supports (39).

It has been widely acknowledged in the literature that older women (>40) undergoing BPM suffer heightened perception of BC risk and anxiety before BPM (54, 64, 71, 78, 103), however
this decreases significantly following surgery (48, 73, 113). While many younger women in our study felt relief from anxiety following BPM, to the researcher’s knowledge it is a novel and significant finding that some younger women are still concerned about their risk of developing BC after undergoing BPM. In context, a woman with a BRCA1/2 mutation who has not had BPM has up to a 60% lifetime risk of developing BC (110). However, a BRCA1/2 carrier who has had BPM has only a 5-10% risk of developing BC (depending on the type of mastectomy) (26). One previous study had suggested older women may overestimate their risk of BC following BPM, (67), however these women were a self-selected sample (n=19) who had regrets about BPM and it is therefore not surprising they would continue to feel distressed.

No women in our study regretted their decision to undergo BPM despite some suffering surgical complications. Those still considering BPM were uncertain if they would be relieved of anxiety following surgery and expressed concern about their risk of BC after BPM. These findings potentially identify a difference between younger and older women in relation to perceived risk of developing BC after BPM. However, a direct comparison is needed. It is possible that confusion surrounding residual risk of BC following BPM could account for the uncertainty related to perceived risk post-BPM. As undertaking BPM reduces the risk of developing BC by up to 95% (26) it poses a significant problem for clinical practice if this risk reduction is not reflected in younger women’s (<35) perception of their own risk and more research is warranted.

The women in our study held heightened and sometimes inaccurate perceptions of risk, influenced by health professionals or information they had read online. The influence of health professionals and other organisations leading to a woman’s increased risk perception in this context, has not previously been reported in the BPM literature and is an important finding. Hoskins et al. (39) found visits to health professionals increased young women’s risk perception because it was a reminder of their high risk. In our study, health professionals appeared to contribute to younger women’s risk perception by highlighting worst case scenarios (e.g. you will not see your children grow up if you do not have BPM). Often, such comments scared women and ultimately encouraged them to undergo BPM.

5.6.1 Clinical Implications
These findings have salient implications for practice, particularly that younger women are not as relieved of anxiety by undergoing BPM as previous research suggests. A recommendation that all women considering BPM undertake psychological consultation could assist in identifying very anxious patients who may be at risk of continuing to overestimate their risk of
developing BC after BPM (109). It would be useful to explore the role of a psychological consultation prior to BPM and the impact (if any) on risk perception. More research is needed to investigate who is at risk of not feeling relieved following BPM. Future research could also focus on understanding why women interpret information differently. Furthermore, these findings highlight the importance of accurate and consistent communication of risk statistics to younger women, particularly those with no known genetic mutation. Emphasis should be placed on communicating the residual risk of developing BC post-BPM. The way women perceive information given to them by health professionals needs to be taken into account when discussing risk with younger women. Tong et al. (46) recently reported that a critical role of genetic counsellors is communication of accurate risk statistics as these will often have important implications for understanding and decision-making regarding preventative surgeries. This should be widened to other health professionals to ensure that younger women are being quoted consistent risk statistics. Accurate risk perceptions are important when making informed decisions about health.

5.6.2 Limitations
Limitations of our study include the possibility of recall bias for those who have already undergone BPM. The findings are based on participants’ reports and interpretations and there is the potential for inaccurate recollections. Sampling bias is another possible limitation with a self-selected sample of women who were willing to share their stories. As we reached saturation and the study was conducted involving women sampled across Australia and New Zealand, the findings are robust and provide salient examples of risk perception in younger women undergoing or considering BPM. The rigour of this analysis is evidenced by the multiple methods of recruitment from across Australia and New Zealand thus obtaining a diverse sample.

5.7 Conclusion
In conclusion, there are a number of factors that influence how younger women (<35) at high risk of developing BC perceive their risk of BC, including information from health professionals or organisations that induce fear, underlying anxiety and fear, individual participant differences and screening anxiety. The finding that younger women (<35) appear less relieved by BPM in comparison to previous research with older women (>40) is a significant finding and should be investigated further. It is important to ensure the risks of developing BC are accurately communicated to younger women at high risk of developing BC. Implications for practice with younger women include identifying who is at risk of not feeling
relieved following BPM surgery, the implementation of psychological consultation for all women considering BPM and providing consistent and accurate risk estimates.
Chapter 6. Perceived influence of psychological consultation on psychological well-being, body image and intimacy following bilateral prophylactic mastectomy: A qualitative analysis

6.1 Chapter Overview
This chapter presents a published paper discussing the importance of undergoing a psychological consultation prior to BPM and how this can provide psychosocial benefit to younger women, particularly in relation to psychological well-being, body image and intimacy. Permission to include this publication in this thesis can be found in Appendix 17 and a copy of the front page of this publication in Appendix 18.


6.2 Abstract
Objective: This study explored whether psychological consultation offered to women prior to bilateral prophylactic mastectomy (BPM) appeared to provide psychosocial benefit to younger women (<35 years) at high risk of developing breast cancer due to a mutation or family history.

Methods: Qualitative interviews guided by interpretative phenomenological analysis were conducted retrospectively with twenty-six women who had undergone BPM. Participants were recruited from New Zealand and Australia, via a genetics clinic, registry, research cohort, and online.

Results: Three themes were identified: psychological well-being and adjustment, satisfaction with intimacy, and body image. Participants that had seen a psychologist reported being more prepared for BPM and appeared to adjust positively post-surgery. They appeared to have improved psychological well-being, reported satisfaction with intimacy and a more positive body image, compared to those who had no support.

Conclusions: Women who undergo psychological consultation prior to BPM appear to adjust positively after surgery. Implications for practice include standard psychological consultation for younger women (>35 years) considering BPM.
6.3 Introduction

Bilateral prophylactic mastectomy (BPM) is a risk-reducing surgical procedure undertaken by women at high risk of developing breast cancer (BC), to reduce their risk. Women consider BPM for many reasons, though fear of developing BC is a common motivator (62, 103, 105). This fear results in many women undergoing surgery without considering the psychological, emotional, and physical consequences (62). Many of these women struggle with the subsequent changes to their body post-surgery (114).

Researchers suggest women could benefit from psychological support prior to BPM (80, 83, 114). In 2000, Lalloo et al. (115) developed a protocol for women considering BPM, suggesting they undergo a psychological assessment to ensure they understand the information received and have realistic expectations of potential psychological outcomes. Similar guidelines have been developed for women at familial risk of BC, suggesting women who elect to have BPM undergo psychological assessment (116). However, psychological consultation is not routine practice (80). Patenaude et al. (80) reported that high risk women considering BPM would have preferred a psychological consultation to assist their decision-making and preparation for surgery (80). A further study assessing acceptability and support needs, found that of 70 women, 19% reconsidered their decision to undergo BPM following psychological consultation (117). These authors did not explore post-surgery outcomes and satisfaction following psychological support.

Previous research suggested minimal distress in women at high risk of developing BC and concluded there is no evidence for routine psychological consultation (118-120). However, the sub-set of women who undergo BPM differ from other women at high risk of developing BC; they usually suffer more cancer-related distress (63, 71), and fear is driving them to undergo BPM (62). Typically, they overestimate their risk of developing BC in comparison to those who choose surveillance (54) compared to age and risk matched controls (71). Following BPM, women experience a range of psychosocial issues, such as negative body image, decreased satisfaction with intimacy and poor emotional adjustment, and these vary by age (8, 73, 114, 121).

Psychological consultation prior to surgery enables women to ensure they have made an informed decision (65, 114). Previous research found women believe psychological consultation should be mandatory (67), though they stress the importance of a therapist who has knowledge of familial cancer and BPM (80). Psychological consultation prior to BPM
provides the opportunity to discuss psychosocial concerns, which surgeons do not necessarily have the time or skills to do (122). Routine psychological consultation could be cost-effective, reducing demands on surgeon’s time during consultations (80, 122).

To our knowledge, no research has explored the provision of psychological support specifically related to undergoing BPM, irrespective of whether genetic counselling was available. Considering the potential costs involved in recommending routine psychological consultation to all women considering BPM, it is important to explore whether it provides any benefits and could assist in positive adjustment following BPM.

The aim of this study was to explore whether psychological consultation (irrespective of genetic counselling) offered to women prior to BPM appeared to provide psychosocial benefit to younger women (<35 years) at high risk of developing BC.

6.4 Methods

6.4.1 Participant recruitment
Ethical approval was sought from The University of Western Australia (REF: RA/4/1/7836), St John Of God Hospital, Subiaco (REF:866) and Royal Perth Hospital (REF:15-095). Participants were recruited from Australia and New Zealand (NZ); online, via Facebook, a private group for those in Perth, The Gift of Knowledge NZ, Genetic Services Western Australia, Register4 and kConFab (HREC # 97_27). Participants were eligible if they had a strong family history of BC evidenced by the National Breast and Ovarian Cancer Centre classification (12) and underwent BPM before 35 years old. Exclusion criteria included insufficient fluency in written or spoken English and a previous diagnosis of BC.

6.4.2 Procedure
This study was a retrospective qualitative design guided by Interpretative Phenomenological Analysis (IPA) theory (87). Using IPA as a theoretical guide allowed for in-depth explorations of psychosocial adjustment in younger women who had psychological consultation prior to BPM. An experienced interviewer (RG) conducted semi-structured interviews (Appendix 11). The interviews covered a range of topics in relation to BPM including, decision-making, risk perception, well-being, informational needs, body image, sexuality, intimacy and psychological support. Data concerning decision-making and risk perception have been published (107, 123). Interview questions concerning psychological consultation, well-being, body image, and intimacy are the focus of this article. Participants provided written informed consent before the interview and were given contact details of the study team, cancer council
helpline and a clinical psychologist in case the interview caused distress or raised concerns. Telephone interviews were conducted between November 2015 and July 2016, lasting for up to 60 minutes. Interviews were digitally audio-recorded and transcribed verbatim. Data collection continued until data saturation was reached (101).

6.4.3 **Analysis**

Data were analysed independently by two researchers (RG, SH), consistent with IPA involving five steps. Step one included reading each transcript in its entirety to familiarise with the account as a whole. Comments were made on the transcripts (exploratory coding) (87). Such comments were content related, linguistic or conceptual. In step two transcripts were read again and coding conducted. This involved transforming initial notes into concise phrases, capturing meaning. Each code referred to a different idea, for example, confidence, relationship, support (87). Some codes clustered together to form an overarching theme. Step three involved further interpretation whereby coding between transcripts was connected and made sense of (99). Step four involved looking for repeating patterns across cases and ensuring important dimensions were not missed. Similarities and differences were identified to connect participants’ experiences and finalise themes (91, 99). Step five involved both researchers discussing and comparing themes reached independently, and the evidence (quotes) for each theme. For greater clarity of interpretation they agreed the first author would conduct second interviews with several (n=3) participants to gain further understanding of available supports prior to BPM. Following this, the researchers discussed and agreed the extra data were sufficient, cross-checked for overlap, and reached consensus (91).

During the analysis codes were derived using language as close as possible to participants’ quotes. For example, the codes ‘prepared for how body would look’ and ‘feelings about the appearance of the body’ led to the body image theme and were evidenced by quotes “the surgery hasn’t impacted my body or my appearance” and “I don’t feel like they prepared me enough for how I would feel to look at myself”.

We offer a credible interpretation of the data by continuing data collection until data saturation, and having two researchers independently analysing the data and reaching consensus (100). Consistent with IPA researchers using inductive inference in the interpretation of data, there were no predetermined themes. Having two researchers independently coding data contributed to rigorous interpretation, credibility through reflection upon, and exploration of, alternative interpretations of the data. We collected further data to gain a greater understanding of
participants’ perceptions and experiences, further enhancing credibility and rigour (92). In the spirit of the interpretative paradigm we acknowledge our findings are one interpretation and that other interpretations are possible.

6.5 Results
Twenty-six women (Mean age = 31) (Table 4) between one and six years post BPM, participated.

Table 4. Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>BPM n=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age – years (mean)</td>
<td>31</td>
</tr>
<tr>
<td>SD</td>
<td>3.89</td>
</tr>
<tr>
<td>Minimum</td>
<td>23</td>
</tr>
<tr>
<td>Maximum</td>
<td>38</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
</tr>
<tr>
<td>De facto</td>
<td>2</td>
</tr>
<tr>
<td>Married</td>
<td>20</td>
</tr>
<tr>
<td>Separated</td>
<td>0</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>26</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>7</td>
</tr>
<tr>
<td>TAFE/Polytechnic</td>
<td>7</td>
</tr>
<tr>
<td>University-Undergrad</td>
<td>9</td>
</tr>
<tr>
<td>University-Postgrad</td>
<td>3</td>
</tr>
<tr>
<td>Country of residence:</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>19</td>
</tr>
<tr>
<td>New Zealand</td>
<td>7</td>
</tr>
<tr>
<td>Genetic testing:</td>
<td></td>
</tr>
<tr>
<td>BRCA1 positive</td>
<td>14</td>
</tr>
<tr>
<td>BRCA2 positive</td>
<td>9</td>
</tr>
<tr>
<td>Family member inconclusive</td>
<td>1</td>
</tr>
<tr>
<td>Have not been tested for BRCA</td>
<td>2</td>
</tr>
<tr>
<td>Family History:</td>
<td></td>
</tr>
<tr>
<td>First degree relatives affected</td>
<td>19</td>
</tr>
<tr>
<td>Second degree relatives affected</td>
<td>7</td>
</tr>
<tr>
<td>First degree relatives died</td>
<td>7</td>
</tr>
<tr>
<td>Second degree relatives died</td>
<td>1</td>
</tr>
</tbody>
</table>

Ten participants (38%) received a psychological consultation prior to BPM, two of these sought this support independent of their treating health professionals and eight were referred by their treating physician. Sixteen women (62%) did not have a psychological consultation prior to BPM; they were not recommended to see a psychologist by their treating physician nor did
they seek this support on their own. Out of the ten women who received a psychological consultation, one woman presented with struggles post-surgery concerning intimacy. Out of the 16 who did not see a psychologist, six had positive outcomes and ten presented with poorer outcomes, particularly in relation to psychological well-being and adjustment and body image. Twenty-three were BRCA carriers and three had no known mutation. There were no women from BRCA positive families who had tested negative for the family mutation, thus at population risk. All women underwent some type of reconstruction surgery. The overall dimension underpinning each content-related theme is the experience (or absence) of psychological support prior to BPM. Psychological support appeared to affect three themes; psychological well-being and adjustment, intimacy and body image. These themes are described with participant quotes (pseudonym, age).

6.5.1 Psychological well-being and adjustment

This theme encapsulates the psychological well-being and adjustment of participants in relation to psychological support. It encompasses autonomy in decision-making, positive adjustment, emotional and mental struggles.

Many women recalled that support from a psychologist assisted their decision-making prior to BPM:

“I had to be assessed by a psychologist...it was deeper than talking to the doctors and it helped a lot, it topped it off for me to be 100% with my decision...I think it’s good to open up and speak about what you’re scared about and what you’re okay with...she made me open up and speak so I could feel okay with it myself” (Ruby, 26).

One woman spoke about how seeing a psychologist was helpful to her when she was feeling anxious, however, she would have preferred a psychologist who was knowledgeable about BPM:

“I was quite anxious and emotional...I saw a psychologist because I thought it would be beneficial....it was helpful, but they weren’t in that field [BPM] and didn’t know a lot about it, that made it difficult to explain, in hindsight I wish I had spoken to somebody who had more knowledge in the area” (Shannel, 30).

For Adele, visiting the psychologist was valuable and helped her process aspects related to surgery that she had not previously considered: “I really benefitted from seeing the
psychologist before my surgery, they brought up a few issues I hadn’t considered, they helped me work through those” (Adele, 28).

On the other hand, those who had no psychological support appeared to struggle emotionally and psychologically following their BPM: “[were you offered psychological support] no [would that have been helpful] yeah I got quite depressed two days afterwards, just the gravity of everything…so it probably would have been good” (Fiona, 32) and “I think there’s a lot of mental things that you have to think about, it’s a physical part of your body you see each day so it would be nice to find some information about that” (Jaimee, 32).

Many women who had not seen a psychologist thought they were prepared for the surgery. However, following their BPM, they felt the outcomes were different to what they expected: “I should have had counselling, I think it needs to be offered, looking back it was a far harder decision to make than I gave it credit for…mentally I think sometimes I still struggle” (Shelly, 34) and

“I thought I was prepared, but it was way bigger than I imagined, I don’t think you can comprehend how massive it is until it happens….realising the mental side, and the emotions….I knew I was doing the right thing but the emotional side you can’t control and that was what spun me out afterwards” (Helen, 28).

6.5.2 Satisfaction with intimacy

This theme captures satisfaction with intimacy for those who underwent psychological consultation before BPM highlighting the potential benefits of communication and discussion about sexuality and intimacy.

Many women felt intimacy was not affected by BPM and that psychological consultation assisted with this by encouraging open communication with their partner:

“she was able to make me think of other people….to keep that communication open [with husband], one of the reasons she wanted to speak with [husband] was to discuss intimacy, she said some couples have a lot of issues because the woman has these new boobs that she knows aren’t the same, don’t look the same, have a different sensation and the partner thinks, I don’t know if she wants to be touched, I don’t know if I am hurting her and then the woman thinks he doesn’t want to touch me, I mustn’t be attractive and it leads to a communication breakdown” (Pat, 28).
Some women thought their psychological consultation raised the topic of intimacy which they had not considered themselves:

“[was the psychologist helpful] definitely, they brought up a few things I would never have thought of, they were asking about your sexual relationship and the way you look and I asked them do people in my situation worry about that” (Adele, 28).

Some women who had undergone psychological consultation believed their relationship with their partner was stronger following BPM:

“I sought it [psychologist] because I didn’t think I was coping very well, I was worried what if my husband missed my breasts cause they are such a huge part of being a woman….I don’t think our relationship has changed, it’s got stronger definitely” (Mary, 31).

One woman specifically sought out a psychologist with BPM experience who asked specific questions about intimacy:

“prior to my surgery I wanted to see a psychologist who was specialised in genetic conditions or had information about my surgery, I got in touch with a clinical psychologist who a couple of women recommended as being familiar with the surgery….I needed someone to make sure I was emotionally ready, and she brought up a few things I hadn’t thought of in relation to my husband and intimacy…..I found it helpful, I would recommend anyone to do that” (Pat, 28).

Only one woman who saw a psychologist struggled post BPM and this was around intimacy:

“I did have ongoing [sessions] for a while.....breasts were a big part of my sexual interest....and the sensation was a big part of activity and it’s not anymore...I do miss that sexual activity” (Zoe, 36).

6.5.3 **Body Image**

This theme defines the importance of awareness regarding aspects of how women may feel about their body post-BPM and how psychological support or lack of support from an experienced psychologist appears to affect body satisfaction, confidence and preparing for BPM.
Some women were concerned about losing their breasts and one woman described how the psychologist explained that her feelings were normal and an important part of processing emotions:

“I was worried about what if I missed my breasts, that was huge for me....she [psychologist] said it’s good you’re talking about it, it’s good that your crying and she said that people who are very stressed out and cry a lot and worry before their surgery often come out a lot better because they have already gone through all those emotions” (Mary, 31).

Many women who saw a psychologist felt their confidence and self-esteem was not affected by BPM: “the surgery hasn’t impacted my body or my appearance or my self-esteem” (Jipsy, 26). Despite some women not being 100% happy with the outcome, they appeared positive about their body image: “I am very happy with the outcomes, they look better than expected...there’s a bit of nipping and tucking I have to do” (Mary, 31).

Seeing a psychologist who was experienced and knowledgeable about both familial cancer and BPM was deemed important:

“I went in for one session and they didn’t know what BRCA was....I had to explain what BRCA was because they were someone women go to if they have BC...I found it really annoying...I had great boobs [how do you feel now] pretty self-conscious, I am single so I don’t want to meet a guy and see the look on their face of shock or disgust” (Joanne, 33).

Many women who did not attend a psychological consultation appeared to struggle with their body image following BPM: “I don’t feel like they prepared me for how I would feel to look at myself, it’s hard to look at yourself afterwards, to be aware of what you’re going to go through like the emotional part of it, it would be nice if they would tell people about it” (Heather, 30) and

“it’s definitely needed [psychological consultation] I think as time goes on it can be harder....when you have your first surgery your basing everything on your mode of survival so you’re not thinking about how you’re going to feel about your body as you get older, I had a view in my head what they might look like and they didn’t look like that” (Rachel, 33).
Some women who did not have psychological consultation felt they had lost confidence in themselves as a result of BPM:

“they look fine with a bra on but without a bra they’re really lumpy, they don’t look natural or nice….I’m not going to take my top off for anyone, they are full of scars and one side is saggy when I lean forward….every time you get dressed you’re seeing it, it’s had a massive impact to my self-confidence” (Jessica, 25).

6.6 Discussion

Findings presented in the current article are part of a larger study concerning BPM. Findings in relation to decision-making and risk perception have been published (43, 107) and other findings will be reported in future publications. For the purposes of the present study, the main finding was that younger women (<35) who underwent psychological consultation prior to BPM appeared to have improved psychological well-being, body image and intimacy post-surgery compared to women who did not receive consultation. To our knowledge, this is the first study exploring psychosocial outcomes for younger women who undergo psychological consultation prior to BPM.

The apparent psychosocial adjustment differences between those who underwent psychological consultation and those who did not is a novel finding. The women in our study who did not have psychological consultation prior to BPM seemed unprepared for the consequences post-surgery. The surgery affected their psychological well-being, often resulting in negative feelings about body image. Those who had psychological support appeared to adjust better psychologically, and felt more satisfied with the outcomes; including feeling positive about body image and femininity. Many believed their relationship with their partner was stronger following BPM. Previous research (80, 115) has predominantly suggested psychological consultation could assist decision-making about BPM. One caveat is the physical appearance of reconstructed breasts, highlighting surgeons need to provide realistic expectations about breast appearance following surgery. Our findings support the recommendation that women considering BPM could benefit from psychological consultation irrespective of current mental health, as part of routine practice.

It appeared important for women to seek support from a psychologist with familial cancer and BPM experience. Women who saw a psychologist who had no experience with women who were BRCA positive or from a high risk family who underwent BPM appeared to adjust similarly to those who did not receive psychological consultation. Our study supports previous
research (80, 124) that psychological consultation by a psychologist who is not experienced in the area of familial cancer or BPM may not lead to positive adjustment. However, more research is needed to ascertain this finding and quantify the experience/knowledge of psychologists who support these women.

Whilst cost is a barrier to psychological consultation, if it benefits women’s decision-making and acceptance of post-surgery outcomes and reduces the demands on surgeon’s time pre and post-surgery thereby reducing healthcare costs, the need for routine psychological intervention may be justified (80, 122).

6.7 **Clinical Implications**

The implementation of routine psychological consultation by appropriately trained professionals for women considering BPM, irrespective of the technicalities of surgery, should be explored. Future research should focus on testing the efficacy and feasibility of a psychological intervention and determining the cost-effectiveness to add further support to this recommendation. Psychological support could help women make an informed decision and assist them with psychological distress (117). As standard practice it will likely lead to fewer psychological adjustment issues post-surgery (109). This could be cost effective and enable surgical consultation time to be used more effectively and efficiently (122). Further research supporting routine psychological consultation could assist in policy recommendations that encourage health care providers to subsidise the cost of psychological consultation for all women undergoing BPM.

6.8 **Study Limitations**

Limitations of our study include the retrospective design and the possibility of recall bias and sampling bias as participants were a self-selected sample willing to share their stories. As the findings are based on participant’s reports and interpretations, inaccurate recollections and distortions are possible. Comparisons between groups are challenging in qualitative studies and need to be further examined in a quantitative study. Participants were all under 35 years old at the time of surgery and therefore findings cannot be generalised to older women. We utilised a wide recruitment strategy by involving women across Australia and NZ. Data saturation was reached and the findings are robust and provide salient examples of the benefits of psychological consultation prior to BPM.
6.9 Conclusion

In conclusion, younger women who undergo psychological consultation prior to BPM appear to adjust positively after surgery with respect to body image, intimacy, psychological/emotional well-being and femininity. Therefore, we suggest that routine psychological consultation be included in clinical practice. This will give women the opportunity to discuss their concerns, prepare them for surgery and encourage consideration of realistic outcomes. The qualitative nature and small sample size of this study are acknowledged and further research is needed to support these findings. Implications for practice include exploring psychological consultation as standard practice for women considering BPM, which could reduce time demands on surgical teams, create more satisfactory outcomes, and result in fewer psychological issues for women. In the longer term this approach could be cost effective for the health sector.
Chapter 7. Influences on satisfaction with reconstructed breasts and intimacy in younger women following bilateral prophylactic mastectomy: A qualitative analysis

7.1 Chapter Overview

This chapter presents a published paper discussing the influences on satisfaction with reconstructed breasts and intimacy satisfaction following BPM in younger women living in Australia and New Zealand with a strong family history of BC. Permission to include this publication in this thesis can be found in Appendix 18 and a copy of the front page of this publication in Appendix 19.


7.2 Abstract

Purpose: The aim of this study was to explore the influences on satisfaction with reconstructed breasts and intimacy following bilateral prophylactic mastectomy (BPM) in younger women (<35) with a strong family history of breast cancer.

