

Running head: RISK-REDUCING SURGERY



DOCTORATE IN CLINICAL PSYCHOLOGY

**Major Research Project**

**The experience of prophylactic bilateral mastectomy in women to reduce the risk of  
breast cancer: An interpretative phenomenological analysis**

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**Table of Contents**

Manuscript .....	4
Abstract .....	4
Introduction.....	5
Method .....	10
Results.....	17
Discussion .....	26
References.....	34
Appendices.....	41
Appendix A: Ethics documentation .....	41
Ai    Letters of ethics and NHS Trust approval .....	41
Aii   Consent Form .....	47
Aiii  Letter to GP .....	48
Appendix B: Participant Information Sheet.....	49
Appendix C: Semi-structured Interview Schedule .....	53
Appendix D: Extended Method.....	56
Di: Plan of Dissemination of Results.....	56
Dii: Reflexivity statement.....	57
Diii Extended description of data analysis.....	58
Appendix E: Example of transcript coding (Claire) .....	60
Appendix F: Instructions for authors .....	61

## Manuscript

### Abstract

**Objectives:** Increasing knowledge of genetics has found that a mutation to the BRCA 1 or 2 genes are associated with a high risk of developing breast cancer throughout the lifespan. A woman with this genetic mutation may consider preventive surgery to reduce the risk of breast cancer. This involves a prophylactic bilateral mastectomy to remove the breasts when there is no cancer present and may be followed by breast reconstruction. This study aimed to explore the lived experience and psycho-social impact on women of this surgery.

**Design:** Interpretative phenomenological analysis was employed in an in-depth study of a small sample of eleven female patients with BRCA 1/2 genetic mutations who had undergone preventive surgery of prophylactic bilateral mastectomy.

**Methods:** Semi-structured interviews were carried out. The transcripts of those interviews served as the data for an interpretative phenomenological analysis.

**Results and conclusions:** Three themes were identified from the Interpretative Phenomenological Analysis to convey the lived experience of participants. These were (1) focus on reduced risk of cancer; taking control, relief and benefit finding, (2) a focus on relationships; family life, medical professional and BRCA support group and other women with lived experience, and (3) Focus on experiencing surgery and impact on self; the importance of reconstruction, loss of sexual attractiveness, impact on self from negative reaction of others and adjusting to surgical results. The implications are discussed in relation to the current literature and clinical practice.

**Keywords:** Preventive medicine, prophylactic surgery, genetic mutations, female

## Introduction

In the UK, guidelines published in 2006 by the National Institute for Health and Clinical Excellence (NICE) suggest that women can be referred to a specialist genetics service for gene testing if they are likely to have a high risk of developing breast cancer in their lifespan (including factors such as relatives with breast or ovarian cancer). Harmful mutations to the BRCA1 and BRCA2 genes are linked to a greater risk of developing breast cancer, of approximately 57%-84% (Hamilton, William, Bowers, & Calzone, 2009; Trivers et al., 2011). In order to get a genetic test, a GP can make a referral to a specialist genetics service and to a specialist breast clinic. Before making the decision whether or not to go ahead with the test, the staff in the genetics service will talk to the patient about their risk and discuss the test. The test result takes a few weeks, sometimes longer, to come back. If the test shows that the patient has a known faulty breast cancer gene there are a number of treatment options which can be discussed with a specialist breast clinic. It is possible to have regular breast cancer screening, or to have risk-reducing surgery to remove the breasts (and possibly the ovaries). In the U.K. research trials are currently taking place for preventive medicines (such as tamoxifen).

NICE suggests that risk-reducing surgery is only suitable for a small proportion of women and there are no definitive preventive recommendations. The decision to have preventive surgery is difficult and complex, and in many ways the process is like having an illness as the women are forced to contemplate the implications of developing severe illness in the future (Hoskins & Greene, 2012). The preventive surgical procedure known as prophylactic bilateral mastectomy (PBM) reduces the risk of developing breast cancer by removing both breasts before disease develops. It can greatly reduce the risk of developing cancer in the future by 95% (Trivers et al., 2011). In a total mastectomy, the entire breast and

nipple are removed. It is possible to have reconstructive surgery. A plastic surgeon will discuss the reconstruction options with the patient. There are choices of reconstructive procedures, the surgeon can insert an implant under the skin and the chest muscles. Another procedure, called tissue flap reconstruction, uses skin, fat, and muscle from the woman's abdomen, back, or buttocks to create the breast shape. The breast reconstruction can be undertaken at the same time as the surgery for mastectomy, or at a later stage. Over the past decade the options for reconstructive surgery have improved and women can be offered this choice almost as routine, and specialist reconstruction breast care nurse posts have been created.

