



DOCTORATE IN CLINICAL PSYCHOLOGY

**Literature Review**

**The Experience of Prophylactic Surgery in Women to Reduce the Risk of Breast and Ovarian Cancer: A Review of Current Literature**

**Katharine Jones**

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# **Literature Review: The Experience of Prophylactic Surgery in Women to Reduce the Risk of Breast and Ovarian Cancer: A Review of Current Literature**

## **Overview of Organisation of the Review**

This review has been structured to set out current literature which explores women's experiences of preventive surgery for breast or ovarian cancer in the context of existing theory. Prophylactic bilateral mastectomy (PBM) to remove both breasts and prophylactic oophorectomy (PO) to remove the ovaries, when there is no cancer present are radical surgeries to reduce the risk of developing cancer in the future. Research has only just begun to explore the experience of women who have undergone risk-reducing surgery. The review starts by introducing the facts around the risk-reducing surgeries and follows with a discussion of health psychology theory to contextualize women's interest in and uptake of surgery. The review continues to consider the current literature around the psychological and social impact post-surgery for PO and PBM. This includes a review and evaluation of the research methodologies that are available. Gaps in the literature are identified with suggestions for further directions in researching this area. The research focus is on PBM due to an opportunity to obtain research participants from a NHS breast care service.

## **Introduction**

### **Literature Review and Context**

Increasing knowledge of genetics has led to the availability of predictive tests for hereditary cancer. NICE (2006) recommends that genetic testing is suitable for a small proportion of women from high risk families. Mutations to the tumour suppressing genes BRCA1 and BRCA2 are linked to a greater risk of developing ovarian and breast cancer in the life span of women of approximately 50-80%, 35-84% for breast cancer and 10-50% for

ovarian cancer (Hamilton, Lobel & Moyer, 2009, Narod, 2010)<sup>1</sup>. Risk-reducing surgery is an intervention that is then considered. PO can significantly reduce ovarian cancer risk and PBM can reduce risk of developing breast cancer by 90% (Rebbeck et al., 2004). An alternative option is increased surveillance, which has no side effects, but does not prevent cancer (Howard, Balneaves & Bottorff, 2009). Prophylactic surgery offers greater certainty for women in reducing their risk and it is estimated that demand for surgery will increase with the developments in genetic testing (Hallowell, 2000). Although it is preventive surgery, in many ways it is like having an illness as the women must cope with the likelihood of developing severe illness in the future and this forces contemplation of the implications of illness (Hoskins & Greene, 2012). In addition, the surgery has potential consequences and the presenting mix of risk and decision making is complex.

## Method

A literature search was carried out using the database PsychInfo with the keywords: “preventive surgery”, “BRCA\*”, “prophylactic surgery” and “prophylactic oophorectomy OR breast”. A total of 280 results were returned. 36 were relevant. Papers were included if they were published in English, in a peer reviewed journal, included female participants aged over 18 and were published in the last fifteen years.

Three further relevant databases were searched – PubMed, Ovid Medline and Scopus and four additional articles were found that were not already covered. Relevant articles cited by the journals found, were also explored. Two papers were review articles, 1 meta analysis, 19 used quantitative methodology, 12 used qualitative methodology, and 2 mixed-methods.

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<sup>1</sup> Although excluded from consideration in this review as it tends to have less significant health implications than for women, men can also carry the BRCA genetic mutation. The raised risk of breast cancer in men with the BRCA1 mutation is 1%, and for BRCA2 it is 7%, and a lifetime risk of developing prostate cancer of 20-25% (Evans et al., 2010, Levy-Lahad & Friedman, 2007).

### **Uptake and Interest in Prophylactic Surgery**

Decision making about whether to have risk-reducing surgery is a difficult and complex process for women at increased risk (Fang et al., 2002). Health psychology theory offers a range of models that attempt to explain factors important to decision-making, particularly in relation to cancer and for health prevention behaviour. Some of these that may be relevant will be considered here. The health belief model (HBM) (Rosenstock, 1974; Becker & Rosenstock, 1987) explains the likelihood that a person will engage in health prevention behaviour. It suggests this is dependent on their belief and perception of threat to health, and evaluation of perceived benefits. Research in the area of risk-reducing surgery has found risk reduction to be a primary motivator for women considering PO, therefore the health belief model has resonance. Higher levels of perceived risk and greater perceived benefits of surgery are reported as predictors of intention to undergo PO by many studies using quantitative methodology (for example Fang, et al., 2005; Meiser et al., 2003). The authors acknowledge that limitations to the studies are that they looked at the intention of women and it does not allow for changes in belief over time. Additionally, the HBM does not take into account social influences on behaviour (Morrison & Bennett, 2012).