Methods: Twenty-six women who had undergone BPM between one and six years ago were recruited from New Zealand and Australia through a genetics clinic, registry, research cohort, and online (Mage = 31). Twenty-three were BRCA mutation carriers. Qualitative interviews guided by interpretative phenomenological analysis were conducted.

Results: Four themes were identified: satisfaction with breasts before surgery, outcome expectations, type of mastectomy, and open communication. Women who liked their breasts pre-BPM appeared less satisfied with their reconstructed breasts post-surgery, and women who disliked their breasts before BPM were more satisfied with their reconstructed breasts. Women with unrealistic expectations concerning the look and feel of reconstructed breasts, were often unhappy with their reconstructed breasts and felt they did not meet their expectations. Unrealistic photos of breast reconstruction and satisfactory communication of realistic outcome expectations by surgeons or psychologists also appeared to influence satisfaction. Communication with partners prior to BPM appeared to improve satisfaction with intimacy post-BPM.
Conclusions: The findings suggest that satisfaction with reconstructed breasts for younger women post-BPM appeared to be influenced by realistic outcome expectations and communication with others concerning reconstructed breast expectations and intimacy post-BPM. Implications for practice include: discussion of realistic reconstructed breast appearance, referral to a psychologist to discuss sensitive issues, and accurate communication of surgical risks and consequences.

7.3 Introduction

A bilateral prophylactic mastectomy (BPM) is a surgical procedure where both breasts are removed. It is undertaken by women at high risk of developing breast cancer (BC) i.e. those with a strong family history of BC and/or an identified genetic mutation increasing susceptibility to BC, such as BRCA1/2. If a woman has a known BRCA1/2 mutation her BC risk to age 70 is around 60% if a BRCA1 carrier and 55% if a BRCA2 carrier (110). Women with a BRCA mutation have approximately a 20% chance of developing BC by age 40 (84). However, for women with a family history of BC but no confirmed mutation, it is not known exactly what the percentage estimate of developing BC is, although it is thought to be approximately 40% (75); these women are considered ‘potentially high risk’ (47). Women in this category can choose to (and do) undergo BPM despite not having a confirmed mutation (33, 68). For any woman BPM reduces the risk of developing BC to almost zero (less than 5%) (26). The uptake of BPM differs worldwide; from ~21% in Australia to 33%-50% in England, Denmark and Wales (36, 45, 125). There is an increase in younger women (<35) undergoing BPM (36, 45, 46), although it is not known exactly how prevalent the procedure is in this group. If women choose BPM it is recommended they undergo this procedure by age 40 (47).

The BPM procedure is not without consequence; most women will choose to undergo immediate reconstruction surgery and the most commonly reported concerns from women are negative effects to their body image, sexuality and satisfaction with intimacy (73, 121, 126, 127). Women are often dissatisfied with the look and feel of their reconstructed breasts, leaving them feeling less sexually attractive and self-conscious (73, 126). Dissatisfaction with body image could also be related to age. Research comparing body satisfaction found older women have higher body appreciation (128) and may be more comfortable with their body image, in comparison to younger women (51). However, to date no research has focused on what contributes to satisfaction with body image and intimacy in younger women (<35) undergoing BPM.
Research with women >40 suggests those who suffer high cancer-related distress before BPM may be at risk of a negative perception of body image post-BPM (114, 129, 130). Furthermore, superior perceptions of physical health prior to BPM may predict more positive body image following BPM, however findings are conflicting (48, 114). A qualitative study identified women unhappy with their breasts prior to BPM were more accepting of their reconstructed breasts following BPM and reconstruction surgery (65).

The type of BPM/reconstruction surgery can influence satisfaction with body image post-BPM. Those who underwent a nipple-sparing mastectomy (NSM) (where the nipple is saved) had higher satisfaction with the outcome of their reconstructed breasts; compared to women who did not have a NSM (131). NSM procedures have been perceived to have a higher BC risk following BPM than procedures that do not spare the nipple, due to the extra breast tissue left behind (131). However, recent research found it is a safe practice with little added BC risk following BPM (132).

Outcome expectations concerning reconstructed breasts may affect how women feel about their body image following BPM, although previous research reveals mixed findings. One study found the majority of women felt their expectations before BPM corresponded to the cosmetic results post-BPM (133). However, others have found that many women had unrealistic expectations about the outcomes of undergoing BPM/reconstruction (72, 127). This could be attributed to women not fully considering what their reconstructed breasts would look and feel like post-BPM (48) or being ill informed about these consequences (127).

It has been reported that women often suffer negative effects to intimacy after BPM, often related to feeling altered perceptions of femininity and sexuality (127). There is, however, a dearth of information focusing on the factors affecting satisfaction with intimacy post-BPM. It has been suggested that for women whose breasts were an important part of intimacy before BPM, felt less enjoyment during intimacy post-BPM (121). Further, emotional distress and negative health-related quality of life appear to influence sexual problems following BPM (130).

In the aforementioned studies, the mean age of the women was 41 years old. While there is no published research on satisfaction with reconstructed breasts or intimacy in younger women who have undergone BPM, there is research with younger women who have undergone mastectomy and reconstruction for BC. These findings report dissatisfaction with body image and intimacy following surgery (134, 135). However, such dissatisfaction is related to weight
gain through various treatments, including the combined effects of radiotherapy and chemotherapy (136). Women undergoing BPM will not have undergone treatments that could cause such changes to their body image (128). In a comparison of older and younger BC survivors, younger women had poorer body image and sexual functioning (137). To date we know little about younger women’s satisfaction with reconstructed breasts and intimacy post-BPM. Most importantly, we do not understand the factors that affect satisfaction with their reconstructed breasts. It is, therefore of utmost importance to understand the influences on satisfaction with reconstructed breasts and intimacy for younger women undergoing BPM to ensure women are informed about any short and long-term issues that can be experienced following BPM (48).

The aim of this study was to explore the influences on satisfaction with reconstructed breasts and intimacy following BPM in younger women (<35) living in Australia and New Zealand with a strong family history of BC.

7.4 **Materials and methods**

7.4.1 **Research design**

This qualitative study was underpinned by interpretative phenomenological analysis theory (IPA) (87) and followed the consolidated criteria for reporting qualitative studies guidelines for the implementation of the study and data analysis (94). IPA is bound by three guiding principles that align with the aim of this study. It focuses on the lived experience and the meaning of that experience; IPA attempts to bracket one’s own knowledge by not having any prior presumptions influencing data collection; and it views research as a reflective process by incorporating the researchers influence on the research context (93). Using IPA as a theoretical guide allowed an in-depth perspective of the influences on satisfaction with reconstructed breasts for younger women following BPM (87). A qualitative approach was taken based on the findings that quantitative studies may not adequately represent women’s experiences (43). A qualitative approach was also selected for its ability to provide in more depth, perceptions, influences and experiences in ways that quantitative research cannot.

7.4.2 **Sample**

Women with a strong family history of BC per the National Breast and Ovarian Cancer Centre classification for women at high risk of developing BC (12), and who underwent BPM <35 years old were invited to participate. Those with insufficient fluency in spoken/written English, a previous BC diagnosis and older than 40 years at the time of recruitment were excluded.
Ethical approval was sought from Royal Perth Hospital (REF:15-095), St John Of God Hospital, Subiaco (REF:866) and The University of Western Australia (REF: RA/4/1/7836). Recruitment related to the current study is described elsewhere (107). In short, participants were recruited through Genetic Services Western Australia, Facebook, Register4 (a registry for BC research) and kConFab (the national consortium for research into familial BC (REF# 97_27)). Informed consent was obtained from all participants included in the study.

7.4.3 **Data collection**

The first author, an experienced interviewer, conducted semi-structured interviews with participants over the phone between November 2015 and July 2016 and the interviews lasted for up to 60 minutes. Interviews were guided by an interview schedule (appendix 11) and participants were asked questions concerning, body image, intimacy, reconstruction surgery, their outcome expectations and psychological well-being. Data collection continued until data saturation was reached (101). Interviews were digitally audio-recorded and transcribed verbatim. Demographic information (including genetic status) was collected from participants by self-report, via an online survey, except for participants recruited through kConFab (n=5) who provided participant demographics.

7.4.4 **Data analysis**

RG and SH analysed the data consistent with IPA using five steps. In step one each transcript was read in its entirety by both researchers independently to become familiar with the account. Content, linguistic or conceptual comments were made in the left hand margin as part of initial exploratory coding (87). Step two involved transcripts being read a second time where meaning was captured by initial exploratory coding (ideas), forming codes (phrases). Each idea referred to a different code. Codes that clustered together were identified and developed into themes. Further interpretation was undertaken in step three whereby codes between transcripts were connected. Step four identified repeating patterns across transcripts. Similarities and differences were identified to ensure experiences were connected and themes were finalised. Finally in step five consensus was reached by the researchers discussing and comparing their independently identified themes and cross-checking for overlap. Any differences were resolved in these discussions.

The rigour of the analysis is evidenced by reaching data saturation and having two researchers independently analysing the data who met to share their coding results and to reach consensus regarding identification of themes. This enabled reflection upon, and exploration of, alternative
explanations and interpretations. The codes identified in the analysis were derived using inductive analysis and closely mirrored participant’s’ quotes. We provide reliable, rich examples of satisfaction with reconstructed breasts and intimacy following BPM by using women’s direct quotes. The provision of an in-depth description enables readers to interpret the findings (100).

7.5 Results
Twenty-six women between one and six years post-surgery (M=2.15; SD=1.80) participated. At time of the interview the mean age was 31 years (range 23-38). Four (15%) women were single and the remaining had a spouse. All women underwent some type of reconstruction (Table 5). Twenty-three were BRCA mutation carriers and three had no known mutation. Four themes were identified that influence a woman’s satisfaction with reconstructed breasts and intimacy following BPM; satisfaction with breasts before surgery, outcome expectations, type of mastectomy, and open communication. Each quote is followed by pseudonym (used to report participants’ views) and age.

Table 5. Type of reconstruction

<table>
<thead>
<tr>
<th>Type of Reconstruction</th>
<th>Total (n=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implants</td>
<td>16 (61.6%)</td>
</tr>
<tr>
<td>TRAM flap</td>
<td>4 (15.4%)</td>
</tr>
<tr>
<td>DIEP flap</td>
<td>2 (7.7%)</td>
</tr>
<tr>
<td>Lat Dori</td>
<td>3 (11.5%)</td>
</tr>
<tr>
<td>Guteal free flap</td>
<td>1 (3.8%)</td>
</tr>
</tbody>
</table>

7.5.1 Satisfaction with breasts before surgery
Women who recalled liking their breasts prior to BPM appeared less satisfied with their reconstructed breasts post-BPM: When asked “how do you feel about your body after BPM?” Rachel said:

“it’s changed quite a bit, I always liked the way my boobs looked, they looked quite good, I wanted them the size they were but they were smaller and they don’t look the same as they did before so that sort of body image wise made things a bit harder and even still does, I just find my clothes don’t fit the same way, I can’t wear clothes that I would have before” (Rachel, 33).

For women who were unsatisfied with their breasts pre-BPM, it appeared that they had improved satisfaction with their reconstructed breasts and body confidence post-BPM. Angela said:
“I didn’t love my boobs, I had big boobs that didn’t sit up very straight, whereas now my new boobs look a lot better than my old ones, I look at them and I am happier with my body than I was before, I think because I feel better physically with how I look up the top I am probably more confident in clothing now….I was an E cup\(^1\) and I had very saggy boobs, I’ve ended up a 12D\(^2\) and they don’t look nearly as big as they used to” (Angela, 32)

Similarly Mary felt she was:

“not very comfortable [with body image before surgery] just because of the size of my breasts I had ginormous breasts, they were really awful and I had two babies suck the life out of them….much better [now] I can wear different clothes, I can exercise without pain and I still think my breasts look sexy so I feel like a woman” (Mary, 31).

7.5.2 **Outcome expectations**

Unrealistic outcome expectations concerning the appearance and feel of reconstructed breasts appeared to influence satisfaction post-BPM. Women were often unhappy their reconstructed breasts did not meet their expectations:

“I had a view in my head what they might look like and they didn’t look like that, in your mind they tell you everything is going to be this way and you don’t necessarily get the idea, mine are very hard, they are a little bit odd shaped when I don’t have a bra on, they are not necessarily breast looking when I don’t have a bra on and mentally I think I still struggle, I am probably a lot worse now with body image, more than anything” (Shelly, 34).

Some women also spoke about how discussions with medical professionals and psychologists played a role in their expectations of their reconstructed breasts:

“I don’t feel like they prepared me enough for how I would feel to look at myself and all that sort of stuff, it’s very hard to look at yourself afterwards and I am completely numb in that area and it just feels really awkward, they said that eventually the nerves could grow but it’s a very slow process and could take years but that it’s possible to

\(^1\) Conversion USA: DDD and UK: E

\(^2\) Conversion USA and UK: 34D
get feeling back, so I sort of thought ooh okay I’ll wake up with feeling” (Heather, 30)

and

“one of the sessions [with the psychologist] I did before the surgery focused a lot on image and how I would react to them [reconstructed breasts] afterwards and I don’t feel like I had as big a reaction as they were saying, I wouldn’t say I’m 100% happy with the result, my left side may need further surgery” (Adele, 28).

For some, their expectations of reconstructed breasts appeared to be based on seeing results of others, either in person or through photos. These women emphasised the importance of a variety of photos that would best encourage realistic expectations:

“My auntie’s were great they looked like a boob job, it didn’t look like she’d had a mastectomy, they looked fantastic so I think I was expecting that with mine, I think my expectations definitely came from seeing such a good one and expecting that you’re going to get that as well…it’s hard because people are always going to develop some sort of expectation but I think the best thing would be to try and get all levels of pictures, ask the surgeon because I didn’t ask the surgeon, you don’t have to see scary ones, just a few different pictures so that you can see they are not all the same, I think if I had seen that my expectations would have been a little bit different but id obviously only seen one and it was great so I didn’t think I needed to see any pictures” (Jade, 23).

7.5.3 Type of mastectomy

A few women spoke about how choosing to keep their nipples increased their satisfaction with the look of their reconstructed breasts:

“I kept my nipples which has made a big difference with aesthetics….I am comparing to my sister because she didn’t keep her nipples, mine look a lot more like a natural breast I suppose with nipples that still react even though there’s no sensation” (Angela, 32).

Some women felt not keeping their nipples contributed to how they felt about their reconstructed breasts: “looking at [sisters] hers look heaps better than mine because she was able to keep her nipples, they look a lot more natural than mine, I don’t have nipples” (Mary, 31).

One woman suggested she may have kept her nipples had she realised what it would look like without them: “I chose not to keep my nipples just so that it lowered my risk as much as possible
but I feel like looking in the mirror it is very hard to get used to so I sort of wish I kept them” (Heather, 30).

7.5.4 Open communication

Open communication with partners prior to BPM appeared to be important when considering intimacy satisfaction post-BPM. Jade discussed both the effect of not being able to communicate with a previous partner and communicating with her new partner about BPM:

“Before surgery it’s good to communicate….me and my partner broke up not long before my surgery, he was very supportive of me having the surgery but he couldn’t talk about it which made it hard…I met a new partner midway through my surgeries and he’s been amazing, I can talk about it, he’s easy going…when I came out of surgery I didn’t actually show him and he was really funny, he thought I didn’t want to and he said to me why aren’t you showing me but I thought he was scared to see, you really need to communicate with your partner because they are going to be very careful with you and it made me think something that wasn’t true….he was standoffish, the reason I was probably like that with him is because I had tried to communicate with my first partner and I guess I placed that on my future relationship” (Jade, 23).

Many women recalled speaking with their partners about losing their breasts, and issues around intimacy, before their surgery:

“It worried me that having different breasts would be a problem for my husband, how he would feel about that, even though we had already talked about that, it would bother me if I felt like it was bothering my husband and it was effecting my relationship but it hasn’t changed anything” (Jane, 34).

In comparison, some women who appeared unable to communicate effectively with their partners, recalled feeling that their relationships suffered:

“It changed for my spouse and I, it wasn’t his view of me changed, I think it was my view of myself changed….I pushed my husband away…you really struggle with your sexuality and what makes you feminine and I think sub-consciously I didn’t realise I was doing it at the time but I didn’t want him to touch me, I thought he would think it was gross….we split up and then got back together after some time, but that was one of the leading causes of it” (Shelly, 34).
7.6 Discussion

These findings suggest that having realistic expectations and being able to discuss and communicate effectively with others are key to satisfaction with reconstructed breasts and intimacy post-BPM for younger women. It appeared that a woman’s pre-BPM feelings towards her breasts, the type of mastectomy and unrealistic expectations about what reconstructed breasts would look and feel like influenced women’s satisfaction with their reconstructed breasts. Seeing in person the outcomes of breast reconstruction or photos may assist women to prepare for what their reconstructed breasts may look like. An important and novel finding was that open communication with partners appeared to influence satisfaction with intimacy following BPM.

Women who liked their breasts before BPM appeared to be less satisfied post-surgery versus women who disliked their breasts before BPM, who were more satisfied with their reconstructed breasts. This supports previous findings by Lloyd et al. (65). However, our finding contradicts more recent research, albeit with older women, that suggest those with lower body image prior to BPM are less satisfied with their body image following BPM (48). This finding could suggest a difference in body image perception between younger and older women.

Some women in our study had unrealistic expectations of what their reconstructed breasts would look and feel like. It appears discussions and communications held with surgeons and psychologists about breast reconstruction prior to surgery play a role in expectations. Previous research reports mixed findings with respect to unrealistic expectations. Our study differs from findings by Brandberg et al. (133) that found most women had realistic expectations concerning the appearance of reconstructed breasts. While Brandberg et al.’s (133) study included younger women (44% <39 years old) their findings were not broken down by age and it is possible the differences in our study are age-related. Our study supports findings by Hallowell et al. (72) who reported women (<41 years old) often did not have realistic expectations. Seeing breast reconstruction outcomes either in person or via photos contributed to post-reconstruction expectations for the participants. Women emphasised photos need to be realistic. Further research to ascertain the role of expectations and reconstruction outcomes for younger women is warranted (51).

A NSM appeared to enhance satisfaction with reconstructed breasts for some women. Some women who did not keep their nipples described how not having nipples influenced their
feelings about the appearance of their reconstructed breasts. Previous research reports mixed findings on satisfaction with body image and mastectomy type. van Verschuer et al. (138) suggest there is no difference in terms of satisfaction with body image between a skin-sparing mastectomy and a NSM. Others have found a NSM provided greater satisfaction with body image and intimacy (131, 139). In further support of this option, women who underwent a NSM did not have higher risk perceptions (131). A NSM is not a technical surgical option for all women undergoing BPM and reconstruction. Nevertheless, it may warrant more discussion with women for whom it is an option, particularly focusing on associated risks.

Influences on satisfaction with intimacy following BPM have not previously been investigated in younger women. Our study found open communication with one’s partner both prior to, and after, BPM appeared to make a difference to satisfaction with intimacy. Those who did not, or felt they were unable to, communicate with their partners about intimacy surrounding their BPM felt their relationships suffered. This needs to be investigated further using an appropriately designed, quantitative study. Nevertheless, younger women undergoing BPM should be encouraged to communicate openly with their partners about their surgery.

7.7 Clinical Implications
These findings provide specific implications for clinical practice with younger women. They highlight the important role of surgeons in conveying realistic expectations, as well as consistent and accurate information and discussion of different mastectomy and reconstruction types, including conveying accurate risk. Routine referral for psychological consultation prior to BPM could provide women the opportunity to discuss concerns about reconstructed breasts and raise issues they may not have considered. This will likely provide women with more realistic expectations and ensure they are fully aware of what their breast reconstruction may look and feel like (i.e. their reconstructed breasts will not look like their old breasts). Surgeons do not necessarily have the time or the skills to discuss psychosocial concerns with women (122). Partners’ involvement in psychological consultations should be explored to encourage open communication concerning BPM and intimacy. Likewise it would be useful for single women to discuss future intimate relations with an experienced psychologist. A larger quantitative study could assist clinical practice by investigating the predictors of satisfaction with body image and intimacy for women undergoing BPM.
7.8 Limitations and Strengths

Our study has some limitations, including the possibility of recall or sampling bias due to the retrospective design and self-selected sample of women. The women in this study underwent BPM before 35 years old, most were in a de-facto relationship and underwent an implant type reconstruction; the findings may not be the same for those who do not fit these descriptions. This study is the first to investigate the potential influences on satisfaction with reconstructed breasts and intimacy in younger women undergoing BPM and we provide salient examples where changes in practice could increase patient satisfaction. Participants were recruited from a wide geographic area and a diverse sample was obtained through multiple methods of recruitment across Australia and New Zealand.

7.9 Conclusion

In conclusion, realistic expectations and communication are key to satisfaction with reconstructed breasts and intimacy for younger women (<35) post-BPM. Open communication with partners is important and appeared to play a key role in satisfaction with intimacy. Discussion with surgeons and psychologists concerning realistic outcome expectations also appeared to influence satisfaction. Implications for practice include, routine referral to a psychologist, surgeons focusing on communicating realistic outcomes of breast appearance, and accurate communication of the risks of BC between different mastectomy types. Future research could include a robust quantitative study of predictors of satisfaction with body image and intimacy post-BPM for younger women.
Chapter 8. Patients’ perspectives and experiences concerning barriers to accessing information about bilateral prophylactic mastectomy

8.1 Chapter Overview

This chapter presents a published paper. This paper’s focus is to explore the barriers and experiences of accessing information for women who have received genetic risk assessment/testing results for breast cancer and are considering a bilateral prophylactic mastectomy and, exploring participants’ preferences concerning information and support needs. Permission to include this publication in this thesis can be found in Appendix 20 and a copy of the front page of this publication in Appendix 21.


8.2 Abstract

Purpose: To explore the barriers and experiences of accessing information for women who have received genetic risk assessment/testing results for breast cancer (BC) and are considering a bilateral prophylactic mastectomy (BPM) and, exploring participants’ preferences concerning information and support needs.

Methods: A qualitative retrospective study guided by interpretative phenomenological analysis was utilised. Semi-structured interviews were conducted with forty-six women who were either considering BPM or had already undergone the surgery.

Results: Three themes identified barriers to accessing information; difficulties accessing information, inconsistent information and clinical focus/medicalised information. A fourth theme - preferences of information and support needs, identified three subthemes; these were, psychological support, clearly defined processes and photos of mastectomies/reconstruction surgeries.

Conclusions: Barriers to accessing information appeared to be widespread. A lack of integrated services contributed to inconsistent information, and medicalised terminology/clinical focus of consultations further complicated understanding. Preferences for information include clearly defined processes, so women know the pathways after confirmation of familial BC risk.
Clinical implications include a multidisciplinary team approach, and a protocol that reflects current practice.

8.3 **Introduction**

Women who choose bilateral prophylactic mastectomy (BPM) desire more information concerning psychological well-being, body image and sexuality after surgery, and post-operative pain management (65, 72, 83, 140). They often report inconsistent and conflicting recommendations, and at times misinterpret information (141). As a consequence, many fail to accurately understand their familial BC risk and strategies to modify their risk (41, 83, 142). At present, there are gaps in our understanding of how this information should be provided. Insufficient information has been associated with dissatisfaction following BPM (143).

A protocol for women at familial BC risk choosing BPM was developed in 2000 (115). A multidisciplinary (MD) team approach was encouraged, including patient consultations with a geneticist/oncologist, a psychiatrist (for a psychological consultation) and a breast and/or plastic surgeon. An oncologist/geneticist would conduct genetic counselling. With advances in genetic testing and availability of genetic counsellors, aspects of this protocol may be outdated. Currently those at familial BC risk may not consult with oncologists or psychiatrists and such extensive consultations would not be cost-effective in current clinical practice. Nevertheless, other aspects of these recommendations, such as a psychological consultation, is still not standard practice across clinics in Australia and New Zealand (NZ) (144).

Similar recommendations have been developed, which discuss the management of those choosing BPM (116). Furthermore, a decision-aid (145), telephone peer-support program (146) and MD clinic (147) have been adopted with some success, to further address the reported lack of information provided to those at familial BC risk. More recently a model for understanding information needs of BRCA+ carriers before and after genetic testing is being explored (148). The main focus of such interventions is assisting genetic counselling and testing, decision-making and reducing distress (148-150). These studies do not focus specifically on BPM or the associated issues with choosing BPM, such as compromised psychological well-being, body image, sexuality and intimacy and they fail to address the lack of information women report (65, 72, 83, 140).

Predominately, BPM research has focused on BRCA+ carriers (80, 148), rather than those at familial BC risk without an identified mutation. Women choosing BPM continue to desire more information (38, 43, 72). We know little concerning the barriers to accessing information or
the influences on decision-making. This is vital to ensure that misinterpretation or lack of risk understanding does not cause women to undergo BPM unnecessarily.

The main aim of this research was to explore the barriers to and experiences of accessing information for women who have received genetic risk information and when considering BPM, and explore participants’ preferences concerning information and support needs.

8.4 **Method**

8.4.1 **Design**

Interpretative Phenomenological Analysis (IPA) (87) guided this retrospective qualitative study and allowed in-depth explorations of the barriers to accessing information and understanding of patient preferences for information and support needs.