Research has only just begun to explore the experience of women following a PBM. There are potential limitations to undergoing surgery and little is known about the longer-term impact of having PBM and reconstruction for women (Hallowell, 2000). Although not yet applied in the area of risk-reducing surgery, health psychological theories and models have potential relevance to help us to understand individual response and adjustment to PBM, which is a stressful life event. These include the health belief model which explains the likelihood of health preventive behaviour (Rosenstock, 1974; Becker and Rosenstock, 1987), and social cognition models such as Leventhal's self-regulation model that suggests once an individual is confronted with a potential illness, cognitive and emotional representations will be triggered and based on these, they will be motivated to act to regain equilibrium (Leventhal, Diefenbach, & Leventhal, 1992). Meaning making appears particularly important when 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, to restore a sense of the world as meaningful and their own lives as worthwhile. If this process is successful it leads to better adjustment to the stressful event (Collie & Long, 2005). Research has also begun to focus on the experience of positive change that can occur

as a result of struggling with highly challenging life events, including enhanced personal relationships, greater appreciation of life, a sense of increased personal strength, greater spirituality and a valued change in life values and goals (Tedeschi & Calhoun, 2004). A recent review has found an additional category of a new awareness on the body (Hefferon, Grealy, & Mutrie, 2009). Recent research has tentatively suggested such benefit finding in both women who have survived breast cancer, and following hereditary genetic testing (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Hoskins, Roy, Peters, Loud, & Greene, 2008; Low, Bower, Kwan, & Seldon, 2008). A gap in knowledge is how these factors operate in women's lives over time (Howard, Balneaves, & Bottorff, 2009). It is not yet known what the process is of meaning making and coping strategies in women with a BRCA genetic mutation who subsequently have a PBM.

Studies have reported that up to 97% of women report they were satisfied with their decision to have PBM, although younger women (under 50 years old) were significantly less likely to report satisfaction than older women (Contant et al., 2004; Frost et al., 2000; Metcalfe, Esplen, Goel, & Narod, 2004). Overall, there is no general consensus of the psychological impact. Some studies suggest little psychological impact of PBM with lower psychological morbidity including reduced anxiety (Claes et al., 2005; Hatcher, Fallowfield, & A'Hern, 2001; Wasteson, Sandelin, Brandberg, Wickman, & Arver, 2011). For some women PBM results in a negative impact on sexuality and body image (Brandberg et al., 2008; Frost et al., 2000). In a clinical study using self-report measures following PBM, 21% of women reported no negative change and 66% reported only minor change in body image (Hopwood et al., 2000). However, up to one in five women reported feeling quite a bit or very much less sexually attractive or self-conscious about their appearance. It was not clear whether the women had breast reconstruction, which has associated medical risks. It has been

suggested surgical complications can account for higher levels of reported distress following surgery which may have necessitated further intervention (Hopwood et al., 2000).

Several authors raise concerns about adverse psychological and social consequences of PBM for some women. In addition to body image concerns and feeling less sexually attractive, these include negative impact on self-esteem, sense of femininity and increased life stress (Frost et al., 2000; van Oostrom et al., 2003). In a qualitative study women reported in retrospect that they would have liked more information about the physical and emotional consequences of surgery (Hallowell, 2000). In a qualitative study using grounded theory "suffering and countering multiple loss", which included unhappiness with body image, was found to be central in women's experience post PBM. The importance of the social context in women's experience, difficulties of isolation, and of eliciting support were also highlighted (Lloyd et al., 2000). However, 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 for those who faced greater uncertainty (Lloyd et al., 2000).