Social cognition models examine factors that predict behaviour and consider predicted outcomes. The theory of planned behaviour assumes that people act in a goal directed way and that people logically weigh up the implications of an action. It includes psychological and social influences including outcome expectancy, perceived control and subjective norms, which can account for variance in actual behaviour (TPB) (Ajzen, 1991). The authors of one study applied it to survivors of breast cancer. They noted that the relation between depressive symptoms and adherence to medication was fully mediated by TPB process (Manning & Bettencourt, 2011). However, cancer, its potential meaning and consequences, arouses high

levels of emotional responsiveness in the individual, which are not considered in TPB (Hallowell & Lawton, 2002).

An additional model that could account for emotional response to potential illness as well as the behavioural actions accounted for by TPB is Leventhal's self-regulation model (SRM) which assumes people are active problem solvers, and that once an individual is confronted with a potential illness (the problem), cognitive and emotional representations will be triggered and based on these, they will be motivated to solve it to regain equilibrium (Leventhal, Diefenbach & Leventhal, 1992). Findings are inconsistent about its utility in breast cancer patients. A recent qualitative study with survivors of breast cancer drew on SRM. The authors suggested that when adjusting to life after surgery patients indeed strived for normality. Themes varied in importance between participants highlighting the importance of ascertaining what the individual believes to be normal (Denford, Harcourt, Rubin, & Pusic, 2011). Rees, Fry, Cull and Sutton (2004) used an element of SRM, illness representations, to try and explain distress in women with high breast cancer risk, but did not find any strong predictors. These findings could suggest the quantitative methods used were not sensitive enough to provide sufficient insight into the complex situation of this group of women (Kelly et al., 2005; van Oostrom et al., 2007).

Another theory that may be relevant to develop our understanding of the individual reactions and adjustment of women following risk-reducing surgery is meaning making (Taylor, 1983). Meaning making appears particularly important in confronting highly stressful life experiences (Park, 2010). When faced with distress individuals are assumed to attempt to reduce the discrepancy between appraised and global meaning in order to restore a sense of the world as meaningful and their own lives as worthwhile. Individuals attempt to regain mastery of the experience and of their lives in general, and to restore self-esteem. If

this process is successful it leads to better adjustment to the stressful event and is associated with improved outcomes (Collie & Long, 2005).

Women vary in how they process threatening information. In one study women who rejected PBM had a higher level of trait anxiety and a detached coping mechanism as opposed to the problem solving focus of those who chose PBM (Bebbington Hatcher, Fallowfield, & A'Hern, 2001). Another suggestion is that women who are vigilant information-seekers, or high monitors, are likely to attend to threat and be interested in surgery, but may become avoidant when the risk is perceived as very high (Fang, Miller, Daly, & Hurley, 2002). However, it was unclear when the risk would be such that women would become avoidant. There is also the role of affect. In several studies with participants interested in PO desire to reduce anxiety or reducing cancer related worry was found to be the strongest predictor of interest in surgery (Fry, Rush, Busby-Earle, & Cull, 2001; Hurley, Miller, Costalas, Gillespie, & Daly, 2001). These results are limited as the sample size would appear to be too small for the statistical methods used. Studies using qualitative methodology have also found that women "acutely aware" of their future cancer risk favoured risk-reducing surgery, as they found it hard to trust surveillance because they became too anxious between appointments (Hamilton et al., 2009). Anxiety can cause an interpretative bias that increases focus on perceived risk (Loewenstein, 1996; Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir, 2005). If the main decisional factor was to reduce worry, this could dominate the decision making process and alternative ways of managing anxiety such as a psychological consultation or decisional aids could be beneficial for some women (Schwartz et al., 2009; Tan et al., 2009).