8.4.2 **Recruitment and procedure**

Ethical approval was obtained from four locations (Figure 6). Participants were recruited from Australia and NZ through, two hospitals in Perth, Genetic Services Western Australia, Register4 and kConFab (HREC # 97_27) (whereby participants were invited to participate), and online via a Facebook post (whereby interested participants contacted the researcher directly). Eligibility was based on family history evidenced by the National Breast and Ovarian Cancer Centre classification (12). The sample consisted of 46 women who had undergone BPM (n=26) and were considering BPM (n=20). Due to the multiple methods of recruitment, including online and through third parties (Register4 and kConFab) the number of women invited to participate or how many saw the Facebook advertisement is unknown, therefore, a response bias analysis could not be conducted. Women with insufficient fluency in written/spoken English or a previous BC diagnosis were excluded. Further details are published elsewhere (123).

Written informed consent was provided and semi-structured interviews conducted by an experienced interviewer (RG) (appendices 11 and 12). The study team, Cancer Council helpline and a clinical psychologist’s contact details were given to participants in case the interview raised concerns. Data collection continued until data saturation was reached (101). Data were audio recorded and transcribed verbatim.

8.4.3 **Analysis**

Data were analysed consistent with IPA. Two researchers (RG, SH) independently read each transcript as a whole to acquaint with the account. Exploratory coding (87) was conducted and
comments made in the left hand margin. A second reading of each transcript was undertaken and initial comments formed phrases (codes) capturing meaning. Themes were developed from codes that clustered together and coding between transcripts were connected. Transcripts were compared and contrasted and repeating patterns were identified to finalise themes (99). Both researchers discussed their independent findings and after cross-checking for overlapping themes they reached consensus (91).

Data is a credible interpretation evidenced by continuation of data collection until data saturation was reached (100). There were no predetermined themes and therefore inductive inference was used in the data interpretation. Independent analysis and coding of findings by two researchers contributes to credibility and rigour, interpretation by reflection and exploration of the data. We acknowledge that based on the interpretative paradigm, our findings are one interpretation and other interpretations are possible.

Ethical Approval:
- The University of Western Australia (REF: RA/4/1/7836)
- St John Of God Hospital, Subiaco (REF:866)
- Royal Perth Hospital (REF:15-095)
- kConFab (REF: 97_27)

Excluded (n=20):
- Did not meet inclusion criteria (n=10)
- Declined to participate (n=10)

Assessed for eligibility (n=66) between Nov 2015 and July 2016

Semi-structured telephone interviews (n=46)

BPM Group (n=26)

Considering Group (n=20)

Figure 6. Flow diagram of recruitment and procedure

8.5 Results

Forty-six women participated (Table 6). Those in the BPM group were one-six years post-surgery and all underwent reconstruction surgery. Barriers to accessing information identified three themes; difficulties accessing information, inconsistent information and clinical focus/medicalised information. A fourth theme, preferences for support needs, was identified
and included three subthemes - psychological support, clearly defined processes, and photos of mastectomies/reconstruction surgeries.

Table 6. Participant demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total n=46</th>
<th>BPM n=26 (56.52%)</th>
<th>Considering n=20 (43.48%)</th>
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<tr>
<td>Age – years (mean)</td>
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<td>31</td>
<td>29.5</td>
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<tr>
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</tr>
<tr>
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<td>38</td>
<td>34</td>
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<tr>
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</tr>
<tr>
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<td>6</td>
</tr>
<tr>
<td>have not been tested for BRCA</td>
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</table>

The themes identified were the same for both groups. Quotes are used to report participants’ views 3. Each quote is followed by a pseudonym, age, BPM status (‘C’ for considering BPM and ‘M’ for those who had undergone BPM) and State or Country.

3 In accordance with Sandelowski (151) pronouns will represent indeterminate quantities where ‘many’ implies approximately 75%, ‘some’ implies approximately 50% and ‘few’ implies approximately 20%.
8.5.1 **Difficulties accessing information**

Many women appeared unsure about how to manage their familial BC risk after receiving genetic information; recalling a lack of information on who to contact and feeling they had to find their own information:

“They gave me a booklet about what it meant to be BRCA+, but they didn’t give me any contact information, I found that on my own, I would have liked more support after finding out about the gene rather than before…it wasn’t really available” (Helen, 28, M, WA).

There appeared to be a lack of integrated services. Some Familial Cancer Clinics (FCCs) told women to contact their general practitioner (GP) to manage their familial BC risk, however, some GPs appeared to have limited knowledge about BRCA or BPM:

“They [FCC] said go and see your GP and get a referral but the GP knew nothing much about BRCA or even the surgery [BPM], it was frustrating, the doctors weren’t really helpful” (Rachel, 33, M, NZ).

Some women felt their doctors were dismissive and were upset at the perceived judgement of their GP: “I was disappointed in the GP, they told me genetic testing was basically a waste of time and a load of rubbish and it just upsets people, they didn’t believe in it” (Autumn, 30, C, WA).

Some women felt their surgeons were time poor and consequently they did not get enough information:

“my surgeon was straight down the line, this is what will happen, if you want it you contact the cosmetic surgeon and then come back to me, but she didn’t really give me any information” (Shannel, 30, C, NSW).

8.5.2 **Inconsistent information**

The lack of integrated services seemed to lead to inconsistent information and women recalled feeling frustrated by this: “my issue with all this is it’s not consistent” (Yvette, 34, C, QLD).

A source of confusion was the different risk estimates quoted to women:

“The risk percentage differs between who I talk to, I went to genetics, they said BRCA2+ carriers have a 50% chance of getting BC, and when I went to the breast clinic they said I have an 80% chance of getting BC” (Natasha, 31, C, WA).
Likewise the reduction in BC risk from undergoing BPM was inconsistent across different services: “the percentage reduction once you have BPM changes depending on which person I talk to, my surgeon said you would reduce it to almost nothing, the breast clinic said 10%” (Natasha, 31, C, WA).

There are inconsistencies in how women received genetic results; either via telephone or in person. Those who were told their genetic results via telephone had to wait for an appointment with a genetic counsellor which they felt disappointed with:

“we got our results over the phone and it wasn’t until about two months later that we saw the genetic counsellor….maybe they should have sent out a booklet to read through to tie me over until we had the counselling session” (Laura, 27, C, WA).

8.5.3 Clinical focus/medicalised information

Clinicians appear to follow a medical model and explain the surgery process to women: “the person who gave me the most information about it [BPM] was the plastic surgeon, she went through everything in detail about what my surgery entailed, whereas it’s a bit vague through other health professionals” (Laura, 27, C, WA).

However, many found the reliance on the medical model meant the information was laced with clinical medical jargon not easily understood: “I did get some information written down but it was all medical, a medical leaflet saying this is what will happen and the risks associated” (Jaimee, 32, M, QLD).

Health literacy appeared to affect the understanding of information. Those whose backgrounds were in the health field had an advantage in understanding what clinicians were explaining to them: “I had information sent out to me and it’s not written for someone who doesn’t have medical training” (Joanne, 33, M, WA).

8.5.4 Preferences of information and support needs

8.5.4.1 Psychological support

A few women felt that seeing a psychologist could assist with the clinical environment surrounding BPM: “I think it is probably really beneficial [psychological consultation] because it’s very medicalised” (Amy, 27, C, NZ).

Some women reported wanting the opportunity to have a psychological consultation before and after their BPM to discuss their feelings about the surgery:
“I would like some counselling in hospital once I’ve done it, not so much the decision but how I feel about it now. I think someone should come and consult with you while you’re on the ward” (Kayla, 33, C, WA).

Furthermore, women wanted practical and emotional support from others in similar situations to themselves:

“There wasn’t really a lot of a support network for women who had been through the surgery and I wanted to know the implications of everyday life” (Jaimee, 32, M, QLD).

8.5.4.2 Clearly defined processes

Many women want clearly defined pathways to managing their familial BC risk and BPM. They specifically wanted a step-by-step guide: “if the process is clearly defined, step one is this, here is your surgery and here is your recovery and it’s a timetable of what you are going to do” (Natasha, 31, C, WA).

Some women felt defined processes and identification of pathways in a non-clinical/medicalised way would be easiest to understand:

“I think something that is simple, not written by a medical person., this is the process from beginning to end, you meet your plastic surgeon, they talk about size and shape and these are your options for different surgeries, you’ll go and meet with….and this is where you’ll talk about this, we didn’t have that” (Joanne, 33, M, WA).

Some women felt a leaflet would have assisted them:

“I never found a leaflet with the options of surgery, complications and possible emotional feelings, a lot of information is for women with existing cancer not in the high risk category” (Zoe, 36, M, NSW).

Many women were unable to find information specific to their location: “just stressing state by state information…I found by looking up hospitals you don’t get any information” (Meredith, 29, C, QLD) and “I was fully informed of the American options [of surgery] before I went to the breast surgeon who then outlined what we do in NZ and it didn’t match what they do” (Shawney, 38, M, NZ).
8.5.4.3 Photos of mastectomies/reconstructions

Many women felt seeing photos of reconstructive surgeries would have been beneficial: “I didn’t see any photos….I think that would help because in your mind they tell you everything is going to be this way and you don’t necessarily get the idea” (Shelly, 34, M, NZ).

Those who did see photos felt that it aided them: “a lady I talked to actually sent me photos from the surgery when she had it which was really helpful” (Rachel, 33, M, NZ).

However, women suggested it was important to see a timeline of photos:

“my doctor showed me a heap of pictures but he didn’t show me any of what they will look like when you first wake up, that they will be black and blue and lumpy…that was something I wasn’t prepared for…I think you need to be aware of what they look like over time” (Jipsy, 26, M, NSW).

8.6 Discussion

The barriers to accessing information for women undergoing BPM appear to be wide ranging. Women had difficulty accessing information after being identified as BRCA+ and recalled a lack of guidance about who to see next. There appeared to be poor integration of services between FCCs, GPs, and breast clinicians. This seems to have led to inconsistent and conflicting information (41, 141). Risk estimates for developing BC and the risk reduction post-BPM was a source of confusion. It appeared that both women considering BPM and women who had already undergone surgery, experienced similar barriers to accessing information, and had comparable preferences for support needs. Until now it has been unclear that poor integration of services could contribute to barriers to accessing consistent information.

Many women recalled feeling isolated after finding out their genetic results and this continued throughout their BPM journey. Those who received genetic results via telephone appeared disappointed with the wait for genetic counselling - sometimes up to eight weeks. Discontinued contact with clinicians following BRCA testing has left women feeling abandoned (53). Women require adequate support and information immediately following confirmation of familial BC risk; this avoids misconceptions and inaccuracies in risk perception, which may cause some to undergo BPM unnecessarily (152).

After receiving genetic results some women recalled being advised to contact their GP, however, were disappointed with their GP’s lack of knowledge about familial BC risk and lack
of clear pathways for them. It appears GPs needed further education concerning familial BC risk and BPM. This finding supports previous research that primary healthcare providers often lack familial cancer knowledge (153, 154).

Women were often dissatisfied with information they received because they did not understand medical terminology clinicians used. Consultations were very clinical and surgeons were often time poor, meaning in-depth discussions about psychological well-being, were lacking. Health literacy appeared to influence understanding; those with health backgrounds seemed to understand information provided better than those without; previous research with BRCA+ women supports this finding (39).

Participants identified strategies that could assist them accessing the information they desired. Women felt seeing a psychologist would assist preparing for surgery in a non-medical environment. Recent research found women who see a psychologist prior to BPM appear to have increased psychological well-being and higher satisfaction with body image and intimacy, in comparison to those who have no support (144). Furthermore, women wanted information from clinicians on where they could seek support from others considering BPM. Previous research supports this finding (80, 148).

Women sought clearly defined pathways in everyday language about the process of surgery and recovery relevant to their location. They suggested a step-by-step guide, or flow diagram, including clear information on where to go when leaving FCCs, who to see and what would be discussed (see Figure 7 for a proposed example). Similar findings have been identified for women after a BRCA+ confirmation (148). Photos of mastectomies/reconstruction surgeries at different stages would help women understand what their breast reconstruction may look like. However, photos need to be realistic (e.g. photos of the same reconstruction surgery).

Limitations of our study include the retrospective design, the possibility of recall and sampling bias as participants were a self-selected sample willing to share their stories, and the inability to conduct a response bias analysis. As the findings are based on participants’ reports and interpretations, inaccurate recollections and distortions are possible. Participants were <35 years old at the time of surgery and findings are not generalised to older women.
Figure 7. A proposed patient-centred pathway to information about undergoing bilateral prophylactic mastectomy

2 Some women may only meet a breast surgeon, whilst others may meet both a plastic surgeon and breast surgeon. It is important that consistent information is relayed by all clinicians.
8.7 **Clinical implications**

These findings have clinical implications, specifically encouraging a MD team, developing a protocol reflecting current practice, continued education for GPs and a resource for women (Table 7). Additionally, the opportunity to see a psychologist and view photos of mastectomies/reconstruction surgeries should be explored. The development of standards of care in this area would ensure everyone involved has a clear understanding of their role and the roles of others. Early research suggested the preferred management of women at familial BC risk was by a MD team (155). A resource may lead to increased satisfaction with information. However, some women may prefer further information from their clinicians directly. The recommendations proposed in Figure 7 and Table 7 are based on the present study alone. Further research is required to examine the needs of younger women considering and undergoing BPM.

**Table 7. Proposed recommendations for clinical practice**

<table>
<thead>
<tr>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Encourage a MD team approach to the management of women at high risk of developing BC, including genetics, GPs, high risk clinics, surgeons and psychologists.</td>
</tr>
<tr>
<td>2. Develop a protocol based on current clinical practice for the MD team, including clear guidance on where to refer women and in what order, and what the clinical pathway should be following identification of increased risk of BC.</td>
</tr>
<tr>
<td>3. The provision of education and professional development for GPs on genetic susceptibility, mutations associated with BC and the management options should be explored.</td>
</tr>
<tr>
<td>4. Additionally, resources for women identifying clearly defined pathways and relevant support networks, including who they see, what is discussed, where they go and in what order could help alleviate the lack of information issue women report.</td>
</tr>
</tbody>
</table>

8.8 **Conclusions**

Women report a number of barriers to accessing information. A lack of integrated services between those involved in the management of women at familial BC risk appeared to contribute to inconsistent information. These barriers often led women to feel isolated and unsure where to seek more information. Women’s preferences for information included clearly defined pathways so they knew who to see and when. They felt it was important to see a psychologist and have a support network when undergoing BPM. We suggest a MD team approach to the management of these women, an updated protocol and continued education for GPs. A resource could also assist women with some of the barriers identified.
Chapter 9. Psychological well-being of younger women at high risk of breast cancer considering or having undergone bilateral prophylactic mastectomy

9.1 Chapter Overview

This chapter presents the quantitative component of this study – an online questionnaire investigating the factors affecting the psychological well-being of younger women (<35 years) at high risk of breast cancer who are considering, or have undergone bilateral prophylactic mastectomy. This chapter has not yet been submitted for publication, however, it may be published in the future and the chapter is therefore formatted like a manuscript.

9.2 Abstract

Objective: The objective of this study was to investigate the factors affecting psychological well-being of younger women (<35 years) at high risk of developing breast cancer (BC) considering or having undergone bilateral prophylactic mastectomy (BPM).

Method: This study was a cross-sectional quantitative design. Forty-five women who had either undergone BPM (n=25) or were considering BPM (n=20) completed an online questionnaire consisting of the depression, anxiety and stress scales short-form, the impact of events, the sexual activity questionnaire and a body image and risk perception questionnaire. Participants were recruited from Australia and New Zealand via hospitals, a genetics clinic, a research cohort, a registry and online.

Results: Those who had undergone BPM had significantly more cancer-related worry than those still considering BPM (U=164, p=0.49 and U=131.5, p=.007). Neither group identified negative feelings toward body image and intimacy. Three-quarters of women did not accurately recall the lifetime risk of BC to any women in the general population, and they overestimated their own risk of BC.

Conclusions: In conclusion, younger women who undergo a BPM suffer more cancer-related worry than those still considering BPM. Findings that women who have undergone BPM have no negative feelings toward body image and intimacy, contradict previous findings and more research is needed. Clinical practice should focus on communication and education of risk information to women at high risk of developing BC who are considering BPM.
9.3 Introduction

The literature focusing on younger women (>40 years) and BPM is scarce (43). To date, six studies have focused on younger women with a strong family history of BC (37-42), two on decision-making (40, 42), two on informational needs (37, 40), one on risk perception (39) and one on the needs of younger women (41). These studies included some women who had undergone a BPM, however, findings in relation to younger women were often reported as secondary findings and were not the main focus of the study. Studies include only those with a BRCA1/2 mutation. The above studies are all qualitative and there is currently no known quantitative data on younger women with a strong family history of BC who have undergone a BPM.

Younger women may have different experiences of undergoing a BPM. Women typically have various roles they play at certain points in their life and consequently have different priorities and responsibilities across their lifespan (60). Women in their 20’s and 30’s may be concerned with body image, sexuality, fertility, relationships, and career development. Some may be newly married with small children or planning to have a family in the near future (61). Others may not yet have met their life partner, or may be in new relationships. Women in their 40’s, and 50’s are more likely to be in a more secure stage of life, married or in a long-term relationship, have school age or older children, an established career (60) and may be less concerned with their body image (51). As women further age their role demands change and may focus more on independence, retirement, widowhood, constrained finances and physical/mental function decline (61).

Studies focusing on younger women have not investigated how they feel about their body image or intimate relations following BPM. A recent systematic review suggested BPM does not cause negative effects to a woman’s psychosocial well-being (129). However, it would seem the situation may be more complex. Research with older women has suggested a woman’s perception of her body image can change as a result of a BPM. Women often report their reconstructed breasts look and feel unnatural which makes them feel less attractive (8, 73, 81). The negative beliefs women hold about their body image have been attributed to poor reconstruction outcomes and complications with surgery, which can result in increased psychological distress (8, 63). Studies report mixed findings on intimacy following BPM in older women (129), however, suggest BPM can have a negative impact upon sexuality. Many women report a lack of sensation in their reconstructed breasts, and this can result in a negative impact on the woman’s sex life (8, 65, 72).
Research has suggested anxiety and cancer-related worry is higher in women undergoing BPM, when compared to women (with a strong family history) who opt for regular screening (64, 71, 78). It has been reported that many younger women undergo BPM as an alternative to living with the fear of developing BC, believing waiting was not worth the risk (39). In the literature older women, have reported that distress and anxiety experienced before surgery decreases after a BPM, attributed mostly to women no longer living with the fear of a BC diagnosis (63, 64). Several studies have suggested that following BPM some women continue to worry about BC (129), however, this has not been fully established.

Prior to the current research only one study has investigated risk perception specifically in younger women (<36) (39). They found visits to health professionals increased participants’ risk perception because it was a reminder of their high risk. Women felt their risk perception heightened when considering their children and the adverse effects a diagnosis of BC could have on them (39). Other studies report mixed results of women’s self-reported risk perception and the influence this has on the decision to undergo a BPM. Bresser et al. (64) reported that women who underwent a BPM had an inflated perception of their BC risk, compared to those who opted for surveillance. However, the majority of those in the BPM group were BRCA carriers and the majority of those in the surveillance group were high risk due to a family history of BC, but not a proven mutation. Heiniger et al. (71) found that risk perception and cancer-related worry were higher prior to surgery for those who had a BPM compared with matched controls. However, the study was limited by a small sample (n=17) and no details were reported on the women’s BRCA or high risk status. Metcalfe et al. (78) compared a woman’s perception of developing BC to actual computed estimates of their risk based on self-reported family history. They found that on average women estimated their lifetime risk of developing BC to be 76% compared to computer generated estimates of 59% for BRCA carriers and 17% for those with a family history of BC (78).

9.3.1 Aim
The aim of this study was to investigate the factors affecting the psychological well-being of younger women (<35 years) at high risk of BC who are considering, or have undergone BPM.
9.3.2 Research Questions

1. Are there significant differences between women considering BPM and women who have already undergone BPM with respect to depression, anxiety and stress?

2. Are there significant differences between women considering BPM and women who have already undergone BPM with respect to cancer-related worry?

3. Are there significant differences between women considering BPM and women who have already undergone BPM with respect to body image?

4. Are there significant differences between women considering BPM and women who have already undergone BPM with respect to intimate relations and sexual functioning?

5. Are there significant differences between women considering BPM and women who have already undergone BPM with respect to risk perception?

6. What proportion of women considering BPM and women who have already undergone BPM, believe in the efficacy of screening?

9.4 Methods

9.4.1 Design

This study was a cross-sectional quantitative study. The online questionnaire was designed on the online survey platform Qualtrics (156).

9.4.2 Ethical Approval

Ethical approval was obtained from The University of Western Australia (UWA) (REF: RA/4/1/7836), St John Of God Hospital, Subiaco (REF:866) (SJOG)), Royal Perth Hospital (REF:15-095 (RPH)) and kConFab (HREC # 97_27).

9.4.3 Recruitment

Recruitment took place throughout both Australia and New Zealand. Participants were recruited from Genetic Services Western Australia where women contacted for follow-up were invited to participate, through kConFab (a national familial cancer research consortium) and Register4 (an online registry for BC research) via written invitation to participate and online via Facebook post.

Due to the limited data on younger women and conflicting data on older women, hypotheses were unable to be formed. Therefore, research questions were developed to be tested.

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Eligibility was measured by family history as evidenced by the National Breast and Ovarian Cancer Centre classification for women who are at high risk of developing BC (12) and underwent BPM before 35 years old or were considering BPM and were <35 years. Exclusion criteria were insufficient fluency in written and spoken English and previous diagnosis of BC.

9.4.4 Procedure

Participants completed an online questionnaire consisting of six sections (Appendix 23). The first section asked demographic information including age, ethnicity, marital status, education, country of residence and birth and when they underwent their BPM or when they planned to. Participants were asked about their family history and whether or not they had undergone genetic testing, and if so what the outcome was. Where applicable, participants were asked questions about their surgery, whether they had any complications, if they had immediate reconstruction or not, and what type of reconstruction. Women who were considering BPM were asked what information they had sought and from whom. The remaining five sections consisted of validated measures. The questionnaire was completed between November 2015 and July 2016. As this study was part of a wider qualitative study, participants were emailed the link to the online questionnaire following their interview. They were given a unique ID that they were asked to enter before beginning the questionnaire, in order for their questionnaire to be matched to their interview transcript. The questionnaire took a mean time of 15 minutes to complete.

Qualtrics is supported by UWA and is widely used by students and staff. In order to maintain privacy and confidentiality Qualtrics uses Transport Layer Security encryption which is a secure connection between their server and the participant’s server. Access to Qualtrics is through UWA’s secure network which requires individual login details; the researcher is the only one to have this access. Questionnaire responses were securely transferred from Qualtrics by the researcher using the export function straight into an Excel spreadsheet. This spreadsheet is a “TrueCrypt” file and password protected and only accessible to this person. Any identifying information was removed. The spreadsheet is stored on the UWA network drive.

9.4.5 Instruments

9.4.5.1 Depression Anxiety and Stress Scales short-form (DASS-21)

The Depression, Anxiety and Stress Scales short-form (DASS-21) (157) measured depression, anxiety and stress. The DASS-21 is validated with both clinical and non-clinical samples and has concurrent validity with the Beck Depression Inventory, Beck Anxiety Inventory and the
State Trait Anxiety Inventory (158). Internal consistencies are high for all scales in previous research, ranging from .82 to .94 and has an overall Cronbach’s Alpha of .93 (158, 159). The internal consistencies (Cronbach’s Alpha) for the current study are high for all scales; stress -.89, anxiety -.74 and depression -.84. The DASS-21 is a valid measure of depression, anxiety and stress. There is also evidence it can measure a more general element of psychological distress (159). The scores of the DASS-21 are summed to create subscale scores for each of depression, anxiety and stress.

9.4.5.2 Body Image

The body image scale used in this study was developed by Gopie et al. (114), based on Lodder et al’s. (113) body image questionnaire (which was established following recommendations from Hopwood (160)). This scale was chosen as the only suitable measure of body image for both populations in this study. A number of authors have reported the lack of a body image measure suitable for measuring body image in women who have undergone BPM and women opting for surveillance (113, 160). Body image scales constructed on the recommendations of Hopwood (160) have however, reliably and validly been used in BPM research (85, 113, 114). The scale consists of 13 items scored on a five point Likert scale from 1-5 (totally disagree, disagree, neutral, agree, and totally agree). The scores are computed to create a mean scale score and higher scores indicate positive body image (114). The scale showed high internal consistencies of .89. This body image scale has overlapping questions with the Body Image Scale (BIS) (55) which also has high reliability; Cronbach’s alpha .91 and test-retest reliability shown by patients completing the test at two different time points one month apart. The internal consistencies for the current study were low, Cronbach’s Alpha .55.

9.4.5.3 Impact of Events (IES)

The Impact of Events Scale (IES) measured cancer-related worry. The IES is designed to measure stressful life experiences, namely post-traumatic stress disorder, however, can be tailored to suit specific events (161). The IES has frequently been used in BPM research (48, 64, 71, 114). It consists of 15 items and has two subscales – the intrusion subscale (7 items) and the avoidance subscale (8 items) (161). Each item is on a 4 point scale; 0, 1, 3, 5 with 0 not at all and 5 often. The IES has been used with non-clinical populations and is reported to be a reliable measure; it has internal consistencies of .78 - .88 for the intrusion scale and .82 - .88 for the avoidance scale (161, 162). The internal consistencies (Cronbach’s alphas) for the current study are high for all scales; intrusion .88 and avoidance .84. Norms and cut off scores
were not available for a non-clinical sample, however, other studies report scores higher than 13 on the intrusive scale and 11 on the avoidance scale are clinically significant (64).