It is apparent that there may be psychological and social impacts of PBM. Additionally, the individual's experience is closely linked to those around them. In a qualitative study of women who had undergone prophylactic oophorectomy (removal of the ovaries), which also included five women who had a PBM, 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). Counselling is provided during genetic testing but is not routinely offered post-operatively counselling. One study noted that 75% of women thought that a post-surgical psychological consultation would be helpful to discuss the emotional and interpersonal impact (Patenaude et al., 2008). There appeared to be value in peer consultation with women of a similar age and marital status, and/or surgical characteristics, and of support groups



(Meiser et al., 2000; Patenaude et al., 2008). It would seem beneficial for studies to explore further the needs of women post-PBM.

Research suggests that PBM may have negative repercussions for some women and little is known about the longer term effects of the surgery. To date there have been few studies attempting to gain insight into this group of women's experiences and no existing studies that solely include women who have PBM following genetic testing for a known faulty breast cancer gene. Qualitative methodologies are recognised for their usefulness in understanding the experience of individuals and utilising their insight, which can complement outcome and quantitative research by providing in- depth and contextual information about an event (Hodgetts & Wright, 2007). This study aims to extend this body of research using the qualitative methodology interpretative phenomenological analysis (IPA). IPA is a method that allows application of a flexible framework to explore idiographic meaning. The orientation of IPA is open and concerned with understanding lived experience (Smith et al., 2009). IPA is a dynamic process which enables the researcher to integrate research and practice with a focus on the understanding and personal meanings of particular individual experience (Reid, Flowers, & Larkin, 2005). Drawing upon the subjective experiences of eleven women who have undergone PBM, this research aims to use IPA to explore what having the operation meant to the participants and their personal perception of life following the event.

This is the first known study to date that explores the lived experience of women who are BRCA1/2 mutation carriers following PBM. This study has the following broad aim: to gain an understanding from the lived experience perspective of women who are BRCA mutation carriers the experience of PBM post-surgery. The research question is to explore the psychological and social impact of PBM on current life experiences. It is hoped that this study may improve understanding of the needs of women post-surgery and how they feel they

might be best supported after PBM. It is hoped that this will provide feedback to clinicians that could contribute to systems of care in order to be more sensitive to the needs of the patient and their family.

## **Method**

### **Participants**

Criteria for inclusion included women who had genetic testing and were BRCA1 or BRCA2 mutation carriers and had subsequently undergone a PBM to reduce the risk of developing breast cancer.

Women undergoing treatment for cancer were excluded. Participants with a personal cancer history of breast cancer were not excluded if they had recovered and were disease free, before they undertook genetic testing.

The aim of this study was to explore the participants' experiences in detail with a case by case analysis of individual transcripts. In order to achieve this aim the total participant number was limited in a concentrated focus to answer the research question. There is no agreed requirement for sample size in IPA, but a rough guide given for professional doctorates is around ten (Smith et al., 2009). Recruitment took place until this number was reached. In total fourteen participants were approached, one participant did not return the researcher's follow up call and three participants cancelled their interviews. In the event of one participant contacting the researcher to rearrange her interview, there were eleven participants.

Socio-demographic and disease related variables were collected pre-interview and can be seen in Table 1. All of the participants had breast reconstruction at the same time as the PBM with the exception of Hannah who had breast reconstruction four years later.

### **Service User Involvement**

During design on this study the researcher attended a support group of BRCA carriers (with consent from the facilitators and the group members), to seek consultation about the study, and acceptability and clearness of the language in the participant information sheet. The women expressed a positive response to the study. The researcher also consulted with Participant 1 (Lucy) following a pilot interview (not included in the analysis), regarding the acceptability of questions.

### **Ethical Considerations**

Formal ethical approval was gained from the University of Exeter Ethics Committee and NHS South West REC board<sup>1</sup>. Dissemination of the results is planned to include those involved in the study, those directly involved in the service and to the wider audience of those who are interested in gaining insight into the experiences of service users.<sup>2</sup>

### **Recruitment**

The specialist breast clinic from which the recruitment took place is a unit for the assessment and treatment of breast cancer based within a medium sized NHS teaching hospital in a city in South West England. The district area population is approximately 118,000, and ethnicity 93% white. The unit treats approximately 550 women a year who are diagnosed with breast cancer. Additionally, approximately 10 women a year are referred from the genetics service. The clinic was interested to find out more about women's experiences of PBM and provided an opportunity for recruitment.