Psychological or medical factors do not exist in isolation but in the context of family relationships, and this suggests greater complexity. Although the genetic status of BRCA1/2 can be a "pivotal point" of decision processes of women (Howard, Balneaves, Bottorff, &

Rodney, 2011), often women have started decision making processes about risk management strategies before testing as they have experienced family members with breast cancer (McQuirter, Castiglia, Loiselle, & Wong, 2010). Several studies suggest that women who had lost their mothers to cancer were motivated to take risk-reducing surgery as they did not wish to follow their mothers experience (Hamilton, Williams, Bowers, & Calzone, 2009; Howard et al., 2011; Metcalfe, 2004).

Research suggests that women's decisions about risk-reducing surgery are often made in terms of perceived consequences on others including their children, partner and other family members. Fulfilling social obligations to family was found to be as important as other factors such as risk reduction and fear containment (Hallowell, 1998). In a study using grounded theory the main decision making processes were found to be "preserving the self", including physical health, self-identity as a woman, relationships with others and emotional well-being. The decision making process was conceptualized both in the present, and in the future, as a woman and in relationships with others, and this interaction influenced decision making for risk-reducing surgery (Howard et al., 2011). However, the studies are limited as the theory requires testing in different contexts, with quantitative methodology and larger samples.

### **Psychological and Social Impact of Prophylactic Surgery**

This paper will now consider the literature around the psychological and social impact of undergoing prophylactic risk-reducing surgery. Research carried out in this area suggests that the majority of women, 70-80%, are satisfied with their decision to undergo PBM (Contant et al., 2004; Frost et al., 2000; Metcalfe et al., 2004). A qualitative evaluation using content analysis methodology found that 90% women who underwent a PO were satisfied with their decision (Babb et al., 2002). With the increase of interest in positive psychology as opposed to focusing on negative responses to illness, research has begun to focus on the

experience of positive change that can occur as a result of struggling with highly challenging life events (Seligman & Csikszentmihalyi, 2000; Tedeschi & Calhoun, 1996). Recent research has tentatively suggested this may have relevance in women who have survived breast cancer. In a cross-sectional study matched with healthy comparisons, it was suggested that there was greater post-traumatic growth in the cancer group, who found benefits in their experience in relating to others, appreciation of life, and spiritual change. The authors conclude that this was unrelated to level of distress, and that focusing on distress may lead to an incomplete and potentially misleading picture of adjustment to cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Research suggests that this may be the same for women who find that they are carriers of the hereditary gene mutation, who described similar changes to those observed in cancer patients such as improved relationships and appreciation of life (Hoskins, Roy, Peters, Loud, & Greene, 2008; Low, Bower, Kwan, & Seldon, 2008). Although not yet considered for women who have had risk-reducing surgery this may have resonance. It is not yet known how these factors operate in women's lives over time (Howard et al., 2009).

**Psychological and social impact of prophylactic oophorectomy.** As discussed previously, research findings suggest that a desire to reduce cancer worry was an important factor for women pre-surgery, however, findings are mixed following risk-reducing surgery. One study reported a reduction in cancer distress from 34.3% pre-surgery to 18.6% after PO. Therefore, a number of women continued to experience significant cancer distress (Finch et al., 2011). A study investigating the psychosocial outcome of PO compared with women who were having regular screening for ovarian cancer found that there was no change or significant difference in reported level of cancer worry in women who had undergone surgery than in the screening programme. Women who had undergone surgery had more physical and emotional symptoms than those in the screening programme. The authors suggest that

younger, premenopausal women are particularly vulnerable to distress following PO, even with hormone replacement therapy (HRT) (Finch et al., 2011; Fry et al., 2001). A limitation to these studies is that they relied on self-report measures in use of questionnaires, and as the authors of the longitudinal study acknowledge, the timing of the baseline a month before surgery may have caused a selection bias in that participants responded who were more distressed.

Research using qualitative methodology can complement those that use quantitative methods. A study of 14 women who had undergone PO, which also included five women with total mastectomies, found a positive psychological impact of reduced fear of developing cancer and minimal impact of the surgery on their lives. However, half of the participants who had mastectomies reported an impact on their sense of femininity as a visible sign of change. The importance of social support was highlighted and of having a supportive partner. Additional support needs were highlighted post- surgery in several studies (Josephson, Wickman, & Sandelin, 2000; Meiser et al., 2000).