9.4.5.4 Sexual Activity Questionnaire (SAQ)

The 10 item Sexual Activity Questionnaire (SAQ) measured sexual functioning. The SAQ was originally developed by Thirlaway and Fallowfield (163) to investigate the sexual functioning of women at high risk of developing BC and the impact of long-term Tamoxifen use, and it has been previously used in BPM research (54, 71, 73). The SAQ has three sections; the first assesses hormonal status (all women complete this section), the second section assesses reasons for sexual inactivity (women who are not involved in sexual activity complete this section), section three assesses sexual functioning (women who are sexually active complete this section). Eight questions of sexual functioning are assessed on a four point scale ranging from 0 (not at all) to 3 (very often) and two questions are assessed on a four point frequency scale. The SAQ has three subscales, pleasure (higher scores (0-18) = higher pleasure) discomfort (lower scores (0-6) = lower discomfort) and habit (assessed as a single item) (163). The pleasure and discomfort scales have shown to be reliable measures of sexual functioning with internal consistencies of .84 and .80 respectively (71). The internal consistencies for the current study were high for the pleasure scale .87, however, they were low for the discomfort scale .39.

9.4.5.5 Risk perception

BC risk perception was measured using five questions modelled by Evans et al. (164) and Hopwood et al. (165) following guidelines by Lerman et al. (166). Risk perception measures using these guidelines have shown reliability with internal consistencies of .63. This style of measuring risk perception is used in BPM research (54). For the purposes of this study the risk perception questions were scored individually and no internal consistencies were calculated.

9.5 Statistical Analysis and Assumptions

The data from the online questionnaire was coded and analysed using the Statistical Package for the Social Science (SPSS) version 22. Descriptive statistics were conducted to answer the above research questions and determine any trends or relationships among the two groups. To examine the relationship between the groups’ significance testing was performed with the depression and stress scale on the DASS-21 and the IES scale. The significance level was set at p=0.05. There are unfortunately no published data to estimate the likely psychological, and physical well-being differences in younger women whom have either undergone BPM or are considering the procedure. Despite the small sample size a power calculation was completed
employing a power of 0.9 with an alpha of 0.05 which estimated that a sample size of 22 (in each group) would be sufficient to detect a mean difference of 5 between mild and moderate anxiety. There were however, only 20 women in the considering group which may have decreased the power of the sample.

9.5.1 **DASS-21**
Statistical significance tests were performed between the two groups for stress and depression, however, not for anxiety, as the mean score between the groups was similar. Unfortunately the assumption of a normal distribution was violated (the stress and depression data for both groups was markedly skewed) to conduct a t-test. A log10 transformation in SPSS did not normally distribute the data. Therefore, the non-parametric Mann Whitney U-Test was utilised. This data met all of the assumptions for the Mann Whitney U-Test.

9.5.2 **IES**
There were three missing data for this scale (questions, 2, 10 and 14 for different participants). In order to maximise the numbers for a statistical analysis it was decided acceptable to substitute the mean score of each question for the three missing data. The assumption of a normal distribution was violated for this measure. The distribution of the considering group on both scales was markedly skewed. Following a log10+1 transformation, the data appeared better distributed in both groups, however, still mildly skewed. It was therefore decided to use the Mann Whitney to compare any differences between the groups. This data met all of the assumptions for the Mann Whitney U-Test.

9.6 **Results**
Forty-five women participated in this study (Table 8). One woman was excluded because she did not complete the questionnaire.
Table 8. Participant demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total n=45</th>
<th>BPM n=25 (56.52%)</th>
<th>Considering n=20 (43.48%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age – years (mean)</td>
<td>30.4</td>
<td>31</td>
<td>29.5</td>
</tr>
<tr>
<td>SD</td>
<td>3.55</td>
<td>3.89</td>
<td>2.91</td>
</tr>
<tr>
<td>Median</td>
<td>31</td>
<td>32</td>
<td>30</td>
</tr>
<tr>
<td>Range</td>
<td>15</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Minimum</td>
<td>23</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Maximum</td>
<td>38</td>
<td>38</td>
<td>34</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Living with partner</td>
<td>9</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Married</td>
<td>29</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>44</td>
<td>25</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>9</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>TAFE/Polytechnic</td>
<td>9</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>University – Undergrad</td>
<td>18</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>University – Postgrad</td>
<td>10</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Country of residence:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>35</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td>New Zealand</td>
<td>11</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Genetic testing:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1 positive</td>
<td>21</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>BRCA2 positive</td>
<td>15</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Family member inconclusive</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Have not been tested for BRCA</td>
<td>8</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

9.6.1 Group differences on depression, anxiety and stress

The means and standard deviations for the DASS-21 subscales of stress, anxiety and depression are presented (Table 9).

Table 9. Comparison of stress, anxiety and depression between those considering BPM and those who have already undergone surgery

<table>
<thead>
<tr>
<th></th>
<th>BPM Group</th>
<th></th>
<th>Considering Group</th>
<th></th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
<td>Range</td>
</tr>
<tr>
<td>Stress</td>
<td>25</td>
<td>8.08</td>
<td>5.82</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Anxiety</td>
<td>25</td>
<td>3.68</td>
<td>4.27</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Depression</td>
<td>25</td>
<td>2.72</td>
<td>3.36</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>

The descriptive statistics for the DASS-21 subscales show that both groups’ scores are within normal range (stress 0-14, anxiety 0-7, depression 0-9). The considering group has higher
scores on all three subscales, suggesting more stress, depression and anxiety. However, there was no significant difference for stress (U=212, p=.38 (two tailed)) and depression (U=225, p=.55 (two tailed)) between those who had undergone BPM and those who were considering the surgery.

9.6.2 Group differences for body image

The means and standard deviations for the body image scale are presented below (Table 10).

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>BPM</td>
<td>25</td>
<td>3.01</td>
<td>.51</td>
<td>3.08</td>
<td>1.92</td>
</tr>
<tr>
<td>Considering</td>
<td>20</td>
<td>3.21</td>
<td>.27</td>
<td>3.30</td>
<td>1.08</td>
</tr>
</tbody>
</table>

The mean scale scores for both groups are similar and indicate a neutral score.

9.6.3 Group differences for cancer-related worry

The means and standard deviations for the IES two subscales (avoidance and intrusion) are presented below (Table 11).

<table>
<thead>
<tr>
<th></th>
<th>BPM Group</th>
<th></th>
<th></th>
<th>Considering Group</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
<td>Range</td>
<td>N</td>
</tr>
<tr>
<td>Avoidance</td>
<td>25</td>
<td>12.20</td>
<td>8.29</td>
<td>10</td>
<td>33</td>
<td>20</td>
</tr>
<tr>
<td>Intrusion</td>
<td>25</td>
<td>15.56</td>
<td>8.92</td>
<td>15</td>
<td>34</td>
<td>20</td>
</tr>
</tbody>
</table>

The descriptive statistics show that the means for both the avoidance and intrusion subscales of the IES are medium (8.5-19) for the BPM group but low for the considering group (1-8.5). There was a significant difference for the avoidance scale (U=164, p=.049) between those who had undergone BPM and those who were considering the surgery. There was also a significant difference for the intrusion scale (U=131.5, p=.007) between those who had undergone BPM and those who were considering the surgery. t-tests of both these scales were also conducted and were significant (Appendix 24). Those who had already undergone BPM displayed significantly higher cancer-related worry.

9.6.4 Group differences on intimate relations and sexual functioning

The means and standard deviations for the SAQ’s three sub scales, pleasure, habit and discomfort are presented below (Table 12).
Table 12. Means and standard deviations for SAQ sub-scales

<table>
<thead>
<tr>
<th></th>
<th>BPM Group</th>
<th></th>
<th></th>
<th>Considering Group</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
<td>Median</td>
<td>Range</td>
<td>N</td>
</tr>
<tr>
<td>Discomfort</td>
<td>20</td>
<td>.80</td>
<td>.76</td>
<td>1</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Habit</td>
<td>21</td>
<td>1.62</td>
<td>1.50</td>
<td>1</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Pleasure</td>
<td>19</td>
<td>13.42</td>
<td>3.96</td>
<td>15</td>
<td>13</td>
<td>15</td>
</tr>
</tbody>
</table>

No differences between the groups were found. High scores represent high pleasure (pleasure sum) and a low score represents low discomfort (discomfort sum). For the habit score, a score of 1 was *about the same* and a score of 2 was *somewhat more*.

9.6.5 Group differences on risk perception

Only 24% and 30% (Table 13) of those who had undergone BPM and those considering BPM respectively, correctly answered the estimated lifetime risk of BC to any woman in the general population.

Table 13. Frequencies of lifetime risk of BC to the general population

<table>
<thead>
<tr>
<th>Frequency</th>
<th>BPM Group (%)</th>
<th>Considering Group (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 chance in 2</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>1 chance in 3</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>1 chance in 5</td>
<td>12%</td>
<td>5%</td>
</tr>
<tr>
<td>1 chance in 6</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>1 chance in 8</td>
<td>24%</td>
<td>30%</td>
</tr>
<tr>
<td>1 chance in 10</td>
<td>28%</td>
<td>30%</td>
</tr>
<tr>
<td>1 chance in 12</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>1 chance in 20</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>1 chance in 50</td>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>1 chance in 100</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Very unlikely</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

For those who had already undergone BPM, 40% answered it was very unlikely they would develop BC (Table 14). For those who were yet to undergo BPM, 30% felt it was inevitable they would develop BC and 35% thought their chance was 50% (Table 14).

Table 14. Frequencies of women's own lifetime risk of developing BC

<table>
<thead>
<tr>
<th>Frequency</th>
<th>BPM Group (%)</th>
<th>Considering Group (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inevitable</td>
<td>12%</td>
<td>30%</td>
</tr>
<tr>
<td>1 chance in 2</td>
<td>16%</td>
<td>35%</td>
</tr>
<tr>
<td>1 chance in 3</td>
<td>4%</td>
<td>15%</td>
</tr>
<tr>
<td>1 chance in 4</td>
<td>0%</td>
<td>15%</td>
</tr>
<tr>
<td>1 chance in 6</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>1 chance in 8</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>1 chance in 10</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>1 chance in 50</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>1 chance in 100</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Very unlikely</td>
<td>40%</td>
<td>0%</td>
</tr>
</tbody>
</table>
For those who had undergone BPM 56% felt that screening would help in comparison to 95% of those who were still considering BPM (Table 15). 32% of those who had undergone BPM were uncertain if screening would help.

Table 15. Percentages of whether screening will help

<table>
<thead>
<tr>
<th></th>
<th>BPM Group (%)</th>
<th>Considering Group (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>56%</td>
<td>95%</td>
</tr>
<tr>
<td>No</td>
<td>12%</td>
<td>5%</td>
</tr>
<tr>
<td>Uncertain</td>
<td>32%</td>
<td>0%</td>
</tr>
</tbody>
</table>

9.7 Discussion

Those who had undergone BPM suffered significantly more cancer-related worry than those still considering surgery. Younger women did not appear to have negative feelings towards body image or intimacy, and there were no differences between those who had already undergone BPM and those considering surgery. Three quarters (24% and 30%) of women could not accurately recall the lifetime risk of BC to a woman in the general population. Over a quarter of women who had already undergone BPM over-estimated their risk of BC. Almost all of those who were still considering BPM thought screening could help detect BC, in comparison to only half of those who had undergone BPM. This is the first quantitative study to investigate younger women who have undergone BPM or are considering the surgery. These findings are discussed in more depth below.

No significant differences were found between those considering BPM and those who had undergone BPM with respect to stress, depression and anxiety. Despite this finding there is a trend suggesting younger women still considering BPM may suffer more stress and depression. More research is needed to explore, stress and depression in women considering BPM. However, it is possible the IES (discussed below) which can be tailored to suit different situations may be a more suitable measure of distress in this population of women; in comparison to the DASS-21 which measures clinical levels of depression, anxiety and stress.

Those who had undergone BPM suffered significantly more cancer-related worry (measured by the IES) than those who were yet to undergo the surgery. These findings support qualitative research (shown in Chapter Five) that suggests younger women who undergone BPM are more anxious than those considering the surgery (107). Other research also supports this finding. Bresser et al. (64) reported women who underwent a BPM had an inflated perception of their BC risk compared to those who opted for surveillance. BPM reduces the risk of developing BC by up to 95% (26). If this risk reduction is not reflected in younger women’s (<35 years)
perception of their own risk, this poses a problem for clinical practice, and more research is warranted.

This study did not find that younger women, before or after BPM, have a negative perception of their body image. Both groups displayed similar neutral mean scores on the body image scale. This contradicts previous research with older women (>40 years), which suggests they have negative feelings about their body image post-BPM, (8, 73, 81); although, it is possible this could get worse over time. This is the first quantitative study to examine body image in younger women and it could identify a difference between younger and older women. An unpublished qualitative study (Chapter Seven) found that increased satisfaction with reconstructed breasts in younger women may be dependent on a number of factors (i.e. satisfaction with breasts before surgery, outcome expectation and type of mastectomy). Alternatively, despite this body image measure being previously used with populations of women who have undergone BPM, it is possible it is not suitable for this younger population and further research is warranted.

No differences in sexual functioning between those who had undergone BPM or those who were still considering the surgery were found. Over the past month both groups reported their sexual functioning was ‘about the same’ as usual (participants were asked to rate their sexual functioning from over the last month). This is inconsistent with previous research, which suggests that a woman’s sex life can be negatively impacted by BPM (8, 65, 72). However, existing research is only with older women (>40 years), thus this could be related to age.

While only a quarter of women in this study ‘correctly’ estimated the lifetime risk of BC to any woman in the general population, another quarter only very slightly underestimated the risk of BC to a woman in the general population (1 in 10 instead of 1 in 8). For those who had undergone BPM only 40% felt it was very unlikely they would develop BC; 12% felt it was inevitable. For those who had undergone BPM, only a quarter accurately estimated their risk of developing BC post-BPM (between 1 and 10 percent). The literature suggests that following BPM the risk of developing BC is less than 5% (depending on the type of mastectomy) (26). The literature suggests older women’s perception of risk significantly decreases following a BPM (48, 73, 113). These findings differ and support qualitative research (Chapter Five) that younger women continue to have increased risk perception following BPM (107). A direct comparison should be explored to ascertain whether younger women have higher risk perceptions than older women.
Interestingly, only just over half of those who had undergone BPM felt that screening would help, in comparison to almost all (95%) of those who were still considering BPM. Thirty-two per cent of those who had undergone BPM were uncertain if screening would help, in comparison, all women considering BPM were certain screening would help. This finding could suggest women who choose to undergo BPM may not have confidence in screening methods and therefore choose BPM. Those still considering surgery and currently undergoing screening have more confidence in screening methods, and this could be why they are choosing to wait for BPM rather than rush the decision. This supports previous research which has suggested anxiety and cancer-related worry is higher in women undergoing BPM when compared to women (with a strong family history) who opt for regular screening (64, 71, 78).

9.8 Limitations

One limitation of this study was sampling bias as these were a self-selected sample of women willing to participate. The women in this study were aged less than 35 years old and therefore findings cannot be generalised to older women. The small sample size is a limitation and it is possible there is the increased likelihood of low statistical power or type II errors. A large effect in a small sample was identified, however, it is the only, and therefore largest, study of this cohort of women. There were only 20 women in one group which minimises the likelihood that a statistical difference would be found. The substitution of the mean score for the three missing data on the IES is also a limitation. Reliabilities (Cronbach’s Alpha’s) were low for the body image measure (.55) and the discomfort sub-scale of the SAQ (.39), however, as these means were similar, no significance testing was conducted with these measures. This could indicate these measures are not reliable for this cohort of women.

9.9 Clinical implications

This study has implications for clinical practice. Most importantly these findings highlight the importance of accurate and consistent communication of risk statistics to younger women. Emphasis should be placed on communicating the residual risk of developing BC post-BPM, in an effort to reduce the cancer-related worry that participants who have undergone BPM experience. The findings that younger women following BPM continue to have concerns about their risk of BC following BPM is clinically relevant, with respect to the management of older vs younger women considering BPM. It may be that those who are younger need slightly different approaches to their management and added focus to consultations with clinicians. Future research should include a larger quantitative study which includes a direct comparison with older and younger women.
9.10 Conclusion

In conclusion, this quantitative data suggest younger women who undergo BPM suffer more cancer-related worry than those still considering BPM. There was a non-significant trend suggesting those considering BPM suffered more stress and depression, although it is possible the DASS-21 is not a suitable measure for this population of women who are unlikely to have clinically significant depression and anxiety. No negative feelings towards body image and intimacy were identified in those who had undergone, which contradicts previous findings and further research is needed. Clinical practice should focus on communication and education about risk information to women at high risk of developing BC considering BPM, both before and after surgery.
Chapter 10. General Discussion

10.1 Chapter overview
This chapter forms the discussion of the research findings. It begins with a brief overview of the importance of the topic, summarising the rationale for the study. The key findings from Chapters Four to Nine are reviewed and discussed; including interactions between topics and important findings. The contribution of this research to the literature is detailed, as is the contribution to improving outcomes for women at high risk of breast cancer. This chapter concludes with the limitations and strengths of the study as a whole, clinical implications, future research and a summary of the main findings and recommendations.

10.2 Justification for this study
Younger women with a strong family history of breast cancer (BC) face difficult and challenging medical decisions about their risk reduction, presenting unique psychosocial and medical challenges (41). Although the literature on younger women and BPM is scarce, few studies have tried to explore the experiences of women undergoing BRCA1/2 testing at young ages (<30) (53). These studies report disadvantages such as, women having to make important life decisions sooner than they would have, due to their increased risk of developing BC (53). Previous research has highlighted that younger women may have different experiences to undergoing bilateral prophylactic mastectomy (BPM) than older women; finding that younger women (less than 50 years) were less likely to report satisfaction with BPM (86). It is important to understand the experiences of younger women who pursue BPM as a risk management option for their higher risk of developing BC, given the limited research with this population and the far-reaching consequences of undergoing an irreversible medical procedure without a process of informed decision-making.

Health professionals are faced with challenges in ensuring that younger women who often lack experience in health-related decision-making, are emotionally ready to make important medical decisions about their risk reduction (41). The consequences of how younger women’s decisions will affect them emotionally and physically are not fully understood. Medical decision-making must take into consideration both short and long-term psychosocial and health concerns, however, younger women may not understand or consider such consequences.

Furthermore, previous research examining BPM has not adequately represented women’s experiences due to limitations in design and method (8). Research in the area of BPM has mostly been quantitative, however, a recent systematic review found between 87-100% of
quantitative studies reported women were satisfied with the information they received prior to their BPM. However, two qualitative studies reported that in fact women wanted more information about scars, numbness, pain and implants. They wanted more support and focus on the emotional aspects of undergoing BPM, as opposed to the practical aspects. They also requested more psychological support. The authors concluded that more qualitative research needs to be conducted with this cohort of women to gain greater understanding into their experiences and to explore the challenges they face (143).

10.3 Key findings

10.3.1 Clinicians’ role in decision-making and risk perception

A key and novel finding of this research was the potential influence that clinicians’ have on younger women’s decision-making and risk perception. Previous research suggests that clinicians’ initiating discussion about BPM could influence the decision to undergo surgery (67). However, the present study identified additionally that clinicians’ appeared to influence women’s decision to undergo BPM by highlighting worst case scenarios to the women. By highlighting worst case scenarios clinicians’ appeared to increase women’s already heightened, and sometimes inaccurate, risk perceptions. This seemed to result in fear and in turn, appeared to influence the decision to undergo BPM. There is currently no research exploring how clinician factors (for example, personality traits, previous experience, professional opinion) (108) influence decision-making or risk perception in younger women considering BPM.

10.3.2 The role of individual differences on risk perception and decision-making

The study identified the possibility that individual differences (i.e. personality, a tendency to be more anxious or exposure to different life experiences) and how women perceive and understand information could contribute to decision-making and risk perception. There appeared to be no differences in risk perception between those with BRCA1/2 mutations and those at high risk due to family history, but with no identified mutation. Despite those with a BRCA1/2 mutation being confirmed to have up to an 80% chance of developing BC, those without an identified gene mutation appeared to be just as anxious about their risk of developing BC. This is the first study with younger women to include those at high calculated risk due to family history, but without a known BRCA mutation, and the lack of apparent differences appear to suggest both groups experience similar perceptions of risk. This is a novel and clinically important finding, suggesting that it is possible heightened risk perception could be related to a tendency to be more anxious (e.g., those who had no known mutation and those who had already undergone BPM appeared more anxious than their counterparts) and/or the
way women interpret the information they are told. This could represent individual participant differences which previous research supports, finding that a person’s prior attitude, expectation and level of understanding can influence their perceived risk perception and subsequent decision-making (39); lending support to this tentative conclusion.

Communication of risk information to women and how they assimilated this information appeared to differ between individuals. Health literacy appeared to play a role; those whose backgrounds were in the health field, appeared to have an advantage in understanding the information surgeons presented. Three quarters of women in this study could not accurately recall the lifetime risk of BC to a woman in the general population and more than a quarter of women who had already undergone BPM over-estimated their risk of BC after surgery. Other research supports these findings; it has been reported that women who were able to process the genetic information they were given found the experience less stressful, in comparison to those who did not understand the information in context (39). Furthermore, a significant correlation between low health literacy and increased risk perception in those at high risk of BC has been previously identified (112) and those with medical/biological backgrounds often understand genetic information better than those without such prior knowledge (39). In further support of individual differences playing a role in decision-making and risk perception, the younger women in this study appeared to be more anxious and have higher perceptions of risk in comparison to previous studies with older women (105, 106). This suggests younger women may cope with the uncertainty surrounding their risk of developing BC differently to older women, however, a direct comparison is needed and more research is warranted.

10.3.3 Risk perception and estimates

The importance of education and improved, and consistent, risk estimates is highlighted in this study. Some women in this study decided before they received genetic test results that they were going to undergo BPM, regardless of the testing result. Tong et al. (46) reported a critical role of genetic counsellors is the communication of accurate risk statistics since these have important implications for the understanding of, and decision-making involved in preventative surgeries. These authors highlighted the need for pre-genetic counselling as this often has an impact on decision-making.

Furthermore, some younger women in this study reported that they continued to feel concerned about their risk of developing BC after undergoing BPM. This is a novel and salient finding. For those who had undergone BPM only 40% felt it was very unlikely they would develop BC.
and 12% felt it was inevitable they would develop the disease. Only a quarter of women who had already undergone BPM accurately estimated their risk of developing BC post-BPM (between 1 and 10 percent). The majority of published research with older women suggests that undergoing BPM significantly decreases prior anxiety and heightened risk perception (48, 73, 113). One study suggested that women may continue to overestimate their risk of BC following BPM (67). However, participant selection for Payne et al.’s study was on the basis of regrets about BPM and therefore selection bias may have influenced these findings. In this study those still considering BPM were also uncertain if they would feel relief from anxiety and worry after undergoing BPM. Findings from this study suggest there may be a difference between younger and older women’s perception of risk after undergoing BPM (i.e. younger women continue to be anxious). For a woman with a BRCA mutation who has not undergone BPM, her lifetime risk of developing BC is about 60% (110). In comparison, for a BRCA carrier who has undergone BPM, her risk of BC is less than 5% (26) and, with modern surgery, approaching 1%. In context, it is a major problem for clinical practice if this actual risk reduction is not reflected in younger women’s perceptions of their risk.

Giving women an accurate statistic of their risk of developing BC is often difficult and inconsistencies (different clinics and clinicians give women different percentages) are common. This confuses women who are already uncertain about their risk of developing BC and complicates their thinking on the best way to manage their high risk. It is difficult to understand an accurate risk associated with a BRCA1/2 mutation as these often vary (i.e. between 50%-80%). Accurate risk is further challenging for those who have no such mutation but a strong family history of BC who are often labelled ‘potentially high risk’, with no reliable way to estimate their percentage risk of developing BC. Metcalfe et al. (75) identified those with no known mutation to have approximately a 40% risk of developing BC, however there are a number of reasons why one may have no identified mutation (they may have been tested and no mutation was found or they may not have not been tested as they are ineligible for public genetic testing). There are currently too many variables in the category of ‘potentially high risk’ to estimate individual risks for those without confirmed mutations.

Many published articles report different risk statistics and reference difference sources. For example, Singh et al. (167) report 56-84% lifetime risk for BRCA1/2 carriers, Rueth et al. (168) 80% lifetime risk for BRCA1/2, and Patenaude et al. (80) BRCA1/2 risk between 56% and 85%. Those with a BRCA1 mutation are said to have a higher risk of developing BC as opposed to those with a BRCA2 mutation (approximately 15% higher risk for BRCA1 carriers).
However, Stuckley et al. (169) quoted that those with a BRCA1 mutation have an 87% risk and close behind BRCA2 carriers with an 84% risk of developing BC and St-Pierre et al. (170) report those with a BRCA1 or BRCA2 mutation have up to an 85% lifetime risk of developing BC.