Participants were recruited by the field worker (a specialist breast care nurse). The participants were sampled in a systematic way by contacting every 4<sup>th</sup> name on an

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<sup>1</sup> See Appendix Ai: Ethics documentation.

<sup>2</sup> See Appendix Di: Plan for dissemination of results.

alphabetical list of patients until the number of participants reached the sample size. The field worker telephoned participants to tell them a study would be taking place and if they asked for further information, a participant information sheet<sup>3</sup> was provided. If they gave consent to be contacted by the researcher, one follow up call was made. If the participant requested to take part in the study, an interview was arranged. Formal consent was gained at the beginning of the interview.<sup>4</sup> At the request of the NRES Committee and with the participants consent, a letter was sent to their GP informing them of their participation in the study.<sup>5</sup> Participants were paid travel expenses if appropriate.

Interviews were conducted over a four month period (November 2012 to February 2013). Interviews were arranged at the participant's convenience. One woman chose to be interviewed at her place of work, five at a NHS Hospital and five women at home. All interviews took place individually with a researcher and participant. NHS lone worker's policy was adhered to when necessary.

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<sup>3</sup> See Appendix B: Participant Information Sheet.

<sup>4</sup> See Appendix Aii: Participant consent form.

<sup>5</sup> See Appendix Aiii: Letter to GP.

Table 1

*Participant socio-demographics and disease related variables*

<b>Participant pseudonym</b>	<b>Age Group</b>	<b>Ethnicity</b>	<b>Occupation</b>	<b>Educational level</b>	<b>Marital Status</b>	<b>No. of Children</b>	<b>Approximate time since surgery</b>	<b>Personal cancer history</b>	<b>Family history of breast or ovarian cancer</b>
Marie	45-54	White British	Healthcare	'A' Level	Married	Two sons	6-12 months	Yes	Yes
Sally	35-44	White British	Leisure and sport	GCSE/ 'O' level	Divorced	Two daughters	2-3 years	No	Yes
Claire	35-44	White British (not born in U.K.)	Teacher	University	Married	A daughter and a son	1-2 years	No	Yes
Amy	35-44	White British	Retail/leisure	GCSE/ 'O' level	Married	Two daughters	1-2 years	No	Yes
Nicola	25-34	White British	Self employed	GCSE/ 'O' level	Living with partner	Three daughters and a son	2-3 years	No	Yes
Jessica	25-34	White British	Administration	'A' level	Married	Two sons	1-2 years	No	Yes
Katie	35-44	White British	Office Manager	GCSE/ 'O' level	Married	A daughter	5+ years	No	Yes
Hannah	55-64	White British	Self employed	GCSE/ 'O' level	Married	Two daughters and a son	5+ years	Yes	Yes
Emma	45-54	White European	Legal profession	University	Married	None	1-2 years	Yes	No
Becky	35-44	White British	Teacher	University	Married	Two sons and a daughter	Less than 6 months	No	Yes
Charlotte	65+	White British	Retired	GCSE/ 'O' level	Married	Two daughters	2-3 years	No	Yes

### **Interview schedule**

A semi-structured interview schedule was developed to gain insight into participants experiences of risk-reducing surgery, and included the context leading up to the surgery<sup>6</sup>. Questions were not necessarily used in the same sequence and the wording was adapted to suit the context that they were used in (Willig, 2012). The researcher encouraged participants to talk about their experiences by using reflective techniques and additional questions or prompts were posed which were aimed at clarifying meaning. Participants' experiences of the following topics were included:

- Onset of awareness that the participant had for a high risk of cancer
- Genetic testing
- Prophylactic bilateral mastectomy
- Post surgery
- Help and support
- Social context

The interviews were recorded with a digital recorder and transcribed verbatim. The duration of the interviews ranged from 27 minutes to one hour and ten minutes.

### **Analysis**

The data was analysed using Interpretative Phenomenological Analysis (IPA; Smith et al., 2006). IPA is an idiographic approach that is thought to be suitable in respect of the research questions as it offers the researcher the opportunity both to explore the research questions at a 'lived experience' level and 'making sense' by using psychological theory to offer an interpretation of the processes that may underlie this (Reid et al., 2005; Smith et al.,

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<sup>6</sup> See Appendix C: Semi-structured interview schedule.