One prospective study using mixed methods found that up to 67% of women thought a post-surgical psychological consultation would be helpful for discussing emotional and interpersonal impact. Research also suggests that peer consultation with women of a similar age and marital status, and/or surgical characteristics and support groups are helpful (Meiser et al., 2000; Patenaude et al., 2008).

**Psychological and social impact of prophylactic bilateral mastectomy.** Research reporting the psychological and social consequences of PBM studies using quantitative methodology also has mixed findings. Women who had a PBM with immediate reconstructive surgery reported a decrease in anxiety at 6 months and further at 18 months, the women maintained a positive body image and had no change in sexual activity (Bebbington Hatcher et al., 2001; Hopwood et al., 2000). However, one in five participants

reported feeling quite a bit or very much less sexually attractive or self-conscious about their appearance (Brandberg et al., 1998; Frost et al., 2000; Hopwood et al., 2000). In addition to the above, adverse psychological and social consequences were reported by some women: impact on self-esteem (23%), impact of feelings of femininity (25%) and increased life stress (18%) (Frost et al., 2000; van Oostrom et al., 2003). It is suggested surgical complications account for higher distress (Hopwood et al., 2000).

Few studies have explored the in-depth personal experience of women after undergoing PBM. Loss and suffering was found to be central in all aspects of women's experience of PBM from decision making to processing loss post-surgery in one study using grounded theory (Lloyd, Watson, Oaker, Sacks, Rovere, & Gui, 2000). As in the above study, support from others and open communication was seen as key to recovery and psychological wellbeing. However, the sample only included two women who had undergone genetic testing. The authors suggest that psychosocial consequences may be different for women who make a choice to have risk-reducing surgery following genetic testing rather than those with greater uncertainty (Lloyd et al., 2000). There are gaps in our understanding of women with a known faulty breast cancer gene experiences and needs post-surgery, and more research is needed in this area.

## Discussion

Research has only just begun to explore the experience of women who have undergone risk-reducing surgery. Research to date has led to a broad overview of the topic and considerable knowledge of factors influencing decision making for women considering prophylactic surgery (Claes et al., 2005; Fang et al., 2002; Fang et al., 2005; Fry et al., 2001; Hamilton et al., 2009; Howard et al., 2011; Hurley et al., 2001; McQuirter et al., 2010; Meiser et al., 2003; Schwartz et al., 2005; Schwartz et al., 2009; Tan et al., 2009). Research suggests that an individual's perceived higher risk of cancer is well established as reason for taking up

risk-reducing surgery, in addition to greater level of worry and exposure to cancer (Lobb & Meiser, 2004). The findings suggest for the majority of women little impact is found on psychological and social functioning following surgery. As indicated in the research there may be benefits to the surgery, in terms of reduced cancer worry and more research would be helpful to explore this. This is not to suggest that women should benefit from the experience, or to minimize distress and loss following these surgeries, rather to explore how coping can affect mood and recovery (MacBrayer, 2007). Although not yet applied in the area of risk-reducing surgery, psychological theories and models including the HBM, TPB, SRM and meaning making have potential relevance and help us to understand individual response and adjustment to risk-reducing surgery, which is a stressful life event. Future research could address this gap in understanding.

However, younger women appear to experience more distress and some women report negative body image, continuing cancer concerns and negative impact on relationships (Bebbington Hatcher et al., 2001; Brandberg et al., 1998; Contant et al., 2004; Finch et al., 2011; Frost et al., 2000; Hopwood et al., 2000; Metcalfe et al., 2004; Rolnick et al., 2007; van Oostrom et al., 2003). Psychological needs should be considered in the psychosocial context. Relationships with family impact on decision making and recovery, and should be anticipated by health professionals (Hamilton et al., 2009; Howard et al., 2011). A number of studies using qualitative or mixed methodology have contributed to knowledge of women's experiences of the impact of PO (Babb et al., 2002; Hallowell, 1998, 2000; Meiser et al., 2000; Patenaude et al., 2008). The few studies have focused on the experience of women who have PBM suggest loss and suffering as central to experience, and highlight the importance of support (see Lloyd et al., 2000; Wasteson et al., 2011). The negative repercussions of risk-reducing surgery should be taken seriously for the care of patients (Contant et al., 2004).