Mavaddat et al. (110), conducted a prospective study estimating cancer risks of 1,887 BRCA1/2 carriers and found the cumulative risk of BC for BRCA1 is 60% and BRCA2 55%. Likewise Antoniou et al. (68) found some years ago that the cumulative risk of BC for BRCA1 was 65% and for BRCA2 45%. Cancer Australia (79) reports BRCA1/2 carriers have a 30-60% risk of developing BC but an 80% chance up to 80 years old. The National Cancer Institute in the United States reports BRCA1 carriers have a 55-65% of developing BC and BRCA2 carriers 45% (10). Based on the different estimates that are quoted in published papers and on reputable websites it is not surprising that Hopwood et al. (171) found women did not understand their lifetime risk of developing BC. It is possible that measuring numeric risk (e.g. via percentage as opposed to categorical (‘potentially high risk’)) could be easier for women to understand. The women in Hopwood et al’s (171) study accurately and consistently recalled their numeric risk (articulated as gambling odds); however, they did not recall or understand lifetime risk. They also found that those who could not recall their risk increased over time. This, however, poses a problem for those with no confirmed mutation. While numeric risks may be easier for women to understand it would need to be consistent across the board to avoid confusion.

10.3.4 Contrasts between quantitative and qualitative studies
It was identified in the literature review (Chapter Two) that quantitative studies may not adequately represent women’s experiences and this research adds further support to the limitation of quantitative studies alone. The quantitative study found no differences between body image satisfaction for those still considering BPM and for those who had already undergone the surgery. Neither group indicated poorer body image satisfaction and both groups reported they felt neutral about their body image (i.e. they neither disagreed or agreed with statements such as ‘I was satisfied with the appearance of my breasts’).

However, the qualitative component of this study paints a different picture. For women who had undergone BPM some recalled feeling unhappy with the cosmetic result of their reconstructed breasts. This appeared to be influenced by their feelings towards their breasts before surgery, outcome expectations and type of mastectomy. Those who reported not liking
their breasts prior to BPM, felt their reconstructed breasts were an improvement on their previous breasts. In comparison, those who liked their breasts prior to BPM, appeared less satisfied with their reconstructed breasts. Those who had a nipple-sparing mastectomy (NSM) appeared to be more satisfied with their reconstructed breasts than those who did not keep their nipples. Some women appeared to have unrealistic expectations of what their reconstructed breasts would look and feel like post BPM, and this contributed to dissatisfaction with their reconstructed breasts. Seeing breast reconstruction outcomes either in person or via photos appeared to contribute to unrealistic expectations of reconstructed breasts for the participants.

Similarly, contrasting findings were found between the quantitative and qualitative components for intimacy and sexual relations. The Sexual Activity Questionnaire (SAQ) did not find any differences between the groups and no high scores indicating lack of pleasure for either group were found. However, the qualitative study identified that open communication with one’s partner both prior to, and after, BPM appeared to make a difference to satisfaction with intimacy. Those who did not, or felt they were unable to communicate with their partners about intimacy surrounding their BPM felt their relationships suffered. The SAQ alone would have be unable to identify this finding.

These findings suggest that it may be inadequate to solely rely on quantitative self-report to measure body image and intimacy satisfaction for women whom have undergone BPM. The quantitative scale used to measure body image was the only suitable measure for both populations in this study. Gopie et al. (114) based on recommendations from Hopwood (160) developed the measure used. Body image scales constructed on the recommendations of Hopwood (160) have reliably and validly been used in BPM research (85, 113, 114). It has overlapping questions with the Body Image Scale (BIS) (55) which also has high reliability. However, for this sample it would appear that this measure is not reliable for this population, evidenced by a Cronbach’s Alpha of .55. It is possible this limitation could contribute to these findings. However, statistical analyses with this measure was not conducted. A number of authors have reported the lack of a suitable body image measure for women who have undergone a BPM and women opting for surveillance (113, 160). To address this, the development and validation of a new tool, inclusive of the variables associated with body image and intimacy satisfaction in women undergoing BPM, should be explored.

The role of quantitative work to investigate the psychological and psychosocial outcomes of BPM has been questioned for a number of years. Many articles from the early 2000s report that
overall the majority of women are satisfied with their BPM (64, 73, 81). Other work has suggested the story may be more complex identifying differences between quantitative and qualitative studies (65). Bebbington Hatcher et al. (54) found in a quantitative study comparing those who opted for BPM and those who declined the surgery, that the decliners maintained higher anxiety from baseline to 18 months. However, half of the same women were also qualitatively interviewed and only three of those who declined surgery reported they felt any anxiety (63). The discrepancies in Bebbington Hatcher’s et al. (54) study could be related to the different methods of inquiry or sample size; there were 60 who opted for surgery and only 20 who declined surgery in the qualitative study, in comparison to 79 who opted for surgery and 64 who declined in the quantitative component. Nevertheless, the findings in this study show that the quantitative measure did not tell the full story. The qualitative component was able to provide context and rich details. This qualitative work enables a greater understanding and more information about the experiences of those who consider and undergo BPM in this population.

10.3.5 Importance of psychological consultation

A psychological consultation prior to BPM (only identified in the qualitative component) also appeared to influence satisfaction with intimacy and body image. This study identified that for women undergoing BPM seeing a psychologist who was experienced in BPM and familial cancer appeared to assist with adjustment and satisfaction with psychological well-being, body image and intimacy. Patenaude et al. (80) as a result of their study supports recommendations for psychological counselling for those choosing BPM to assist with decision-making and ensuring they have realistic expectations (80). This study, however, goes further and demonstrates the potential benefits of such support in comparison to those who receive no such support. This is a novel and clinically important finding. Previously no studies have explored the adjustment of particular psychological elements, such as psychological well-being and body image in those who have counselling compared to those who have not.

It was, however, important for women to see a psychologist who was experienced in BPM and familial cancer; women who saw a psychologist with no or limited experience appeared to adjust in a similar way to those who did not receive psychological support. Counsellors and psychologists are trained to be non-directive whereas doctors have traditionally been trained to be directive (bio-medical model) and therefore, may not be best suited to discuss psychological and emotional concerns with patients. Psychologists, may however, need further professional
development to become experienced with familial cancer and the management and prevention options. It would be useful for future research to explore how this could best be achieved.

It has been recommended that routine screening (for the presence/absence of psychopathology) be undertaken for the general population of those at high risk to identify those who need more psychological support. A number of studies found a lack of distress in those at high risk (118, 119) and deemed routine screening would not be cost effective. However, women at high risk who choose not to undergo BPM will not have to contend with the issues often associated with undergoing BPM (i.e. negative body image). Furthermore, research of those diagnosed with BC has suggested that the need to seek psychological support is not necessarily related to psychopathology (124) which poses a problem for routine screening in women undergoing BPM to identify those who need more support. Therefore, routine psychological consultation has been recommended to aid in satisfaction following BPM (143) and other authors have suggested it should be made mandatory (80). The cost of standard psychological consultation for this group of women could create a barrier to its use. However, if psychological consultation prior to BPM supports satisfaction post-BPM it may reduce the likelihood of psychological issues post-BPM. It is possible that in the long-term it may actually be cost effective (122).

The need for psychological consultation prior to BPM was further highlighted in this study with women suggesting that it could help them discuss their motives for, and feelings about the surgery, and it could also assist in navigating the medicalised environment surrounding the clinical practice of BPM. Women recalled that their surgeons did not recommend or refer them to a psychologist and did not mention undergoing a psychological consultation. For the few participants who recalled that they received a recommendation for psychological consultation from their surgeons prior to surgery, it was still difficult to access. Some women assumed it would be part of the procedure, however, found they had to organise this support themselves and they often did not know who to see or contact and did not know who had expertise in this field.

10.3.6 Barriers to accessing information
Alongside the difficulty to seek psychological support prior to BPM, women identified a number of barriers to accessing information, including a lack of guidance about who to see next and where they could get more information, a likely result of poor integration of services. This led to inconsistent information and confusion for women. Women desire more information with respect to psychological well-being, body image and sexuality after surgery, and how to
manage post-operative pain (65, 72, 83, 140). However, until now, it has been unclear that poor integration of services could contribute to barriers to accessing consistent information. This is a novel and clinically important finding of this study that could have an impact on improving the management of these women in clinical practice.

It is surprising that, at present, there is poor integration of services between Familial Cancer Clinics (FCCs), general practitioners (GPs), and breast surgeons, since a multidisciplinary (MD) team approach has been advocated for many years (115). Patients needed clinical evaluations, clarification of priorities, including patient goals and individualised discussion of risk management and options (155). This also included discussion of possible poor cosmetic outcome with significant other (172). More recently authors concluded that there are guidelines to assist clinicians in managing women at high risk of developing BC that can be translated into practice (173). However, the lack of information women report suggests that these guidelines may not be appropriate or may need amendment, or that such guidelines have not been translated into clinical practice effectively.

As a result of the barriers to accessing information women identified a number of preferences for how they could receive information. These included the opportunity to seek psychological consultation, clearly defined processes, and photos of mastectomies/reconstructions. These are important findings for the delivery of clinical services. Previous research has identified that women often turn to online information, but, would prefer ongoing contact with clinicians to discuss their risk management (38). Hoskins et al. (39) reported that while online organisations (such as Facing our Risk of Cancer Empowered (FORCE) in the United States) provided young women with access to others in similar situations to themselves they often overwhelmed them. Many women in this study found positive information on forums. However, reported that many negative stories are frequent; which has the potential to increase risk perception. The irrelevant information (for example, specific to American surgical practices) women found online further contributed to their confusion. The need for local and/or regional information was identified. Women would have preferred identification of support groups from their clinicians. Younger women need further support and more information than what is provided online (148).

These findings are a major finding of the present study and highlight the greater need for medical information to come from a trained MD team of clinicians to avoid further confusion for women. A resource (as identified in Chapter Eight (Figure 7)) may lead to increased satisfaction with the pathways to information. However, this study identified some women
would prefer further information from their clinicians directly and it is important to be mindful that a resource should not replace patient information from clinicians. A resource should supplement information provided by clinicians and could be used as a hard copy (or web based) reminder of what women have been told. It could also identify avenues where further information can be found.

10.4 Contribution to the literature

This research presents a comprehensive account, focusing specifically on the perceptions and experiences of younger women (under 35 years) who are considering and/or undergoing BPM. Few studies have investigated younger women at high risk of developing BC and no studies have exclusively focused on younger women whom have undergone BPM. Furthermore, no prior research has previously concentrated on women (of any age) whom are considering BPM, but are yet to make a formal decision about the procedure, or on those with a strong family history of BC without a BRCA mutation. This study adds the contribution of women in these cohorts to the literature. Additionally, this study builds on the Australasian research profile by incorporating the experiences of younger women considering and/or undergoing BPM from Australia and New Zealand (NZ), given the majority of research focusing on younger women at high risk of developing BC has come out of the United States. This research provides new insights from a different context.

The study contributes novel and important findings that are previously unreported in the literature. It was identified that health professionals appear to have an influence on decision-making and risk perception. It is possible this is dependent on individual differences (i.e. personality, a tendency to be more anxious or due to life events) and how women perceive and understand information. In further support of this finding, it was apparent that some younger women continued to be anxious about their risk of developing BC post-BPM. Some of those considering BPM were also unsure if they would feel relieved of anxiety post-surgery, yet they were still considering the procedure. This study reported on the importance of psychological support prior to undergoing BPM and suggested that having the opportunity to have a psychological consultation with an experienced psychologist prior to BPM appears to influence satisfaction with psychological well-being, body image and intimacy. Furthermore, feelings towards ones breasts, type of mastectomy and open communication with significant other also appeared to influence satisfaction with reconstructed breasts and intimacy. New insights into why younger women report a lack of information, and the difficulties to receiving information
are identified in this study; as well as ways in which these could be addressed in the service delivery of clinical practice.

10.5 Limitations and strengths

The retrospective design of this study leads to the possibility of recall or confirmation bias for those who have already undergone BPM. The findings are based on participants’ reports and interpretations and there is the potential for inaccurate recollections and distortions. However, the focus of the study was not memory but participants’ perception. Sampling or recruitment bias is another limitation with a self-selected sample of women who were willing to share their stories. Those who elected to be part of the study may have been those with strong viewpoints, those with a story to tell, or those who have more time. It is possible that the difference in sample size for those who did not have a confirmed mutation (n=10) and those who did (n=36) could have also skewed findings. Comparisons between groups are challenging in qualitative studies and the findings suggest group differences need to be further examined. The majority of women were in a de facto relationship and the findings may not be the same for single women. No women identified as being in a same sex partnership, there were no Aboriginal, Torres Strait Islander or Maori women in the study and all but two women identified as Caucasian; as such findings may not be applicable to other women. The majority of women in this study had an implant type of reconstruction.

This study also has a number of strengths. Data saturation was reached in both groups. The study involved women sampled across Australia and New Zealand (NZ). The findings are robust and provide salient examples of decision-making, risk perception, the benefits of psychological consultation prior to BPM, satisfaction and dissatisfaction with body image and intimacy and barriers to accessing information, by using women’s direct quotes and providing rich examples. The rigour of this study is evidenced by the multiple methods of recruitment from across Australia and NZ thus obtaining a diverse sample. This study is also the first to specifically investigate the experiences of younger women who undergo BPM and it provides salient examples where changes in practice could increase patient satisfaction.

In order to minimise the effects of recall bias a more suitable comparison group was women considering BPM, to explore the influences on decision-making prior to undergoing BPM. Lloyd et al. (65) expressed a limitation of their study was not including those who were waiting for surgery or in the decision-making phase of considering a BPM. Given that it has been established women undergoing surveillance are not as anxious as those undergoing BPM they
would not make a good group to explore how women undergoing BPM may have felt prior to their surgery.

10.6 Clinical Implications

These findings have salient implications for practice:

10.6.1 An integrated model of care

These findings identify recommendations for developing an integrated model of care for the management of women at high risk of developing BC (who may consider and/or undergo BPM). At the forefront of such a model is a MD team and a specialist clinic.

The services a MD team should encompass include, genetic counselling and testing, management of risk factors, surveillance and prevention options. A specialist high risk clinic would give women the option to consult with specialist breast physicians, breast surgeons and reconstruction surgeons, should they wish to pursue BPM. The MD team could also encompass professionals whom are able to discuss and manage the side effects of undergoing BPM, such as a psychologist experienced in familial cancer and the management of women at high risk. Ideally the MD team would encompass the following professionals; geneticist, genetic counsellor, breast physician, breast nurse, breast surgeon, reconstruction surgeon and psychologist. These professionals all have important roles to play in the management of high risk women and they need to work together to deliver optimal and satisfactory care. The specialist clinic should also have a good relationship with GPs who are often the first point of call for women at high risk of developing BC.

A MD team would assist in improving the lack of integrated services and inconsistencies/gaps in information reported in this research (i.e. ensure everyone is giving the same information). A specialist clinic encompassing a MD team could also reduce referral times and confusions about referral pathway between specialists, as all involved would be working together. The flow diagram included in Chapter Eight (Figure 7) for those at high risk of BC could be adapted for both patients and clinicians. Regular management meetings for the MD team would allow for discussion and reflection upon practices.

The development of standards of care in this area would ensure everyone in the MD team has a clear understanding of their role and the roles of others. A protocol based on current clinical practice should be developed for the team, including clear guidance on where to refer women and in what order, and what the clinical pathway should be following identification of increased BC risk. A protocol could assist clinicians to cover all the benefits and harms of BPM with
their patients to aid in informed decision-making and would ensure consistent risk estimates are quoted to women, reducing confusion and possibly unnecessary heightened risk perception. Furthermore, resources for both clinicians and patients identifying clearly defined pathways and relevant support networks, including who they see, what is discussed, where they go and in what order, could help alleviate the lack of information women report. The provision of education and professional development for GPs on genetic susceptibility, mutations associated with BC and the management options should also be a priority. An established MD team with clear standards of care and protocols could enable a smooth transition of education to GPs, which includes detailed guidelines of GPs role in the management of women at high risk.

Within the integrated model of care it would be useful to include research activities. A specialist high risk BC clinic would create a unique environment for conducting research to improve health and health care delivery for high risk patients. It would enable clinicians to access a wider range of research projects and easily identify patients who may be eligible for clinical and prevention trials.

10.6.2 Pre-BPM psychological consultation

A recommendation that all women considering BPM undertake specialist psychological consultation could assist in identifying very anxious patients who may be at risk of continuing to overestimate their risk of developing BC after BPM (109). It could also assist them to prepare for surgery in a non-medicalised environment. Furthermore, it could help identify those who need more psychological support, particularly those who seem to be rushing the decision to undergo BPM. Psychological support could help women make an informed decision and assist them with psychological distress (117). Routine referral for psychological consultation prior to BPM could provide women the opportunity to discuss their concerns (such as how they feel about their breasts) and raise issues (such as impact on intimacy) that they may not have considered. It could also help to ensure women’s expectations are accurate. Involvement of the partners’ of women considering BPM in psychological consultations should also be explored to encourage open communication concerning BPM and intimacy. Likewise it would be useful for single women to discuss future intimate relations with a psychologist experienced with BPM and familial cancer.

Surgeons do not necessarily have the time or the skills to discuss psychosocial concerns with women (122); they should, however, be aware of whether younger women’s perceptions of
risk are justified, particularly those with no known mutation. Psychological support for women prior to BPM could assist clinicians by ensuring adequate discussion of risk perception and decision-making. The implementation of routine psychological consultation by appropriately trained professionals for women considering BPM, irrespective of the technicalities of surgery, should be explored. As standard practice it will likely lead to fewer psychological adjustment issues post-surgery (109). This could be cost effective and enable surgical consultation time to be used more effectively (122).

10.6.3 Communication of risk statistics
Younger women appear to be not as relieved of anxiety by undergoing BPM as previous research suggests. These findings highlight the importance of accurate and consistent communication of improved risk statistics to younger women, particularly those with no known genetic mutation. Emphasis should be placed on communicating the residual risk of developing BC post-BPM. Communicating improved and consistent risk statistics in clinical practice is important for patients to make informed decisions about their BC risk management. Those who have inaccurate perceptions of BC risk may undergo BPM unnecessarily. It is important to identify why a woman wants to undergo BPM. This is key given the fear younger women who undergo BPM recount. The lack of apparent differences between BRCA1/2 carriers and those with no proven mutation is a novel finding suggesting both groups may experience similar perceptions of BC risk (107).

10.6.4 Communication with clinicians
The way women interpret information given to them by clinicians needs to be taken into account when discussing risk with younger women. Communication of accurate risk statistics should be encouraged by all clinicians (not just those confined to genetics clinics) to ensure that younger women are being quoted consistent risk statistics by all other health professionals; the genetic counsellor should communicate to them the risk assessment provided to the woman. Accurate risk perceptions are important when making informed decisions about health. Furthermore, surgeons have an important role in conveying realistic expectations to younger women to achieve greater patient satisfaction post-surgery. Consistent and accurate information and discussion of different mastectomy types, conveying accurate risk and outcome expectations so women can make informed decisions is also important.
10.7 Future Research

There are a number of areas of further research needed. 1. A direct comparison between younger and older women undergoing BPM; 2. contrasts between qualitative and quantitative data for women choosing BPM; 3. who is at risk of continuing to overestimate BC risk post-BPM; 4. the development of a new body image and intimacy measure for this cohort of women; 5. The implementation and effectiveness of an integrated model of care and 6. the effectiveness of a psychological intervention. These will be discussed in more depth below.

It would be useful to conduct a direct comparison with younger and older women undergoing BPM, to further support the suggestion that they have different experiences, and to encourage age-related practices. Particularly, a prospective study which tests the hypothesis generated by this work that older women’s anxiety decreases more after BPM than younger women’s would be useful.

Further research should explore the contrasts between quantitative and qualitative findings, particularly surrounding satisfaction with BPM, focusing on body image and intimacy. More research is also needed to explore the differences between quantitative and qualitative findings for cancer-related anxiety or worry.

More research is needed to investigate who is at risk of continuing to feel anxious about BC risk following BPM. It is possible confusion surrounding residual risk of BC following BPM could account for the uncertainty related to perceived risk post-BPM and more research is warranted. Future research could also focus on understanding why women interpret information differently, including exploring the impact of individual differences and health literacy on decision-making and risk perception.

A body image and intimacy measure for women at high risk of developing BC considering and undergoing BPM should be developed and validated to measure accurately and reliably these elements in this population. Variables that affect satisfaction as identified in this study, such as women’s satisfaction with their breasts before surgery, outcome expectations, type of mastectomy and prior psychological consultation, should be incorporated into the measure. The development of a measure that includes these variables would likely be a more accurate measure of body image and intimacy in this population. A larger study could assist clinical practice by investigating the predictors of satisfaction with body image and intimacy for women undergoing BPM.
It would be useful to conduct a prospective study or a randomised control trial on the feasibility, acceptability and effectiveness of a MD team. Patients could be assessed at baseline during their first visit to the MD team and then again at a later time, or those in the MD could be compared to those with no access to such a clinic. Once established it would be useful for research to investigate the implementation and effectiveness of an integrated model of care for high risk women to strive towards continually improving the service and staying up to date with current practices. Patient and clinician satisfaction with the MD approach would also be useful. It is possible this could be developed in other locations and adapted to other medical issues.

Routine psychological consultation for all women considering BPM could ensure that women’s understanding of risk and BPM is accurate and realistic (109). Future research should focus on testing the efficacy and feasibility of a psychological intervention and determining the cost-effectiveness. It would be useful to explore the role of a psychological consultation prior to BPM and the impact (if any) on risk perception. Research supporting routine psychological consultation could assist in policy recommendations that encourage health care providers to subsidise the cost of psychological consultation for all women undergoing BPM. Furthermore, it would be useful for research to explore the best ways of upskilling psychologists in familial cancer management and prevention options to be able to understand the types of issues and concerns these women may have.

10.8 Summary
The present study sought to understand the experiences of younger women (<35 years) who choose to undergo or consider BPM. The major findings and recommendations for clinical practice are summarised below:

• Important findings were identified with respect to decision-making and the role of clinicians. Clinicians appeared to influence younger women’s risk perception and decision-making in their discussions with women, causing them further anxiety. Individual differences, such as perception or experience and health literacy also appeared to influence risk perception and decision-making. Clinicians should be aware during consultations with younger women that different women may interpret the facts they present differently and they should always communicate accurate risk statistics as opposed to telling stories or identifying worst case scenarios. Risk estimates in this study and the wider literature are frequently inconsistent
creating confusion and increasing risk perception, this in turn also seemed to influence decision-making.

• The differences between the qualitative and quantitative component are important and need to be considered by researchers when contemplating future research with this population of women. Quantitative data alone may not adequately represent the experiences of women undergoing BPM, particularly in relation to body image and intimacy; this needs to be further investigated.

• It appeared that there were a number of important influencers to satisfaction with BPM, which need to be taken into consideration in clinical practice. Prior psychological consultation appeared to assist satisfaction with body image, intimacy and psychological well-being post-surgery. Specialist psychological consultation for all women considering BPM should be introduced into all clinical practice.

• It is important that women hold realistic expectations about the look and feel of their reconstructed breasts post-BPM, this study identified that medical professionals and psychologists can both assist in realistic outcome expectations by discussing this with their patients, but also using appropriate photos.

• A major finding of this study was that a lack of integrated services appears to have led to inconsistent information. Women perceive further barriers to accessing information are the clinical/medicalised environment of consultations. A MD team approach could assist with consistent information and clearly defined processes for both women and their clinicians. This study identifies that a resource could assist women to understand the pathways to information when considering BPM; however, women continue to want information from their health professionals and a resource should not replace this.

The findings presented in this study are a unique comprehensive body of work exploring the previously unknown experiences and concerns of younger women considering and/or undergoing BPM. It identifies a number of areas to improve the outcomes for women at high risk of BC in clinical practice; including detailed ways clinical practice can improve their services to incorporate the needs of younger women when choosing BPM.
References


Appendices

Appendix 1: Scientific Meeting Multidisciplinary Team Poster

The need for a multidisciplinary approach to the management of younger women at high risk of developing breast cancer considering bilateral prophylactic mastectomy (BPM)

Rachael Glassey1, Moira O’Connor1, Angela Ives1, kConFab Investigators1,4, Sarah J. Hardcastle1 Christobel Saunders1

Purpose
To understand from the patients perspective, the current care of younger women (<35) in relation to BPM, focusing on information received/needed and how this could be approached in the clinical setting.

Background
• Women undergoing BPM want more information (Hallowell et al., 2012).
• We do not know why or what influences the lack of information.
• Early research suggested a multidisciplinary (MD) team should manage women (Goodwin, 2000).
• There are some guidelines to management (Wuttke & Phillips, 2015).
• However, it would seem these have not been translated into clinical practice.

Methods
• Recruited women <35 years old considering or having undergone BPM.
• A strong family history of breast cancer or a BRCA1/2 mutation.
• Recruited throughout Australia and New Zealand.
• Semi-structured interviews were conducted.
• Demographic details were obtained via an online survey.

Participants
• Forty-six women participated.
• 26 had undergone BPM, 20 still considering BPM.
• Mean age 30.4 years.
• 36 BRCA carriers and 10 with no known mutation.

Less medicalised terminology
• “they didn’t really explain much they just spoke in their doctors terms”.

Psychological well-being
• “there’s been no psychological impact, things like that, it’s just been very clinical, this is what’s going to happen, this is what you should do”.