2006). The stages of data analysis can be seen in table 2. A detailed explanation of the process is included in the appendix<sup>7</sup> and an example of transcript coding<sup>8</sup>. In an attempt to reduce bias associated with the researcher's own preconceptions and theories, a diary was kept to include reflection on their own subjectivity and discussed with supervisors.

The reason for choosing IPA over any other qualitative approach was due to suitability to the research question. It offered the opportunity to integrate research and practice with a focus on the understanding and personal meanings that people make of a particular experience. It was felt that in discourse approaches the focus would be on how people talk and interact about the experience and how this is socially constructed in a specific setting (Smith et al., 2009). The narrative approaches were thought to offer more of a focus on content or genre (Crossley, 2000), or how people structure their narratives (Gergen & Gergen, 1998). Grounded theory, of which there is overlap with IPA, was felt to have more of a focus on factors and developing a theoretical account of the phenomena (Reid et al., 2005; Smith et al., 2009).

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<sup>7</sup> See extended data analysis in appendix Diii.

<sup>8</sup> See example of transcript coding in appendix E.

Table 2  
*Analysis Procedure (Smith, Flowers, & Larkin, 2009)*

Stage	Description
Stage 1: reading and re-reading	Listening to the audio and reading the transcript, author notes anything of interest or significance.
Stage 2: initial noting	Producing a detailed set of notes and comments on the data (descriptive, linguistic and conceptual).
Stage 3:developing emerging themes	Looking for emerging themes and attempting to reduce the volume of detail whilst maintaining complexity.
Stage 4:moving to the next case	Moving onto the next transcript and repeating the process.
Stage 5:searching for connections between emergent themes	Drawing together the emerging themes and exploring a spatial representation of how they relate to each other (including abstraction, subsumption and polarisation).
Stage 6:looking for patterns across cases	Measuring recurrence across cases using a table of themes which may include relabeling and reconfiguring of themes.



## Results

The experiences of the participants in this study are complex and unique. An attempt has been made to find themes that relate to the group as a whole, whilst using idiographic detail of participants experience through transcript extracts. The resulting themes are interrelated and over lapping. It is hoped that they represent the experience of the risk-reducing surgery for the participants although at times this may detract from the richness of their individual stories.

Three superordinate themes were identified relating to how the participants experienced the impact of surgery and what it meant to them (1) focus on reduced risk of cancer; (2) focus on relationships; (3) Focus on experiencing surgery and impact on self.

Table 3  
*Table of themes*

Superordinate themes ( <i>number of participants</i> )	Themes ( <i>number of participants</i> )
1 Focus on reduced risk of cancer (11)	1.1 Taking control (11) 1.2 Relief (8) 1.3 Benefit finding (11)
2 Focus on relationships (11)	2.1 Family life (7) 2.2 Medical professionals (11) 2.3 BRCA support group and other women with lived experience (9)
3 Focus on experiencing surgery and impact on self (11)	3.1 Importance of reconstruction (10) 3.2 Loss of sexual attractiveness (6) 3.3 Impact on self from negative reaction of others (11) 3.4 Adjusting to surgical results (8)

## 1. Focus on risk of reducing cancer

This superordinate theme captures the participants accounts of the risk-reducing nature of PBM, including taking control, relief and benefit finding. For all of the participants following genetic testing the decision to have PBM was ultimately the only option that made sense to them. The significance of this event shaped their subsequent experiences, with none participants experiencing regret about having the surgery as it reduced risk:

Jessica: “I know my risk has been massively reduced, like I say I can go for weeks without even thinking about it”.

### 1.1 Taking control

Nearly all the participants perceived their risk of developing cancer as inevitable pre-surgery. Sally described feeling she felt like a “literal ticking time bomb”. PBM was seen as a way of taking control over disease.

The participants varied in their belief in how much the PBM could completely control their risk of developing cancer. Some participants felt the risk was located solely in their breasts and they became “something that had to go”. Some of the participants’ perceived cancers as a threat until ‘deadlines’ were reached of past bereavements:

Katie: “I think about it more now since having my operation, not so much that i’m frightened anything’s going to happen now, that’s gone, but it’s always on my mind, I can’t wait to be (age) because mum was (age of her mother’s death).”