Limitations include the high level of prospective studies due to the small numbers of women undertaking these interventions, and some of the studies only considered women's intentions, which may change over time and they might not actually choose surgery. Sample sizes are small and lack power, and are often not matched. Meta analysis has been used to improve the reliability of studies reporting of emotional experience after genetic testing and determining the changes in distress over time (Hamilton et al., 2009). A possible drawback to quantitative methodology is that of priori hypotheses leading to assumptions about how people think which may not capture in-depth personal experience (Smith, Flowers, & Larkin, 2009).

Research findings are mixed about the impact of PBM and it may have negative repercussions for some women. No studies to date have explored the psychological and social impact of the surgery for the population of women with a BRCA 1/2 genetic mutation. Use of qualitative methods could potentially add to the knowledge base, as psychometric measures alone might not provide a complete picture (Weston et al., 2011). Research using qualitative methodologies complements the broader quantitative studies by examining the personal experience in detail, which can add to the existing evidence. Three types of qualitative analyses commonly used in clinical health psychology will be considered here in view of their suitability to the research question to explore the experiences of women with a known faulty breast cancer gene post-surgery and the psychological and social impact of PBM: discourse analysis, grounded theory and interpretative phenomenological analysis (IPA).

Discourse analysis is an interdisciplinary field covering for example, psychology, sociology and linguistics. There are many kinds of discourse analysis, within psychology the most popular is from Potter and Weatherall (1987). Discourse analysis involves examining texts in order to analyse how phenomena are discussed for a particular group, the discourse that the participant draws on and the position that the participant takes (Barker, Pistrang, &

Elliott, 2002). It is concerned with how people make use of cultural resources and the function of language as a social action. There is a focus on language as a social construction in social interactions, and the reflexive nature of psychological theory (Barker et al., 2002).

Grounded theory starts from a theoretical position that aims to produce rich descriptions and to generate theory (Barker et al., 2002). Developed from Glaser and Strauss (1967) it encompasses different versions. The constructivist version is most widely used in psychology (e.g. Charmaz, 1991). It aims to understand the person's inner world, the meanings and understanding of their experience. Grounded theory is often on a larger sample scale than other qualitative approaches, and the developing theory informs the sampling strategy. It focuses on a high level conceptual account that is grounded in the data.

IPA is an approach that is concerned with detailed examination of lived experience (Smith et al., 2009). As in grounded theory, IPA's theoretical foundations are in phenomenology, in exploring in detail how participants make sense of an event in their personal and social world. IPA is a method that allows application of a flexible framework to explore idiographic meaning. In many ways grounded theory overlaps with IPA, however IPA tends to involve smaller samples and emphasizes commonalities and divergence between participants, and analysis of individual experience (Smith et al., 2009). IPA enables the researcher to integrate research and practice with a focus on the understanding and personal meanings of a particular experience in a dynamic process (Reid, Flowers, & Larkin, 2005).

Little is known about the longer term impact of PBM (Hallowell & Lawton, 2002). There is currently a gap in knowledge about the experiences of women with the BRCA genetic mutation post PBM. Understanding patients' perceptions and beliefs is important as this determines how they respond to the intervention and how their needs can be met. IPA is well suited to guide and analyze the complex enquiry about the experience of PBM, what it means for women, and the psychological and social impact (Smith et al., 2009). IPA has been

used successfully to explore adjustment among survivors of oesophageal cancer (Clarke, McCorry, & Dempster, 2011) and personal experiences of managing appearance changes resulting from cancer treatment (Wallace, Harcourt, Rumsey, & Foot, 2007).

### **Conclusions**

It is apparent that there is a developing knowledge base about what PBM means for the individual and their experience post-surgery. There are no known studies concentrating on the experiences of women deemed to be at a high risk of breast cancer with a genetic mutation following risk-reducing surgery. Further research is suggested to develop our knowledge in order to ensure that their needs are met. Qualitative methodology would appear to be suitable to explore this gap in knowledge, and with its aim to explore, understand and describe the individual's experience it is suggested that IPA would be a suitable approach to explore the complexity of the experiences of women with a known faulty breast cancer gene following PBM. In the future further quantitative research could be linked to new concepts that are suggested. This may assist further identification of what may be helpful in supporting women through this experience.

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