Interpretative phenomenological analysis revealed

3 main themes (with subthemes)

Lack of joined up services
• “when I went to the public surgeon she said there was no way she was going to let me keep my nipples, when I went to private I asked can I keep my nipples, what’s your opinion and he goes of course you can keep your nipples, I was really surprised...It was confusing and really hard...these two surgeons who actually work closely together in the public and they are giving completely different advice.”

Location information
• “they [genetics department] said go and see your GP and then get a referral from your GP...I went and saw a doctor and he didn’t even know what the gene was so that was a bit disappointing, he had no idea what I had or what was going on”.

Conclusions
• These themes identify clinical implications for a MD approach to the management of younger women considering BPM.
• Coordination by GP’s, genetics clinics, high risk clinics, surgeons and psychologists is key.
• Routine psychological consultation prior to BPM should be explored to assist with and support, psychological well-being and body image.
• Location specific and clearly defined processes should be developed to provide women with more information.
• A protocol should be developed to enable smooth transition to a MD healthcare approach.

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Appendix 2: kConFab Conference Poster

Heightened risk perception and the influence on decision-making in younger women undergoing bilateral prophylactic mastectomy (BPM)

Rachael Glassey1, Monika O’Connor1, Angela Ives1, Christopher Saunders1, kConFab Investigators2, Sarah O’Sullivan2, Sarah J. Harkness2

Aim
To explore the influence of risk perception on decision-making in younger women (<35) at high risk of developing breast cancer who are undergoing or considering BPM.

Background
- Perceived risk of developing breast cancer influences women’s decision to undergo a BPM.
- BPM is associated with a reduction in anxiety post-surgery (van Dreel et al. 2016).
- BPM before age 40 gives the greatest risk reduction (Cancer Institute NSW, 2009).
- Women in their 20s and 30s are underrepresented in the BPM literature (Glassey, 2016).

Methods
- Recruited women <35 years old considering or having undergone BPM.
- A strong family history of breast cancer or a BRCA1/2 mutation.
- Recruited throughout Australia and New Zealand.
- Semi-structured interviews were conducted. Demographic details were obtained via an online survey.

Participants
- Forty-six women participated.
- 26 had undergone BPM, 20 still considering BPM.
- Mean age 30.4 years.
- 36 BRCA carriers and 10 with no known mutation.
- Quotes represented by pseudonym, age and M- undergone BPM or C – still considering.

Conclusions
- Fear appears to be the main influence to undergo a BPM. Some women are not relieved of anxiety after BPM.
- Those who had undergone BPM appeared more anxious about developing breast cancer than those who were still considering BPM.
- Heightened risk perception may be related to a tendency to be more anxious.
- It is important to ensure the risks of developing breast cancer and the residual risk after BPM are accurately communicated to younger women at high risk of developing breast cancer.
- Health professionals need to be aware of their influencing over decision-making.
- Psychological consultation for all women considering BPM could help identify anxious patients who may overestimate their risk of developing breast cancer after BPM (Glassey, 2017).

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THE UNIVERSITY OF WESTERN AUSTRALIA

BBM Status

- Already undergone BPM
- Considering BPM

BRCA1/2 carriers
No known mutation

Underlying fear and anxiety
Screening anxiety and fatigue
Influences on decision-making revealed 7 themes
Confusion about residual risk
Relief following surgery
Information increasing fear of breast cancer
Personal experiences with breast cancer
Children

“I had said already that I was having a BPM, didn’t care if they found a BRCA mutation” (Study, 36, M)
“I am less attached to the fact that it is an inevitability, the screening is still good, I don’t need to undergo BPM” (Studley, 32, C).

I serve tea and cake while they are there[ed, the top social mix drink] I tell you to be more upbeat” (Study, 29, F).

“I was doing it for my mum. She would have been so scared if I didn’t do it” (Study, 30, F).

“I suffer from anxiety, quite a lot when I was 26, 27, I had to start taking a pill”.

“I have a lot of anxiety in my day-to-day life” (Study, 25, M).

“I can’t believe I’ve done this” (Study, 23, F).

I want to do what’s best for my daughter (Study, 35, M).

I’m not going to let my children think of me as a cancer victim” (Study, 30, F).
Appendix 3: Commentary Publication

Commentary: Bilateral risk-reducing mastectomy is the safest strategy in BRCA1 carriers

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Keywords: familial cancer, bilateral prophylactic mastectomy, risk management, counseling, psychological support

A commentary on

Bilateral risk-reducing mastectomy is the safest strategy in BRCA1 carriers


Pilgrim and Pain (2014) suggest the best option for BRCA1 carriers is to undergo a bilateral prophylactic mastectomy (BPM). Pilgrim and colleagues suggest that a BPM combined with salpingo-oophorectomy at 25 years old is the best option to minimise risk of developing breast cancer (BC) and ovarian cancer. Undergoing BPM may be the safest option to reduce incidence and mortality, however a diagnosis of a BRCA mutation does not confer a 100% risk and BPM is not the only risk management option. The risk (to 70 years) of developing BC for a BRCA1 carrier is estimated to be about 80% (Mersadat et al., 2017) and it has been suggested women with BRCA mutations may have up to 80% lifetime risk (National Cancer Institute, 2013). We contend BPM it is not necessarily the best option for all women, especially at such a young age and without a process of fully informed and supported decision-making. The purpose of the current paper is to highlight that health professional recommendations to undergo a BPM may lead to patient regret and clinician blame. Our commentary highlights the consequences of undergoing a BPM without a process of fully informed decision-making, including potential emotional and psychological complications associated with body image and sexuality. We suggest health professionals should provide patients with all options, including screening, medical risk reduction (e.g., tamoxifen) and BPM. We propose all women considering BPM should be referred to an experienced counsellor or psychologist to discuss their options, and ensure these individuals are making an informed decision and not one driven by fear or based on the perceived bias of one health professional or other individual, such as anecdotal advice from well-meaning friends or family.

Women with a BRCA mutation are often extremely fearful about developing BC (Deatt, 2016). As such, many are driven to undergo BPM out of fear without considering the consequences (Frost et al., 2000). Furthermore, there is evidence to suggest that discussions initiated by a health professional to opt for BPM may lead to regret post-surgery in some women. For example, Payne et al. (2000) found that initiation of discussion about BPM could influence women’s decision-making. They found that those who had regrets about their surgery reported the discussion about BPM was initiated by a health practitioner. They concluded that a practitioner-initiated discussion about undergoing BPM predicted regret. More recently, there are reports of litigation on the basis that women were ill-informed of treatment options and left with complications following BPM. Early in 2016 an Australian newspaper reported a story of two women using a hospital following BPM on the basis that health professionals did not fully explain treatment options to...
them (Cavazzuti and App, 2016). If health professionals encourage BPM simply based on statistical risk reduction and without taking into account other options and potential consequences of surgery, it may increase psychological issues post-surgery and lead to women blaming health professionals if they are unhappy with the outcome or feel they were not fully informed of other options. Regret may be more common if the solution to a proven BRCA mutation is in practitioners reconsidering BPM and women feeling rushed into surgical options, primarily out of fear, and without a process of informed and supported decision-making (Taylor and Tsichliswotzke, 2014).

Health professionals should discuss with women of all their options in an unbiased fashion, which includes BPM as one option. Women who wish to consider the irreversible procedure of BPM should then be referred by their practitioner to a psychologist to discuss these options, including deferring a decision to a later date, especially if women are as young as 25 years old.

Statistically BPM may be the best option to reduce the risk of developing BC. Although the risk is not reduced to zero, BPM may reduce the relative risk that BC will develop by over 90% (Hartmann et al., 1999; Robbeek et al., 2004). This is important to highlight since there may be the perception amongst patients that BPM reduces the cancer risk to zero, which is not true. The decision to undergo BPM is a personal decision and is often fraught with emotional, psychological and physical complications (von Heijer et al., 2012; Hallowell et al., 2013). The decision needs to be informed and made by the individual (Taylor and Tsichliswotzke, 2014). A decision to undergo BPM needs to take into account factors such as having children, breast feeding, quality of life and intimacy. A woman’s perception of her body can change as a result of BPM, and this can contribute to women feeling less feminine. Women often report their reconstructed breasts look and feel unnatural which makes them feel less attractive and impacts their sex life (Altschuler et al., 2008; Brandberg et al., 2008). Poor cosmetic outcomes, complications from surgery and/or reconstruction are not uncommon and often associated with greater psychological distress (Robbeek et al., 2004).

For these reasons we suggest that there is a need to provide counseling/psychological consultation to BRCA positive women who are considering BPM. This approach is less likely to lead to practitioner blaming and will ensure women are fully informed about the best course of action for them before deciding and undergoing BPM. Patsenaude et al. (2008) demonstrated support for psychological consultation before BPM by an experienced and knowledgeable practitioner. Women in their study suggested it would be helpful to anticipate what they might feel after undergoing surgery. An experienced counselor/psychologist is equipped to discuss psychological and emotional implications of a BPM to ensure women have explored all the options and are able to make an informed decision. Women may often not be able or willing to understand the ramifications of this surgery because they are so driven by fear. Emphasis on ensuring women understand the realities of BPM and making sure they are ready for such surgery, will likely lead to more satisfaction and less psychological adjustment issues following surgery.

In summary, women with BRCA mutations should be fully informed and supported in their decision around treatment both now and into the future, including understanding both benefits and potential complications of all treatment options. Women who wish to consider BPM should be referred for counseling and psychological support to ensure they understand their options and the implications of undergoing BPM.

AUTHOR CONTRIBUTIONS

BG and SH conceived the ideas presented in the article. BG drafted the article. Both SH and CS assisted in drafting and refining the article prior to submission.

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Conflict of Interest Statement: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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1 message

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4 April 2017 10:27:06

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If you have more questions, please do not hesitate to contact me.

With best wishes,

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From: Rachael Glassey
Date: 01/04/2017 03:55 AM

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Dear whom it may concern,

I published the following article in The Breast in 2016: Decision making, psychological wellbeing and psychosocial outcomes for high risk women who choose to undergo Bilateral Prophylactic Mastectomy - A review of the literature.

Appendix 5: Front cover – The Breast publication

Review

Decision making, psychological wellbeing and psychosocial outcomes for high risk women who choose to undergo bilateral prophylactic mastectomy – A review of the literature

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ARTICLE INFO

Article history:
Received 2 February 2016
Revised 1 revised item
23 May 2016
Accepted 26 May 2016

Keywords:
Prophylactic mastectomy
Psychological wellbeing
Anxiety
Body image
Young women
Familial cancer

ABSTRACT

A bilateral prophylactic or preventative mastectomy (BPM) for women at high risk of developing breast cancer (BC) can reduce their risk of developing the disease by up to 90% (relative risk reduction). An increasing number of women, including young women, are taking up this option. However, there is a dearth of information for younger women (under 40 years) choosing preventative mastectomy. In fact, no studies to date have specifically focused on young women’s experiences of BPM and investigated their informational needs.

The purpose of this review is to report on the current literature surrounding the psychological experience of a BPM and the informational needs for women at high risk of developing BC with a particular emphasis on younger women.

Research has highlighted a range of psychological outcomes linked to preventative mastectomy, including positives such as reduced anxiety and negatives including impaired body image and sexuality. The literature strongly suggests women want more information surrounding BPM, particularly related to the after-effects of the surgery, and the impact on their psychological wellbeing. Research method limitations and reporting has resulted in conflicting conclusions, making it difficult for women to be well informed. In particular, there has been little focus on the experiences and needs of younger women opting for BPM. Due to the unique needs of younger women and an increase in BPM rates in younger women, it is imperative that the needs of this group are addressed. Together these findings provide justification and recommendation for further research in this area.

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Introduction

The removal of “healthy” breasts is often seen as a drastic or “radical” procedure undertaken on the basis of fear [12]. A bilateral prophylactic or preventative mastectomy (BPM) is the surgical procedure to remove a woman’s breasts as a precaution to later developing breast cancer (BC), for women with a significant family history of BC, such as two or more first or second-degree relatives on the same side of the family diagnosed with a breast or ovarian cancer or a BRCA1/2 mutation, a BPM can reduce the relative risk that BC will develop by over 90% [1, 4]. Guidelines for BRCA1/2 carriers suggest breast screening should start between the ages of 25–30 years [5–7]. The recommendation for undergoing a BPM is that it has the greatest benefit in risk reduction for women before age 40 years [7]. Uptake of BPM has reportedly differed per country. In an Australian study BPM has been found to be relatively low with only 21% of BRCA1/2 carriers undergoing BPM (n = 325) [8]. However, in two European studies, from England (n = 211) and Denmark (n = 80), the uptake of BPM for high-risk women was estimated to be between 40 and 50% [9, 10]. In both European studies higher uptake of BPM was significantly associated with younger women, with the average age being <35 years and <40 years respectively. These studies suggest that in recent years younger women are undertaking BPM more frequently. However, to date there appears to be no studies detailing the specific experiences of younger women (<40 years) who undergo a BPM.

Other and younger women differ in the various roles they adopt at certain points in their life and consequently have different priorities and responsibilities [11]. Erickson defined young adulthood...
## Appendix 6: Table of studies

<table>
<thead>
<tr>
<th>Author and Country (where study took place)</th>
<th>Focus</th>
<th>Participants</th>
<th>Design</th>
<th>Age</th>
<th>Data collection</th>
<th>Follow up</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altschuler et al. 2007, USA</td>
<td>Long-term psychosocial experiences of BPM and CPM</td>
<td>684 (117 BPM and 567 CPM)</td>
<td>Retrospective Quantitative (primarily but inclusion of two open questions)</td>
<td>&lt;45-46 (7%) &gt;45-638 (93%)</td>
<td>Self-administered survey mailed</td>
<td>None</td>
<td>Conflicting. 70% women responded negative or different comments for open questions yet indicated satisfaction on closed question.</td>
</tr>
<tr>
<td>Bebbington Hatcher et al. 2001, UK</td>
<td>Psychosocial impact of BPM</td>
<td>154 (79 BPM and 64 declined BPM)</td>
<td>Prospective Qualitative Quantitative</td>
<td>Range: 26-57 Mean: 38 BPM; 40 decliners</td>
<td>Semi structured interview and questionnaire</td>
<td>6 and 18 months; 18 months (decliners only)</td>
<td>Psychological morbidity decreased significantly over time for BPM group. Decliners had greater anxiety. BPM group believed they would get BC; decliners believed screening could help. No change in sexual discomfort.</td>
</tr>
<tr>
<td>Bebbington Hatcher et al. 2003, UK</td>
<td>Psychosocial implications of BPM</td>
<td>60 BPM; 20 declined BPM (selected from above study)</td>
<td>Prospective Qualitative</td>
<td>Range: 22-57 Mean: 40</td>
<td>Semi structured interview</td>
<td>None</td>
<td>BPM group were extremely anxious and surgery relieved that. Decliners were not anxious. Women not sure what questions to ask at consultations. More information and support should be offered to high risk women.</td>
</tr>
<tr>
<td>Bonadies et al. 2011, USA</td>
<td>What BRCA carriers wish they knew before BPO</td>
<td>98 BRCA carriers</td>
<td>Retrospective Quantitative (primarily but three open questions)</td>
<td>Range: 30-35 (9.2%) 36-40 (21.4%) 41-65 (69.4%) Mean: 45.5</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>60% of the most common symptoms post-surgery were not discussed with women before surgery. The most common symptoms related to changes in sex life and interest and sleep problems. Majority of women would have liked more information in relation to these changes.</td>
</tr>
<tr>
<td>Borgen et al. 1998, USA</td>
<td>Regrets after BPM</td>
<td>370</td>
<td>Retrospective Quantitative</td>
<td>Range: 25-73 Mean: 45.5</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>Overall satisfaction rate with BPM. 5% (n=21) had regrets. Most common factor was physician initiated discussion of BPM, compared to those who initiated discussion about BPM themselves (19/2)</td>
</tr>
<tr>
<td>Brandberg et al. 2008, Sweden</td>
<td>Psychological reactions to BPM</td>
<td>90 women (56) at all time points</td>
<td>Prospective Quantitative</td>
<td>Range: 20-29 (8%) 30-39 (37%) 40-69 (55%)</td>
<td>Self-administered questionnaire</td>
<td>6 and 12 months</td>
<td>Women reported issues with body image. 48% both for self-consciousness and feeling less sexually attractive. 44% were unhappy with their scars. Sexual pleasure was lower at 12 months than baseline. Anxiety decreased over time.</td>
</tr>
<tr>
<td>Bresser et al. 2007, Netherlands</td>
<td>Distress in women who decide on BPM and BPO</td>
<td>78 (52 BPM and 26 prophylactic salpingo-oophorectomy (BPSO)</td>
<td>Prospective Quantitative</td>
<td>Range: 25-63 Mean: 43</td>
<td>Mailed questionnaire</td>
<td>6 and 18 months</td>
<td>Following BPM significant reduction in anxiety and cancer related worry. At 12 months many women still show clinically high anxiety. Women who opt for BPM as opposed to screening show consistently higher distress.</td>
</tr>
<tr>
<td>Authors</td>
<td>Design / Time Period</td>
<td>Prevalence of Risk Reducing Measures</td>
<td>Prevalent BRCA1/2 Carriers</td>
<td>Study Methods</td>
<td>Review of Pathology / Medications</td>
<td>Follow Up Period</td>
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<td>Collins et al. 2013, Australia and New Zealand</td>
<td>Prospective Quantitative &lt;20 (1%) 20-30 (26%) 31-40 (34%) 41-70 (39%)</td>
<td>325 BRCA1/2 carriers</td>
<td>Review of pathology and medical records</td>
<td>3 yearly</td>
<td>69 (21%) underwent BPM and 125 (38%) underwent BPSO and 9 (3%) took risk reducing medication. Over follow up period 68 (21%) developed cancer 9 ovarian and 52 BC. Small proportion of women underwent BPM.</td>
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<td>Domchek et al. 2010, USA &amp; UK</td>
<td>Prospective Quantitative Mean: 37-40</td>
<td>1619 BRCA1/2 (247 BPM 1372 no BPM)</td>
<td>Prospective Quantitative Range: &lt;40 (39.7%) 41-60+ (60.3%)</td>
<td>Medical records</td>
<td>Follow up for 3 years (median 9 years)</td>
<td>247 underwent BPM of which there were no BC’s over a 3 year follow up compared to 1372 who didn’t have BPM of which 98 BC’s were detected.</td>
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<tr>
<td>Domchek et al. 2010, USA</td>
<td>Prospective Quantitative Mean: 37-40</td>
<td>BC risk for BRCA1/2 negative women 375</td>
<td>Review of pathology and medical records</td>
<td>3 yearly</td>
<td>Two in situ (expected 0.9) and two invasive (expected 4) BC were diagnosed. No increased risk of invasive BC. Moderately increased risk of DCIS.</td>
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<td>Evans et al. 2009, UK</td>
<td>Prospective Quantitative Mean: 37-40</td>
<td>211 BRCA1/2 carriers 3,515 &gt;25% lifetime risk</td>
<td>BRCA1/2: 35-79 (8.7%) 35-45 (40.2%) 46+ (22.3%) Unknown (4.8%)</td>
<td>Medical records</td>
<td>4.19 years</td>
<td>40% of 211 opted for BPM and was significantly correlated with risk and age. In women who were not known to have a BRCA mutation 6.4% at 40-45% lifetime risk underwent BPM and 1.8% at 25-32% lifetime risk underwent BPM.</td>
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<tr>
<td>Frost et al. 2000, USA</td>
<td>Prospective Quantitative Mean: 37-40</td>
<td>572</td>
<td>Self-administered questionnaire</td>
<td>None</td>
<td>70% of women were satisfied with BPM. Positive outcomes such as decreased concern over developing BC however 36% reported decreased satisfaction with body appearance.</td>
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<tr>
<td>Hallowell et al. 2012, Australia and New Zealand</td>
<td>Retrospective Qualitative Mean: 34</td>
<td>Women’s reactions to risk reducing surgery 40 including 8 BPM, 19 BSO and 13 BPM+BSO</td>
<td>Semi-structured telephone interviews</td>
<td>None</td>
<td>Women viewed BPM positively due to reducing their BC risk. Some reported positives in breast shape and size However many women reported body image and sexuality issues and had unrealistic expectations. Women are informed of order of events but not reality of BPM.</td>
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<tr>
<td>Hamilton et al. 2009, USA and Canada</td>
<td>Retrospective Qualitative Range: 18-28 (31.8%) 29-40 (68.2%)</td>
<td>Life trajectory’s of young women with family histories of BC 44 BRCA1/2 carriers (including 23 BPM)</td>
<td>Email (n=33) and phone interviews (n=11)</td>
<td>None</td>
<td>Decisions regarding risk reducing surgery were related to life trajectory’s following genetic testing. Support for importance of understanding in younger age group. One lady was as young as 23 undergoing BPM. Want to have surgery before they become like other family members.</td>
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<tr>
<td>Hartmann et al. 1999, USA</td>
<td>Retrospective Qualitative Range: 18-79 Mean: 42</td>
<td>Efficacy of BPM and CPM 639 (214 high risk: 425 moderate risk)</td>
<td>Questionnaire Review of pathology</td>
<td>None</td>
<td>Gail model predicted 37.4 BC’s in moderate risk group; 4 occurred; BPM offers 89.5% risk reduction. 403 sisters of high risk group who did not undergo BPM 156 (38.7%) developed BC</td>
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<td>Heemskerk- Gerritsen et al. 2007, Netherlands</td>
<td>Retrospective Qualitative Range: 22-55 (BPM women) &lt;30 (11.8%) 30-39 (49.7%) &gt;40 (38.5%)</td>
<td>Risk of BC after BPM 358 (177 unaffected (BPM) and 181 affected)</td>
<td>Data extracted from hospital records</td>
<td>4.5 years post-surgery</td>
<td>In all 358 women no primary BC occurred after BPM. BPM median age was younger in affected women than affected women.</td>
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<td>Study</td>
<td>Country</td>
<td>Study Type</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Time Frame</td>
<td>Main Findings</td>
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<tr>
<td>Heiniger et al. 2014, Australia and New Zealand</td>
<td>Long-term psychosocial outcomes for BPM and BPSO women</td>
<td>223 (17 BPM/39 controls; 38 PSO/94 controls; 15 BPM &amp; BPSO/30 controls)</td>
<td>Prospective Quantitative</td>
<td>&lt;40 (24.3% 40-60+ (75.7%)</td>
<td>Questionnaire</td>
<td>3 years post-surgery</td>
<td>Women who underwent BPM had a reduction in perceived BC risk and cancer related anxiety compared to controls. No differences were found in body image, general anxiety and depression.</td>
</tr>
<tr>
<td>Hoskins et al. 2012, USA</td>
<td>Decision making of BPM for young women</td>
<td>60 BRCA1/2 carriers</td>
<td>Retrospective Qualitative</td>
<td>Range: 21-36 Mean: 29.6</td>
<td>Telephone interview</td>
<td>None</td>
<td>Decision to undergo BPM; screening fatigue, alternative to cancer and risk not worth it; encouragement from family; desire to put high risk in the past. Many young women have an urgency to complete BPM and face timing challenges with respect to family formation. They wished to eradicate devastating outcomes such as cost and stress of screening, radiation and chemotherapy and putting family members through a cancer diagnosis. Young women struggle for some time in deciding on BC risk management.</td>
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<tr>
<td>Hoskins et al. 2014, USA</td>
<td>Young BRCA1/2 positive women managing their risk</td>
<td>32 BRCA1/2 carriers</td>
<td>Retrospective Qualitative</td>
<td>Range: 21-27 Mean: 23.2</td>
<td>Semi structured interviews.</td>
<td>None</td>
<td>Women prior to 25 years needed further clarity with respect to screening and prevention. Expressed need for continuing contact with health professionals for risk management. Women of this age have specific needs; accurate, clear and consistent information and supportive guidance whilst making autonomous decisions.</td>
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<tr>
<td>Josephson et al. 2000, Sweden</td>
<td>Experiences of the decision making process of BPM</td>
<td>15</td>
<td>Retrospective Qualitative</td>
<td>Range: 29-50 Mean: 39</td>
<td>Semi structured interviews</td>
<td>None</td>
<td>Genetic information was hard to understand and lacked psychological support however women were satisfied with the manner it was given. No decision regrets, importance was reduced risk. Authors recommend a multidisciplinary approach including psychologist.</td>
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<tr>
<td>Kauff et al. 2005, USA</td>
<td>BC &amp; ovarian cancer families &amp; who test negative for BRCA1/2</td>
<td>165</td>
<td>Prospective Quantitative</td>
<td>Mean: 51.6 Range: 22-77 Mean age at BC diagnosis 48.5</td>
<td>Questionnaire</td>
<td>Mean 4.6 months</td>
<td>19 new BC’s were diagnosed however only 6.09 were expected. 1 case of ovarian cancer was diagnosed and the expected rate was 0.66. Individuals who test inconclusive for BRCA1/2 and their family members are still at increased risk of BC but not ovarian cancer.</td>
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<td>Klitzman et al. 2010, USA</td>
<td>Process of deciding about BPM and BPO</td>
<td>32 (12 unaffected)</td>
<td>Retrospective Qualitative</td>
<td>Mean: 45</td>
<td>Semi structured interviews</td>
<td>None</td>
<td>Stresses and uncertainties are elicited as a result of surgical options. Communication for health professionals, family members and patient communities raises question on how and what information women want. Health professionals need to be aware of the information wanted and the stresses and uncertainties these women face.</td>
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<tr>
<td>Lloyd et al. 2000, UK</td>
<td>Experience of BPM</td>
<td>10</td>
<td>Retrospective Qualitative</td>
<td>Range: 31-51 Mean: 40</td>
<td>Semi structured interviews</td>
<td>None</td>
<td>Main finding of women’s experiences was suffering and countering multiple loss. Seven themes were identified; social context was important, in particular isolation difficulties and wanting support.</td>
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<tr>
<td>Study Authors (Year, Country)</td>
<td>Research Question</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Data Collection</td>
<td>Follow-up</td>
<td>Findings</td>
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<tr>
<td>Metcalfe et al. 2002, Canada</td>
<td>BC risk perceptions &amp; estimated actual risk in women who have had BPM</td>
<td>60 (33 strong family history; 14 limited family history; 13 BRCA1/2)</td>
<td>Retrospective Quantitative</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>On average women estimated their risk of BC before surgery to be 76% and after surgery 11.4% equally a risk reduction of 64.8%. Average computer generated risk estimate based on family history was 59% for BRCA1/2 carriers and 17% for those with family history. Those without a BRCA1/2 mutation significantly overestimated their risk of developed BC. Many women who undergo BPM have exaggerated BC risk perception before surgery.</td>
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<tr>
<td>Metcalfe et al. 2004, Canada</td>
<td>Psychosocial functioning after BPM</td>
<td>60</td>
<td>Retrospective Quantitative</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>97% were satisfied with BPM but younger women were less likely to report satisfaction. The stronger the family history the more cancer related distress a women felt.</td>
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<tr>
<td>Metcalfe et al. 2009, Canada</td>
<td>BC risk in women with a family member who has tested negative for BRCA1/2</td>
<td>1492</td>
<td>Prospective Quantitative</td>
<td>Telephone questionnaire</td>
<td>6.1 years</td>
<td>65 women developed BC compared to 15.2 expected cases. Those under 40 had the greatest risk elevation but this declined with age. Women with a family history of BC and an inconclusive family BRCA1/2 result have approximately 4 fold (40%) risk of developing BC compared to the general population age specific BC risks.</td>
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<tr>
<td>Patenaude et al. 2008, USA</td>
<td>Attitudes of psychological consultation for women undergoing BPM</td>
<td>108 (26 BPM group)</td>
<td>Retrospective Qualitative</td>
<td>Interviews Questionnaire</td>
<td>None</td>
<td>In 108 women who were considering BPM and CPM more than 50% who had surgery felt a psychological consultation before surgery would have been helpful and 2/3 thought a consultation post-surgery was also needed. Of 37 women still considering BPM or CPM 100% believed a consultation would assist them in decision making and preparing for surgery.</td>
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<td>Patenaude et al. 2013, USA</td>
<td>Daughters of BRCA1/2 mothers – impact and understanding</td>
<td>40</td>
<td>Retrospective Qualitative</td>
<td>Telephone interview Self-report questionnaire</td>
<td>None</td>
<td>Daughters had minimal genetic knowledge; gaps and misconceptions were held. Greater than 1/3 of the young women had high cancer related distress. They had concerns for the future in particular surrounding having children.</td>
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<tr>
<td>Payne et al. 2000, USA</td>
<td>Experience of BPM in women who regret the surgery</td>
<td>19</td>
<td>Retrospective Qualitative</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>Physician initiated discussion of BPM was the most common factor. Distress and lack of available psychological support was reported as most common factor. Further regrets; perception that a BC wouldn’t be detected in tissue; complications with surgery, pain, not educated enough, body image and sexual relations concerns</td>
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<tr>
<td>Phillips et al. 2013, Australia</td>
<td>Risk management of women with strong family history of BC</td>
<td>142 BRCA1/2 mutation carriers</td>
<td>Prospective Quantitative</td>
<td>Self-report questionnaire</td>
<td>3 years</td>
<td>Of BRCA1/2 positive women 11% (8) underwent BPM and of those with a strong family history but no BRCA1/2 test none underwent BPM (32). Uptake of BPM is low in Australia. A concerning amount of women were not undergoing regular screening.</td>
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<tr>
<td>Study Authors</td>
<td>Title</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Data Collection</td>
<td>Follow-Up</td>
<td>Findings</td>
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<td>Rebbeck et al. 2004, North America &amp; Europe</td>
<td>Efficacy of BPM in BRCA1/2 carriers</td>
<td>483 BRCA carriers (105 BPM and 378 controls)</td>
<td>Prospective Quantitative</td>
<td>Phone calls, Self-administered questionnaire, Medical records</td>
<td>6.4 years</td>
<td>Of 105 who underwent BPM 2 were diagnosed with BC. Of 378 controls 184 were diagnosed with BC. BPM reduced risk by up to 90%.</td>
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<tr>
<td>Rolnick et al. 2007, USA</td>
<td>What women wish they knew before BPM</td>
<td>684 (117 BPM and 567 CPM)</td>
<td>Retrospective Quantitative</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>Of 72 BPM women 21% were satisfied with the information they received and 79 wanted more information. Wanted more information on; reconstruction (complications, nipples and longevity) and negative emotions following surgery.</td>
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<tr>
<td>Skyette et al. 2010, Denmark</td>
<td>BBM and BPO timing and uptake in BRCA carriers</td>
<td>306</td>
<td>Retrospective Quantitative</td>
<td>Data retrieved from pathology registry.</td>
<td></td>
<td>Long-term uptake at 10 years is 50% for BPM. 70% choosing BPM did so before age 40. Younger age significantly associated with highest uptake (&lt;40).</td>
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<td>Stefanek et al. 1995, USA</td>
<td>Predictors of satisfaction with BPM</td>
<td>164</td>
<td>Retrospective Quantitative</td>
<td>Mailed questionnaire</td>
<td>None</td>
<td>Women who choose surgery reported more BC worry. They were mostly satisfied with surgery but reported mixed satisfaction with reconstruction. Those who were not interested in surgery reported less scares i.e. biopsy’s and lower risk perception.</td>
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<td>van Oostrom et al. 2003, Netherlands</td>
<td>Long-term psychological impact of BRCA1/2 and Prophylactic surgery</td>
<td>65 (completed questionnaire): of that 51 were interviewed</td>
<td>Retrospective Qualitative</td>
<td>Questionnaire and semi-structured interview</td>
<td>1 to 3 weeks, 6 and 12 months and 5 years</td>
<td>Significant increase from 1-5 years in depression and anxiety. Those who had BPM had lower rates of body image and experienced changes in sexual relations. However these women had a significant decrease in cancer worry. Predictors of distress were; high distress at time of genetic testing, young children, having lost a family member to BC or ovarian cancer. Lack of communication, higher risk perception and validity doubts of genetic testing was associated with long-term distress.</td>
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Appendix 7: Data Management and Storage

