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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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.

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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 [1,2]. 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% [3,4]. 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 = 306), 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 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 [11]. Erickson defined young adulthood
to be between ages 18 and 40 years [12]. Young adults face many new challenges such as independence from parents, educational and career choices, exploring relationships, and making decisions about children and lifestyle [13]. 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 [14]. 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 [11], and may be more comfortable with their body image [15]. As women further age their roles change again and they may focus more on independence, retirement, widowhood, constrained finances and physical/mental function decline [16]. 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.

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.

Methods

This literature search was carried out between July 2014 and July 2015 using the databases PsychInfo, PubMed, and ProQuest, utilizing 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 (Table 1 in the supplementary appendix). 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.

Decision making

Some researchers have suggested that the decision to undergo a BPM is driven by irrational fear [17]. 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 [18]; a strong family history of BC [19]; and/or a desire to live longer for children or other family members [20]. 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 [18].

Actual (or absolute) age based risk estimates are not always a strong influencer for BPM. Rather the age at which a woman’s family member was diagnosed with BC and/or died can motivate women to choose BPM [20]. The closer a women comes to this age the more urgency she feels to undergo BPM [21]. In a qualitative study by Hoskins et al. [21] 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. [20] 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 [14].

Women’s confidence in screening methods may also influence their decision to undergo a BPM. Lloyd et al. [20] 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 [22]. 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 [23]. 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 [23].

Genetic testing

Increasing numbers of younger women are undergoing testing for BRCA1/2 [17]. However due to the limitations in genetic testing younger women also undergo BPM in the absence of a positive BRCA1/2 mutation [8,24]. In countries such as Australia
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. [35] found 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 BRCA2 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 [23].

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." [18]. 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 [18]. Moreover, this finding was shown to be consistent over time (6–12 months) [19,29]. 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 [19,27,35]. However, this finding has been challenged. Bebbington Hatcher et al. [1] 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 [18]. In women who chose to undergo a BPM, poor cosmetic outcomes, complications from surgery and/or reconstruction were associated with greater psychological distress [18,36]. Some women believed they were personally responsible for complications and they attributed this to their own failures; these women especially need more support [20]. Even though most women suffered some degree of pain and discomfort after surgery the majority still thought it was the right decision [18]. Bresser et al. [19] 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 [9,37], psychological consultation before any woman at risk undergoes a BPM is not standard practice. Patenaude et al. [38] 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 making decisions 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 [18,21,38].

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 [29,36]. Maintaining femininity is an important factor for women who try to maintain this after surgery [20]. 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 [29,36,39]. They report their breasts feel different, hard, and cold and they do...
not like to look at their naked reflection in the mirror [28]. 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 [36]. 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 [20]. One year post surgery women still reported being less sexually active and having low sexual pleasure [18]. This has been found to increase psychological and emotional distress [18,36]. 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 [29]. Only two studies report women’s negative concerns relating to surgical scars [28,39]. 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. [20] 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 [28]. 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 [20].

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 [1]. Extensive literature supports this [18,39,40], with women undergoing BPM reporting that they want more information [28,36,39]. Some women have suggested that had they been given enough information they would have reconsidered their decision to undergo a BPM [23]. 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 [41].

Another study found women felt they were not knowledgeable enough to determine what questions they should ask of health professionals [18]. Women struggled to understand information about their risk of developing BC, reporting that they felt emotionally blocked [41]. Hoskins et al. [42] 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 [42]. 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 [43]. There are a number of misconceptions regarding BPM surgery. For example, Payne et al. [23] 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. [39] 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 [39]. In another study one women 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 [20].

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 = 3540) 25% were under 45 years. In six of these studies (n = 1265), only 18% were under 30 years. Younger women may be at an age where their risk of BC is low [32,44] (see Fig. 1 for age based risk estimates), however, research suggests that increasing numbers of younger women are still undergoing BPM [8,10]. 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 [14,21,42,43]. Two of these studies focused on decision making [14,21] and two on informational needs [21,43]. 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 [32]. 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’.

Limitations of published research

Previous research examining BPM may not adequately represent women’s experiences due to limitations in design and method [36]. Research in the area of BPM has mostly been quantitative and the general consensus is that women are satisfied with the outcomes of

![Fig. 1. Shows the absolute age based risk of developing BC for BRCA1/2 positive and inconclusive and the general population.](image-url)
BPM [19,29,39]. 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 [23,28,45]. For example one study [36] 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. [46] 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 [18], 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. [20] 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 [18,39,40]. Moreover, the age of the women in the samples does not reflect the experiences of younger women [18–20] 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 [14,20,23,42] limiting generalizability.

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 over estimate 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.

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Conflict of interest statement

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Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.breast.2016.05.012.

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