Data management, confidentiality and communication

Security, storage and disposal of data is in accordance with the Western Australian University Sector Disposal Authority (WAUSDA). All hard copies of project data are kept in a locked filing cabinet in a room that is locked by electronic access as is the building this is in. Electronic data is recorded in password protected documents and only accessible to the PhD student. The PhD student has been responsible for ensuring the privacy and confidentiality of all data under the supervision of her primary supervisors. The PhD student is the only person to have access to the locked filing cabinet and password protected documents and she has been responsible for the data collection and analysis. However, her supervisors have access to aggregated participant data in terms of providing guidance and supervision for the project. Participant’s identity is not identifiable in the thesis or any published work. On completion of the project all identifying information will be removed and remaining data will be archived and securely kept for a seven year period before being destroyed as in accordance with the WAUSDA. Electronic data will be stored in the principle researchers current department drive, the School of Surgery at UWA. Hard copies such as consent forms will be archived and stored in locked cabinets in the same location. Storage information and details will be placed on a shared drive and the School Manager will be informed.

All electronic data (patient details and ID numbers, interview recordings, transcripts and questionnaire data) is stored on the School of Surgery, UWA network drive in the PhD student’s personal database. The UWA network drive is a secure drive which is backed up nightly. It has strong security network to prevent system comprise or hacking and it includes Sophos software for Anti-Virus and Tamper protection. Workstations are password protected and require login details to access; the workstations are positioned with dividers between them in a way that prevents unauthorised access or viewing of information displayed on screens. The School of Surgery drive is password protected and the PhD student’s personal database is also password protected and she is the only one with access to this.

As the participant consent form (PCF) and participant information form (PIF) was emailed to participants they scanned the signed document and emailed it back to the PhD student. The consent forms were printed and stored separately from any other study data in a locked filing cabinet at Harry Perkins Institute of Medical Research south building on the Fiona Stanley Hospital site. The emailed consent forms were deleted and the hard copies kept in the filling
cabinet. If participants preferred to post the PCF they were posted the document with a paid return address envelope to Harry Perkins Institute of Medical Research south building on the Fiona Stanley Hospital site and the PCF was stored in the same way as the scanned and printed copy. Participants were assigned an ID number when their consent form was returned and this ID number is their identifier code in order to link their questionnaire and interview themes. Identifying information and ID numbers are stored electronically as above and this file is a “TrueCrypt” file (encryption software) and password protected. It is kept securely, and separately from the anonymised data.

Interview

Participants were given their ID number before the interview commenced to enter onto their questionnaire. As soon as possible following completion of the interviews the audio recordings were immediately uploaded onto the network drive and stored as above in the PhD students personal data base which is password protected. To ensure patient confidentiality the file was named with the ID number allocated to the particular participants. Once the interview recording were transferred onto the secure network the original audio recordings were deleted from the recording device. The recordings were stored in this secure location until they are transcribed verbatim.

The PhD student transcribed the interview recordings. This was undertaken within one week of the interview and in one sitting. Transcribing took place at one of the two School of Surgery locations specified and was undertaken in a private room with the door closed to ensure the recordings are not heard by anyone but the transcriber, if a private room was not available the transcriber used ear phones. Any identifying information was removed from transcripts. Once interviews were transcribed interview recordings were deleted and sanitised from the network drive. The transcripts are stored in password protected word documents. They are stored on the network drive in a different location to identifying information. The file names are numbered in the order the interviews took place and their ID number is the first line of the transcription.

Online Questionnaire

Qualtrics is supported by UWA and is widely used by students and staff. In order to maintain privacy and confidentiality Qualtrics uses Transport Layer Security (TLS) encryption (also known as HTTPS) which is a secure connection between their server and the participant’s server. Access to Qualtrics is through UWA’s secure network which requires individual login details; the PhD student is the only one to have this access. Questionnaire responses were
securely transferred from Qualtrics by the PhD student using the exporting function straight onto an excel spreadsheet. This spreadsheet is a “TrueCrypt” file and password protected and only be accessible by this person. Any identifying information was removed. The spreadsheet is stored on the UWA network drive as above with the interview transcripts in order to match responses.
Appendix 8: Social Media Post

Do you have a family history of breast or ovarian cancer? Have you considered or already undergone a preventative mastectomy? Are you under 35 years or were you when you underwent your mastectomy?

If so would you be interested in participating in some research? I am currently undertaking a project on the information needs and experiences of younger women with a family history of breast cancer who are considering or have undergone a bilateral prophylactic mastectomy (preventative mastectomy). The aim of the study is to understand your experiences and informational needs in order to develop an information resource to assist young women in the future.

Your participation is voluntary and would include taking part in an interview and completing a short online questionnaire.

If you are interested please contact (contact details will be inserted) and we will send you an information sheet providing further information and a consent form for you to fill out.
PARTICIPANT INFORMATION SHEET

The information needs and experiences of younger women with a family history of breast cancer considering or having undergone a bilateral prophylactic mastectomy

Investigators: Professor Christobel Saunders, Dr Angela Ives, Dr Toni Mustillo and Rachael Glassey

You are being invited to participate in this research study because you have a family history of breast cancer and have undergone or are considering a bilateral prophylactic mastectomy (prophylactic mastectomy). Knowing what is involved will help you decide if you want to take part in our study. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about.

About the study

This study is being conducted by Rachael Glassey as part of a research project in the School of Surgery at The University of Western Australia, supervised by Professor Christobel Saunders, Dr Angela Ives and Dr Toni Mustillo.

The experiences of young women with a family history of breast cancer who consider or undergo a bilateral prophylactic mastectomy are not well documented. This study aims to better understand young women’s experiences of undergoing or considering a bilateral prophylactic mastectomy and to find out what information women receive before their surgery. We aim to use the information we collect to develop a resource assisting future women to make an informed decision about undergoing a bilateral prophylactic mastectomy.

Why am I being invited to participate?

We are interested in hearing about your experience when considering or undergoing a bilateral prophylactic mastectomy. We are particularly interested in what factors you took into account in making your decision and how the decision has impacted on your life. We are also interested in hearing about the information you received before and/or after your bilateral prophylactic mastectomy.

What will participation involve?

If you agree to participate we will ask you to take part in an interview and complete a questionnaire.

- The interview will be conducted at a time most convenient to you and can be carried out via Skype, or telephone interviews or in person. If you would like to be interviewed in person we will ask you to come to our office to ensure a private location. This would either be at the QEII Medical Centre in Nedlands or at the Fiona Stanley Hospital site in Murdoch, whichever is most convenient for you. If you prefer to conduct the interview via telephone or Skype the investigator will be situated in a private room so your responses remain confidential. The interviewer will ask questions about your family history of breast cancer, your perception of risk and your cancer worry. We will also ask some questions about your feelings and your thoughts and experience of bilateral prophylactic mastectomy. The interview will be audio recorded and will take approximately 45 minutes to complete.

- The questionnaire will ask for some general information about you, your family history of breast cancer and your bilateral prophylactic mastectomy (if applicable). It will also ask you about your emotional well-being, body image and sexual and physical functioning. The questionnaire can be completed online or by paper and pencil if you prefer (with return to us by self-addressed envelope) and will take about 10 minutes to complete.
Please be aware that some of the areas covered in both the interview and questionnaire are sensitive and very personal, such as your family relationships, experiences of anxiety or depression, sexual functioning and body image. You do not have to answer all questions, and can choose to skip any questions you wish.

Your privacy and confidentiality
Please be assured that your confidentiality will be protected. Data will be kept confidential and private according to usual standards of confidentiality and will also comply with the Privacy Act 1988. All data collected from either the interview or questionnaires will be held in strict confidence by the investigators. Hard copies will be kept in a locked filing cabinet. Electronic data will only be accessible via password protected computers and files. Each interview and questionnaire will only be identified by a unique numerical code. Your identifying data such as your name will be removed from your interview and questionnaires and will be kept separate from your responses to maintain your confidentiality. Participants will not be identifiable in any unpublished or published work. We will use some direct quotes from the interviews in any written work however we will use pseudonyms so no participant will be identifiable.

Possible risks, burdens and benefits
Discussing your personal experience and family history of breast cancer and bilateral prophylactic mastectomy may elicit some emotional or stressful feelings. If at any time you feel as though you cannot continue, simply let the interviewer know and the interview will be stopped. You do not have to continue if you do not wish to do so. Whilst it can be normal to experience some distress whilst discussing your emotions and feelings, if the distress directly related to your participation in the research project continues or feels overwhelming, you can ask for some additional help at no cost to yourself. You can contact the study team on 9346 3161 and organise to speak privately with one of the researchers, Dr Toni Misriello who is a Clinical Psychologist. Alternatively if you would prefer an independent service you can contact the Cancer Council helpline, 13 11 20, and speak to a counsellor on the helpline.

Whilst participating in this research project may not provide any direct benefits to you, the information you provide will assist us to help future women with their decision to undergo a bilateral prophylactic mastectomy. We aim to develop a resource to help other women to make decisions regarding bilateral prophylactic mastectomy. This will also provide additional information to health professionals so that they can appropriately support and inform women in making an informed decision for this type of surgery.

Voluntary participation and withdrawal
Participation in this study is voluntary and you are free to withdraw without explanation or prejudice at any time and without affecting your current or future care. If you chose to withdraw any data already collected will be destroyed and not used in the study.

Upon completion of the study we will publish the findings in professional journals and the decision aid resource will be made available online through various organisations. A summary of the study findings will be released on completion of the study and sent to all participants. We will also present our findings at international and national conferences.

Contacts for further information
Approval to conduct this research has been provided by The University of Western Australia, in accordance with its ethical review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing hrec-research@uwa.edu.au

You will be given a copy of this Information Sheet and the signed Consent Form for your records.
Appendix 10: Participant Consent Form

The University of Western Australia
Crawley
Western Australia

CONSENT FORM

The information needs and experiences of younger women with a family history of breast cancer considering or having undergone a bilateral prophylactic mastectomy

Investigators: Professor Christobel Saunders, Dr Angela Ives, Dr Toni Massello and Miss Rachael Glasser

I …………………………………………………….. (NAME) give my consent to participate in the above named research study.

Please read and tick each box

1. I have read the information sheet and I have had the opportunity to ask questions.

2. I understand the aims of the study and any risks/benefits to myself.

3. I understand I can withdraw my participation at any time without reason or prejudice.

4. I understand that some of the questions in the interview and questionnaire are sensitive and that I can skip any questions should I wish to do so.

5. I understand that my personal information and identity will be kept confidential and that the only exception to confidentiality is if documents are required by law.

6. I consent to my direct quotes being published in journal articles as long as my identity is kept confidential.

7. I consent for my interview to be audio recorded.

8. I consent to be contacted for follow up or future studies.

Would you like to receive a summary of the findings at the completion of the study?

Yes  □  No □

If YES, please supply your email address for the findings to be sent to:

_____________________________________________________

I have read and understand all of the above and I give my consent to participate in this study.

_____________________________________________________

Signature

PCF v1 170815 RPH
Print Name

Date

Name of person obtaining consent

Approval to conduct this research has been provided by The University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au
Appendix 11: Interview Schedule – BPM Group

The information needs and experiences of younger women with a family history of breast cancer considering or having undergone a bilateral prophylactic mastectomy

Investigators: Professor Christobel Saunders, Dr Angela Ives, Dr Toni Musiello and Miss Rachael Glassey, University of Western Australia

Interview Schedule – Post-BPM

Introduction

Thank you for agreeing to participate in this study. As you will be aware this study is to investigate the information needs and experiences of younger women at high risk of developing breast cancer (BC) who are either considering or have undergone a bilateral prophylactic mastectomy (BPM). The aim is to develop a resource to assist women when deciding to undergo a BPM to provide them with information based on real life experiences. Your participation in this study is greatly appreciated we would not be able to develop such a resource without your support so again thank you!

This interview will be audio recorded so that I can remember later on what you said. It will be typed out in full by myself, of course maintaining your identity, you will not be identifiable to anyone other than myself. Any personal information that you mention during this interview will be blanked out when it is typed up.

During the interview I will ask you some questions however please feel free to speak freely, if there is something you would like to talk about please do even if it is unrelated to the question I have asked. This interview is about your experiences. Due to the sensitive nature of some questions if you would prefer not to answer one of the questions please say so during the interview and we will move on, it is completely your decision if you wish to respond to any of the questions.

Have you got any questions?

Are you happy with that and ready to begin?

Interview questions
(Please note - questions are a guide only as this is a semi-structured interview (i.e if conversation from previous question answers/leads to the following question that question will not be asked))

Firstly can you please tell me what made you consider a BPM?

**Family History/Genetic Testing**
Okay thank you, I am now going to ask you some questions about your family history of BC and genetic testing.
Can you tell me how your risk of developing BC was calculated and by who? (i.e family history of BC or ovarian cancer).

- Were you offered and did you have genetic testing before your BPM?
- If yes, what was your result?
- Did you see a genetic counsellor or psychologist through this process?

What made you decide to be tested?

If no, why not? (i.e no living relative to be tested or personal choice).

**Risk perception/cancer-related worry**
I will now ask you some questions about your risk perception and cancer worry and that of other’s in your family.
Can you explain to me how you felt about your risk of developing breast cancer before your BPM?

- Can you tell me how you feel now about the risk of BC compared to before your BPM?
- How do you feel about the risk of BC to others in your family?

**Decision making**
I’m now going to ask you some questions about your decision making process of your BPM.

What influenced your decision to undergo a BPM? And was this why you choose to undergo a BPM at a young age or was there something else?

How did you make your decision?

Who did you seek information from regarding a BPM before making your decision?

**Information**
I will now ask you some questions about the information you received prior to undergoing your BPM and how you feel about it now.

What were you told about the surgery?

- Was your BPM surgery what you expected?
- Did the information you received differ from your experiences of how you felt post-BPM? And if so how?
- In hindsight, what else (if anything) would you have liked to know/have been told before you underwent your BPM?
- Where would you like information to be available? E.g. online, a leaflet, only from a health professional. How would you like to receive information?
- Were you asked by any of the health professionals you dealt with in relation to your BPM if you had any questions or if you understood what they were telling you?
- Were you offered any counselling or psychological consultation throughout your BPM journey? If yes, was this helpful and how? If no, do you think this would have been helpful and how?
- What types of information would you like to be discussed in counselling/psychological consultation?
- Would a resource consisting of the most common issues women undergoing BPM surgery face have been helpful for you prior to your BPM?

**Reconstruction**

I am now going to ask you some questions about reconstruction.

Have you had reconstruction? And if so what reconstruction did you have and why?

- Can you tell me what influenced your choice of reconstruction surgery or prosthesis?
- Can you tell me how you feel about that decision now?

**Family/Relationships**

I am now going to ask you some questions about your family and relationships.

Can you tell me about your relationship with significant others (such as spouse, children, wider family) post-BPM? Has it changed at all or is it as was before your surgery?

Do you feel as though your BPM has changed the way others think or feel about you? And if so what makes you think this?
Can you describe the impact (if any) your surgery had/has had on your family?

**Anxiety/Depression**

I am now going to ask you a couple of questions about anxiety and depression.

Compared to before surgery how do you feel about your risk of developing BC now?

- Compared to before surgery do you think you are less anxious?
- How has your BPM impacted on your wellbeing overall?

**Body image/Sexuality/Femininity**

I will now ask you some questions about your body image and sexuality.

Can you tell me how comfortable you were with your body before your BPM?

- Compared to before how you feel about your body after a BPM?
- Do you feel undergoing your BPM changed the way you think or feel about yourself?
- Can you tell me how you feel about your femininity after a BPM?
- How do you feel about your body image since your BPM?
- How do you feel about your sexuality since your BPM?

Compared to before your BPM have your intimate relations/sexual relations changed at all as a result of your BPM?

Lastly a couple of questions to finish.

Taking into account all that we have discussed, overall how do you feel about undergoing your BPM?

Is there anything else you would like to add or you feel that we haven’t covered and you would like to mention?

Thank you for participating in this research project. Your time and experiences is greatly appreciated.
Appendix 12: Interview Schedule – Considering Group

The information needs and experiences of younger women with a family history of breast cancer considering or having undergone a bilateral prophylactic mastectomy

Investigators: Professor Christobel Saunders, Dr Angela Ives, Dr Toni Musiello and Miss Rachael Glassey, University of Western Australia

Interview Schedule – Considering BPM

Introduction

Thank you for agreeing to participate in this study. As you will be aware this study is to investigate the information needs and experiences of young women at high risk of developing breast cancer (BC) who are either considering or have undergone a bilateral prophylactic mastectomy (BPM). The aim is to develop a resource to assist women when deciding to undergo a BPM to provide them with information based on real life experiences. Your participation in this study is greatly appreciated we would not be able to develop such a resource without your support so again thank you!

This interview will be audio recorded so that I can remember later on what you said. It will be typed out in full by myself, of course maintaining your identity, you will not be identifiable to anyone other than myself. Any personal information that you mention during this interview will be blanked out when it is typed up.

During the interview I will ask you some questions however please feel free to speak freely, if there is something you would like to talk about please do even if it is unrelated to the question I have asked. This interview is about your experiences. Due to the sensitive nature of some questions if you would prefer not to answer one of the questions please say so during the interview and we will move on, it is completely your decision if you wish to respond to any of the questions.

Have you got any questions?

Are you happy with that and ready to begin?

Interview questions
Firstly can you please tell me what made you consider a BPM?

**Family History/Genetic Testing**
Okay thank you, I am now going to ask you some questions about your family history of BC and genetic testing.
Can you tell me how your risk of developing BC was calculated and by who? (i.e. family history of BC or ovarian cancer).
Were you offered and have you had genetic testing?
If yes, what was your result?
What made you decide to be tested?
Did you see a genetic counsellor or psychologist through this process?
If no, why not? (i.e. no living relative to be tested or personal choice).

**Risk perception/cancer-related worry**
I will now ask you some questions about your risk perception and cancer worry and that of other’s in your family.
Can you explain to me how you feel about your risk of developing breast cancer?
How do you feel about the risk to others in your family?

**Decision making**
I’m now going to ask you some questions about your decision making process of your BPM.
What influenced your decision to consider a BPM? And was this why you choose to consider a BPM at a young age or was there something else?
What do you anticipate will influence your final decision to undergone a BPM?

**Information**
I will now ask you some questions about the information you have received so far regarding undergoing a BPM.
Who/where have you sought information from regarding a BPM? (i.e. self-online research or health professional)

What have you been told about the surgery?

What else (if anything) would you have liked to know/have been told?

Where would you like information to be available? E.g. online, a leaflet, only from a health professional. How would you like to receive information?

Were you asked by any of the health professionals you dealt with in relation to a BPM if you had any questions or if you understood what they were telling you?

Were you offered any counselling or psychological consultation to guide your decision making? If yes, was this helpful and how? If no, do you think this would have been helpful and how?

What types of information would you like to be discussed in counselling/psychological consultation?

Would a resource consisting of the most common issues women undergoing BPM surgery face have been helpful for you prior to your BPM?

**Reconstruction**

I am now going to ask you some questions on your thoughts about reconstruction surgery following a BPM.

How do you feel about reconstruction following a BPM? Would you consider reconstruction surgery?

What have you been told about reconstruction?

What else (if anything) would you have liked to know/have been told?

**Family/Relationships**

I am now going to ask you some questions about your family and relationships.

Have you discussed BPM surgery with your family?

If yes how would you describe their thoughts on a BPM?

If no, why not?
Do you feel as though a BPM would change the way others think or feel about you? If yes, what makes you think this?

Do you feel as though a BPM would impact (positively or negatively) any of your relationships?

**Anxiety/Depression**

I am now going to ask you a couple of questions about anxiety and depression.

How has your risk of developing BC impacted on your overall well-being?

Do you feel anxious or depressed?

Do you anticipate that anxiety and/or depression would resolve following a BPM?

**Body image/Sexuality/Femininity**

I will now ask you some questions about your body image and sexuality.

Can you tell me how comfortable you are with your body now?

Do you feel as though undergoing a BPM will change the way you think or feel about yourself? If yes, why?

Compared to now do you feel as though your intimate relations/sexual relations will change as a result of undergoing a BPM?

Lastly a couple of questions to finish.

Taking into account all that we have discussed, overall how do you feel about undergoing a BPM?

Is there anything else you would like to add or you feel that we haven’t covered and you would like to mention?

Thank you for participating in this research project. Your time and experiences is greatly appreciated.
### Appendix 13: Permission – Patient Education and Counseling

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Exploration of the decision-making processes, perceptions of risk and psycho-social experiences among young women undergoing bilateral prophylactic mastectomy

**Expected completion date**

Feb 2018

**Estimated size (number of pages)**

200

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Influences on decision-making for young women undergoing bilateral prophylactic mastectomy

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ARTICLE INFO
Article history:
Received 29 April 2017
Revised in revised form 26 July 2017
Accepted 10 August 2017

Keywords:
Prophylactic mastectomy
Fear
Decision-making
Young women
Breast cancer

ABSTRACT
Objective: The objective of this study was to explore the influences on decision-making of younger women (<35) undergoing or considering bilateral prophylactic mastectomy (BPM).
Methods: Qualitative interviews guided by interpretative phenomenological analysis (IPA) were conducted with forty-six women who had a strong family history of breast cancer (BC) who had either undergone (n=28) or were considering (n=18) BPM. Participants were recruited from Australia and New Zealand (NZ) via hospitals, a genetics clinic, a research cohort, a registry and online.
Results: Four themes underpinning the influences on decision-making were identified: fear and anxiety, children, personal experiences with breast health professionals’ influence.
Conclusions: The decision to undergo BPM for younger women (<35) was multifaceted, however it appeared that fear and anxiety were the main influences. Younger women appear more anxious than previous research with older women. There appears to be differences between those with confirmed BRCA1/2 mutations and those with no known mutation and this is clinically significant.
Practice Implications: These findings have important practice implications, particularly improving communication of risk statistics, especially to those with no known mutation. Health professionals need to take into account the way younger women perceive information given to them when discussing risk.

1. Introduction

Bilateral prophylactic mastectomy (BPM) is an option for women at high risk of developing breast cancer (BC) reducing the risk by up to 95% [1]. The greatest risk reduction occurs if BPM is undertaken before age 40 [2]. Up to 20% of women worldwide in Australia and the United States (US), it has been low (23% and 23% respectively) [4,5]. In England and Denmark, uptake is between 40 and 50% [6,7]. BPM uptake and intention has been associated with younger age (<15 years and <40 years respectively) [6-8], however, the literature focusing on younger women (<40) and BPM is scarce [9].

Research with older women (>40 years) has found a number of indicators for choosing BPM, including a closer family member’s cancer death [10], strong family history of BC [11], desire to live longer for family [12] and heightened BC risk perception [13,14]. Women’s confidence in screening methods may influence their decision to undergo BPM. Lloyd et al. [12] found women expressed concern that if BC developed it would not be detected by screening methods. The initiation of discussion about BPM could influence decision-making [15]. Women with regrets about their surgery reported that a health professional(s) initiated discussion of BPM, rather than the woman herself.

Few studies have reported on BPM decision-making in younger women (<40). Findings from these studies are similar to research with older women (>40), such as, not wanting children to experience their mother’s treatment for BC [16] and the possibility
Appendix 15: Permission – Familial Cancer

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Expected completion date: Feb 2018
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Heightened perception of breast cancer risk in young women at risk of familial breast cancer

Rachael Glassoy1,2, Meira O’Connor3, Angela Ives4, Chrisbel Saunders5, iCofFab Investigators4,5, Sarah O’Sullivan6, Sarah J. Hardcastle2

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Abstract. The objective of this study was to explore the factors that influence perceived personal risk of developing breast cancer (BC) in younger women (<35) who are considering or have undergone bilateral prophylactic mastectomy (BPM). Qualitative interviews guided by interpretative phenomenological analysis were conducted with 46 women who had a strong family history of BC and had either undergone (n=26) or were considering (n=20) BPM. Participants were recruited from Australia and New Zealand via hospitals, a genetics clinic, a research cohort, a registry and online. Three main themes were identified: information that increases fear of BC and death, underestimation anxiety and fear and screening anxiety. A further two themes: relief following surgery and confusion about residual risk following surgery were identified. Younger women (<35) appeared to have heightened and sometimes inaccurate perceptions of their BC risk. They appeared less relieved of anxiety and fear of developing BC by BPM surgery, in comparison to previous research with older women (>40). Those who had undergone BPM seemed more anxious about their risk of developing BC than those who were still considering surgery. The research has important implications for practice, particularly improving communication of accurate risk statistics. Future research should examine why some women interpret information differently and explore the benefits of psychological consultation for very anxious women.

Keywords. Prophylactic mastectomy - Risk perception - Young women - Familial cancer

Introduction

A woman’s lifetime risk of developing breast cancer (BC) may be doubled if she has a first degree relative diagnosed with a BC [1]. If a woman has a known mutation in one of the most common cancer susceptibility genes BRCA1 or BRCA2, her BC risk to age 70 is approximately 60% (BRCA1) and 55% (BRCA2) [2]. Some women choose risk-reducing surgery to prevent BC, rather than relying on early detection through surveillance.

Bilateral prophylactic mastectomy (BPM) is a surgical option for those at high risk of developing BC that can reduce a woman’s risk by up to 95% [1]. Uptake of BPM differs worldwide and has reportedly been as low as 21% and as high as 50% [4-7]. Undertaking BPM before age 40 has the greatest benefit in risk reduction [8] and it has been suggested that younger women have a higher intention to undergo BPM [9]. However, there is a dearth of literature focusing on younger women (<40) in relation to BPM [10]. The way women perceive their risk of developing BC could have a strong influence on the decision to undergo
Appendix 17: Permission – Psycho-Oncology

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Perceived influence of psychological consultation on psychological well-being, body image, and intimacy following bilateral prophylactic mastectomy: A qualitative analysis

Rachael Glassy1, Sarah J. Hardcastle2, Moira O’Connor2, Angela Ives1, kConFab Investigators3,4, Chrisobel Saunders1

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2Health Psychology and Behavioural Medicine Research Group, School of Psychology, Curtin University, Perth, Australia
3kConFab Research Department, Peter MacCallum Cancer Center, Melbourne, Australia
4The Sir Peter MacCallum Department of Oncology, University of Melbourne, Parkville, Australia

Correspondence Rachael Glassy, Medical School, University of Western Australia, Perth, Australia.
E-mail: rachael.glassy@research.uwa.edu.au

Abstract

Objectives: This study explored whether psychological consultation offered to women prior to bilateral prophylactic mastectomy (BPM) appeared to provide psychosocial benefit to younger women (<35 years) at high risk of developing breast cancer due to a mutation or family history.

Methods: Qualitative interviews guided by interpretative phenomenological analysis were conducted retrospectively with 26 women who had undergone BPM. Participants were recruited from New Zealand and Australia, via a genetics clinic, registry, research cohort, and online.

Results: Three themes were identified: psychological well-being and adjustment, satisfaction with intimacy, and body image. Participants who had seen a psychologist reported being more prepared for BPM and appeared to adjust positively post-surgery. They appeared to have improved psychological well-being, reported satisfaction with intimacy, and a more positive body image, compared with those who had no support.

Conclusions: Women who undergo psychological consultation prior to BPM appear to adjust positively after surgery. Implications for practice include standard psychological consultation for younger women (<35 years) considering BPM.

Key words

familial cancer, prophylactic mastectomy, oncology, psychological consultation, body image, intimacy, emotional well-being

1 INTRODUCTION

Bilateral prophylactic mastectomy (BPM) is a risk-reducing surgical procedure undertaken by women at high risk of developing breast cancer (BC) to reduce their risk. Women consider BPM for many reasons, although fear of developing BC is a common motivator.1,5 This fear results in many women undergoing surgery without considering the psychological, emotional, and physical consequences.3 Many of these women struggle with the subsequent changes to their body post-surgery.7

Researchers suggest that women could benefit from psychological support prior to BPM.11 In 2000, Lalloo et al.12 developed a protocol for women considering BPM, suggesting that they undergo a psychological assessment to ensure that they understand the information received and have realistic expectations of potential psychological outcomes. Similar guidelines have been developed for women at familial risk of BC, suggesting that women who elect to have BPM undergo psychological assessment.13 However, psychological consultation is not routine practice.6 Parmelee et al.14 reported that high-risk women considering BPM would prefer a psychological consultation to assist their decision-making and preparation for surgery.7 A further study assessing acceptability and support needs found that 70% of women would reconsider their decision to undergo BPM following psychological consultation.8 These authors did not explore post-surgery outcomes and satisfaction following psychological support.
Appendix 19: Permission – International Journal of Behavioral Medicine

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Influences on Satisfaction with Reconstructed Breasts and Intimacy in Younger Women Following Bilateral Prophylactic Mastectomy: a Qualitative Analysis

Rachael Glasey 1, Moira O’Connor 2, Angela Ives 1, Christobel Saunders 1, Sarah J. Hardcastle 2, iConFab Investigators 3,4

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Abstract

Purpose The aim of this study was to explore the influences on satisfaction with reconstructed breasts and intimacy following bilateral prophylactic mastectomy (BPM) in younger women (<35) with a strong family history of breast cancer.

Methods Twenty-six women who had undergone BPM between 1 and 16 years ago were recruited from New Zealand and Australia through genetics clinics, registry, research cohort and online (M age = 31). Twenty-three were BRCA mutation carriers. Qualitative interviews guided by interpretative phenomenological analysis were conducted.

Results Four themes were identified: satisfaction with breasts before surgery, outcome expectations, type of mastectomy, and open communication. Women who liked their breasts pre-BPM appeared less satisfied with their reconstructed breasts post-surgery, and women who disliked their breasts before BPM were more satisfied with their reconstructed breasts. Women with unrealistic expectations concerning the look and feel of reconstructed breasts were often unhappy with their reconstructed breasts and felt they did not meet their expectations. Unrealistic photos of breast reconstruction and satisfactory communication of realistic outcome expectations by surgeons or psychologists also appeared to influence satisfaction. Communication with partners prior to BPM appeared to improve satisfaction with intimacy post-BPM.

Conclusions The findings suggest that satisfaction with reconstructed breasts for younger women post-BPM appeared to be influenced by realistic outcome expectations and communication with others concerning reconstructed breast appearance and intimacy post-BPM. Implications for practice include discussion of realistic reconstructed breast appearance, referral to a psychologist to discuss sensitive issues, and accurate communication of surgical risks and consequences.

Keywords Body image - Intimacy - Open communication - Young women - Prophylactic mastectomy - Influencers

Introduction

A bilateral prophylactic mastectomy (BPM) is a surgical procedure where both breasts are removed. It is undertaken by women at high risk of developing breast cancer (BC), i.e., those with a strong family history of BC and/or identified genetic mutations. A woman with a BRCA1/2 mutation has a BC risk to age 70 of around 60% if a BRCA1 carrier and 55% if a BRCA2 carrier [1]. Women with a BRCA mutation have approximately a 20% chance of developing BC by age 40 [2]. However, for women with a family history of BC but no confirmed mutation, it is not known exactly what the percentage estimate of developing BC is, although it is thought to be approximately 40% [3]; these women are considered 'potentially high risk' [4]. Women in this category can choose to (and do) undergo BPM despite not having a confirmed mutation [5, 6]. For any woman, BPM reduces the risk of developing BC to almost zero (less than 5%) [7]. The uptake of BPM differs worldwide; from 21% in Australia to 33–50% in China.
Appendix 21: Permission – The Breast

Title: Patients’ perspectives and experiences concerning barriers to accessing information about bilateral prophylactic mastectomy

Author: Rachael Glasson, Moira O’Connor, Angela Ives, Christobel Saunders, kConfab Investigators, Sarah O’Sullivan, Sarah J. Hardcastle

Publication: The Breast

Publisher: Elsevier

Date: August 2018

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Appendix 22: Front cover – The Breast

Original article

Patients' perspectives and experiences concerning barriers to accessing information about bilateral prophylactic mastectomy

Rachael Glassey a,⁎, Moira O'Connor b, Angela Ives c, Christobel Saunders d, KConfah Investigators e,⁎⁎, Sarah O'Sullivan f, Sarah J. Hardcastle b

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b School of Psychology and Speech Pathology, Curtin University, Perth, Australia
c Confah, Medical School, Faculty of Health and Medical Sciences, The University of Western Australia, Perth, Australia
d Confah, Research Department, Peter MacCallum Cancer Centre, Melbourne, Australia
e The 2A Peter MacCallum Department of Oncology, University of Melbourne, Parkville, Australia
f General Service of Western Australia, Perth, Australia

ARTICLE INFO

Article history:
Received 16 December 2007
Revised in revised form
17 April 2008
Accepted 7 May 2008

Keywords:
Prophylactic mastectomy
Information needs
Information barriers
Support needs

ABSTRACT

Purpose: To explore the barriers and experiences of accessing information for women who have received genetic risk assessment testing results for breast cancer (BC) and are considering a bilateral prophylactic mastectomy (BPM) and, exploring participants’ preferences concerning information and support needs.

Methods: A qualitative retrospective study guided by interpretative phenomenological analysis was utilized. Semi-structured interviews were conducted with forty-six women who were either considering BPM or had already undergone the surgery.

Results: Three themes identified barriers to accessing information: difficulties accessing information, inconsistent information and clinical focus/medicalized information. A fourth theme – preferences of information and support needs, identified three subthemes: these were, psychological support, clearly defined processes and photos of mastectomy/prophylactic surgeries.

Conclusions: Barriers to accessing information appeared to be widespread. A lack of integrated services contributed to inconsistent information, and medicalized terminology/clinical focus of consultations further complicated understanding. Preferences for information include clearly defined processes, so women know the pathways after confirmation of minimal BC risk. Clinical implications include a multidisciplinary team approach, and a protocol that reflects current practice.

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1. Introduction

Women who choose bilateral prophylactic mastectomy (BPM) desire more information concerning psychological well-being, body image and sexuality after surgery, and post-operative pain management [1–8]. They often report inconsistent and conflicting recommendations, and at times misinterpreted information [9]. As a consequence, many fail to accurately understand their minimal BC risk and strategies to modify their risk [10,11]. At present, there are gaps in our understanding of how this information should be provided. Insufficient information has been associated with dissatisfaction following BPM [13].

A protocol for women at minimal BC risk choosing BPM was developed in 2000 [9]. A multidisciplinary (MD) team approach was encouraged, including patient consultations with a geneticist/oncologist, a psychiatrist (for a psychological consultation) and a breast and/or plastic surgeon. An oncologist/geneticist would conduct genetic counseling. With advances in genetic testing and availability of genetic counselor's, aspects of this protocol may be outdated. Currently those at familial BC risk may not consult with oncologists or psychiatrists and such extensive consultations would not be cost-effective in current clinical practice. Nevertheless, other aspects of these recommendations, such as a psychological consultation, is still not standard practice across clinic in Australia and New Zealand (NZ) [9].

Similar recommendations have been developed, which discuss the management of those choosing BPM [11]. Furthermore, a...
Appendix 23: Questionnaire

The information needs and experiences of younger women with a family history of breast cancer considering or having undergone a bilateral prophylactic mastectomy

Thank you for taking part in our research and helping us by answering these questions. Your time is appreciated. This questionnaire will take approximately 20 minutes to complete.

Please note: Due to the sensitive nature of some questions you can choose not to respond to any question when completing this questionnaire. It is entirely up to you if you wish to respond to any of the questions.

Investigators: Professor Christobel Saunders, Dr Angela Ives, Dr Toni Musiello and Miss Rachael Glassey

Contact Information
If you have any questions about this study, please contact Christobel Saunders on (08) 6151 1122
Section 1 (Demographics)

In this section you will be asked some demographic information about yourself. You will also be asked some questions about your family history of breast or ovarian cancer.

1. What is your age?  
   ______________________

2. What is your marital status?  
   ______________________

3. What is your ethnicity?  
   ________________________

4. What is your highest level of education?  
   ________________________

5. What is your country of residence?  
   _________________________

6. What country were you born in (if different to above)?  
   _________________________

7. What is your family history of breast or ovarian cancer? Please list relationship to you and their age at diagnosed.  
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

8. Have you been tested for the BRCA1/2 gene mutation (or other mutation known to increase susceptibility to developing BC)?  
   _______________________

9. If yes was your result, positive, negative or inconclusive?  
   _______________________

10. If no has anyone in your family been tested for the BRCA1/2 gene mutation and if so what was their result (positive, negative or inconclusive)? Please list relationship to you and their result.  
    ___________________________________________________________________
    ___________________________________________________________________
    ___________________________________________________________________
    ___________________________________________________________________

11. Have you had a bilateral prophylactic mastectomy?  
   ☐ Yes  ☐ No  
   For those who answer yes go to question 15.

12. When do you envision you will make a decision about whether or not to have a bilateral prophylactic mastectomy?  
   _______________________

13. If you decide yes, when do you think you will undergo the surgery?  
   ________________________

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14. Who have you sought information from with regard to undergoing a bilateral prophylactic mastectomy? E.g genetic services, surgeon, breast care nurse, GP, internet, book, pamphlet.

_________________________________________________________________________

You will now be asked a few questions about your bilateral prophylactic mastectomy surgery.

15. Did you have any complications with your surgery? Please identify.

_________________________________________________________________________

_________________________________________________________________________

16. Did you have reconstruction surgery or a prosthesis? Please tick.

☐ Reconstruction    ☐ Prosthesis

17. If reconstruction, which type of reconstruction surgery did you have?

_________________________________________________________________________
Section A. (Depression, Anxiety, Stress Scale (DASS-21))

In this section you will be given some statements about how you may or may not feel. **Thinking about the past week** please circle which number indicates how much the statement applies to you. Please read each statement carefully. There are no right or wrong answers.

Rating scale:

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 the time
3 Applied to me very much, or most of the time

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

In this section you will be asked some questions about body image. Thinking about the past three months please tick which box most applies to you. Please read each statement carefully. There are no right or wrong answers.

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<th>Neutral</th>
<th>Agree</th>
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<td>2 I felt very feminine</td>
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<td>3 I was satisfied with my naked appearance.</td>
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<td>4 I had trouble looking at my naked self.</td>
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<td>6 I was satisfied with the appearance of my breasts.</td>
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<td>7 My breasts felt pleasantly.</td>
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<tr>
<td>8 I felt sexually attractive.</td>
<td></td>
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<tr>
<td>9 I felt comfortable enough to wear V-necked clothing.</td>
<td></td>
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<tr>
<td>10 I felt comfortable enough to wear swimwear.</td>
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<tr>
<td>11 I was embarrassed for my naked body.</td>
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</tbody>
</table>

Thinking about the past three months please tick which box most applies to you. Partner can refer to casual or same sex partners. Please mark N/A if you do not have a partner.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Totally Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Totally Agree</th>
<th>N/A</th>
<th>I'd prefer not to respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 I felt comfortable when my partner touched my breasts.</td>
<td></td>
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<tr>
<td>13 I had qualms about getting undressed in the presence of my partner.</td>
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</tbody>
</table>
Section C (Impact of Events Scale)

In this section you will be asked some questions about cancer related distress. Thinking about your family history of breast cancer or high risk status please tick which box most applies to you. Please read each statement carefully. There are no right or wrong answers.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I thought about it when I didn’t mean to</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I avoided letting myself get upset when I thought about it or was reminded of it</td>
<td></td>
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<tr>
<td>3</td>
<td>I tried to remove it from memory</td>
<td></td>
<td></td>
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<tr>
<td>4</td>
<td>I had trouble falling asleep or staying asleep because of pictures or thoughts about it that come into my mind</td>
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<tr>
<td>5</td>
<td>I had waves of strong feelings about it</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6</td>
<td>I had dreams about it</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7</td>
<td>I stayed away from reminders of it</td>
<td></td>
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<tr>
<td>8</td>
<td>I felt as if it hadn’t happened or it wasn’t real</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I tried not to talk about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Pictures about it popped into my mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Other things kept making me think about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I was aware that I still had a lot of feelings about it, but I didn’t deal with them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I tried not to think about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Any reminder brought back feelings about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>My feelings about it were kind of numb</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Section D (Risk Perception)
In this section you will be asked some questions about your views on the risk of breast cancer. Please read each statement carefully. There are no right or wrong answers.

1. What do you feel the risk of developing breast cancer is for any woman in the general population? Please tick.

   a. Inevitable
   b. 1 chance in 2
   c. 1 chance in 3
   d. 1 chance in 4
   e. 1 chance in 5
   f. 1 chance in 6
   g. 1 chance in 8
   h. 1 chance in 10
   i. 1 chance in 12
   j. 1 chance in 20
   k. 1 chance in 50
   l. 1 chance in 100
   m. Very unlikely

2. What do you think your lifetime risk is of developing breast cancer? Please tick.

   a. Inevitable
   b. 1 chance in 2
   c. 1 chance in 3
   d. 1 chance in 4
   e. 1 chance in 5
   f. 1 chance in 6
   g. 1 chance in 8
   h. 1 chance in 10
   i. 1 chance in 12
   j. 1 chance in 20
   k. 1 chance in 50
   l. 1 chance in 100
   m. Very unlikely

3. Have you spoken to other members of your family about the risk of breast cancer? Please circle.
   
   Yes  No

4. Do you feel you are at increased risk of developing other cancer? Please circle.
   
   Yes  No

5. Do you think screening will help you? Please circle.
   
   Yes  No  Uncertain
Section E (Sexual Functioning Questionnaire)
In this section you will be asked some questions about your sexual functioning. Please read each statement carefully and tick which box most applies to you. There are no right or wrong answers.

1. Are you currently married or having intimate relationships with someone (including casual or same sex partners)?

Yes ☐ No ☐

2. Have you changed your sexual partner in the last 6 months?

Yes ☐ No ☐

3. Do you engage in sexual activity with anyone at the moment (including casual or same sex partners)?

Yes ☐ No ☐
If yes please go to the next page
If no please answer remaining questions on this page

I am not sexually active at the moment because:
(please tick as many of these items as apply )

a. I do not have a partner at the moment ☐

b. I am too tired ☐

c. My partner is too tired ☐

d. I am not interested in sex ☐

e. My partner is not interested in sex ☐

f. I have a physical problem which makes sexual relations difficult or uncomfortable ☐

g. My partner has a physical problem which makes sexual relations difficult or uncomfortable ☐
Please tick the box that best indicates your sexual feelings and experiences during the past month.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Very much</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>I’d prefer not to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Was having sex an important part of your life this month?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Did you enjoy sexual activity this month?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>In general, were you too tired to have sex?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>4</td>
<td>Did you desire to have sex with your partner(s) this month?</td>
<td></td>
<td></td>
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<tr>
<td>5</td>
<td>During sexual relations, how frequently did you notice dryness of your vagina this month?</td>
<td></td>
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<tr>
<td>6</td>
<td>Did you feel pain or discomfort during penetration this month?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7</td>
<td>In general, did you feel satisfied after sexual activity this month?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8</td>
<td>How often did you engage in sexual activity this month?</td>
<td>5 times or more</td>
<td>3-4 times</td>
<td>1-2 times</td>
<td>Not at all</td>
<td>I’d prefer not to answer</td>
</tr>
<tr>
<td>9</td>
<td>How did this frequency of sexual activity compare with what is usual for you?</td>
<td>Much more</td>
<td>Somewhat</td>
<td>About the same</td>
<td>Less than usual</td>
<td>I’d prefer not to answer</td>
</tr>
<tr>
<td>10</td>
<td>Were you satisfied with the frequency of sexual activity this month?</td>
<td>Very much</td>
<td>Somewhat</td>
<td>A little</td>
<td>Not at all</td>
<td>I’d prefer not to answer</td>
</tr>
</tbody>
</table>
Appendix 24: IES t-tests

Our data met all of the assumptions of a t-test for both scales. There was a significant difference between the BPM groups and the considering group using a T test on the avoidance scales $t(43)=3.04, p=.004$ and on the intrusion scale $t(43)=2.32, p=.025$. 