For some participants PBM was seen as only part of their journey of controlling risk, with some of the participants having, or planning, other risk-reducing surgery (such as oophorectomy).

Becky: So other people talk about once they’ve had their mastectomy that it’s you know a relief and the shadows gone, but I don't really feel that, I just feel it’s

something I had to do. I think I'll be able to breathe and sleep easy once the ovaries are gone and I think personally for me that's what I feel under risk from more."

## **1.2 Relief**

The PBM decreased the cancer related fear that most participants had felt. For many this had raised high levels of anxiety that they felt they "couldn't live with". This "menacing" danger located within the body was eloquently described by:

Amy: "I can remember not long after the surgery I had this dream ... I was having surgery and I came round and the surgeon said I've removed a six foot snake from your body and I thought oh my god!, but it was clear as day to me that the six foot snake, it wasn't a snake, it represented fear, and that's how big my fear was."

The surgery brought "peace of mind" and relief from worry for many of the participants and helped them to process the experience. This relief appeared to be stronger in the women who had survived cancer.

## **1.3 Benefit finding**

Many of the participants found positive psychological changes following the stress of undergoing their surgery. As for many of the participants, for Sally, this was a sense of increased personal strength:

"I feel empowered against cancer and taking a stand. Now literally the odds of me getting breast cancer have been slashed. It does empower you, you feel stronger, you feel that you have done something positive".

Some of the participants felt a greater appreciation of life and for some of the women this was a protective factor against physical pain resulting from the surgery such as backache. Most of the participants were focused on what they valued in their lives and saw PBM as allowing them to "get on" with their lives. Claire summarises this: "... kind of puts into perspective what's important in life."

Some of the participants used downward comparison with others to evaluate their experience, including other women who had cancer:

Claire: “my risk is so much lower than it was so I’m actually, if I look at that I am so much more fortunate than she is so.”

## **2 Focus on relationships**

This superordinate theme encapsulates the relationships and support that were important to the participants from a partner/husband, sister, friend or a support group:

Becky: “ It just made me felt like I wasn’t on my own really, my friends were great and they really sort of rallied round and medical people as well ... and what was really great was the group that I’ve been going to, the BRCA group ... I think it was nice to meet people with the same, the same thing, who’d been through the same operation.”

It seemed that the women who perceived that their support was lower in any of these types of supportive relationships seemed to report more feelings of isolation and struggling to cope.

### **2.1 Family life**

The experience of the participants was closely linked to those around them and their whole family. For many participants the importance of open communication with their family was at the fore of their accounts and this enhanced their personal relationships:

Marie: “I received lots of support from my family and its, this might be the one bit I get a bit emotional about, because it’s definitely brought me closer to my dad.”

For the majority participants, the knowledge that they had a hereditary BRCA mutation potentially had implications for their children and sisters. Some participants felt helpless that they were able to take steps to reduce their risk, but could not control the risk for their relative. This cancer related distress for their family was difficult to separate from their experience of PBM (also see Wasteson et al., 2011). A few of the participants had PBM

surgeries at the same time as family members. Sharing these similar experiences meant they had a peer support group in their family which added to their sense of social support:

Nicola: “Yeah my sister did it too we did it together sort of thing so and my other sister had just gone through it as well ... so all three of us and then my mum, all had the same sort of hellish year and we leaned on each other so that was good.”

## **2.2 Medical professionals**

The medical professionals in the breast care unit were highly praised by the majority of the participants. The multi-disciplinary team approach was seen as important. The breast care nurses were valued for passing on and giving information, help and providing reassurance to answer “silly questions” which “put your mind at rest”.

Many participants had an emotional reaction to PBM and the importance of being respectful and sensitive to the amount of medical detail that an individual can cope with was highlighted. For some participants too much detail or a “blunt” directive approach increased their anxiety. The importance of person centred care was highlighted:

Charlotte: “Well they made you feel like you were not just another person you know they spoke to you individually, you know I mean it wasn’t you are having this and that and the other, they did ask you what you felt and they were very good.”

The majority of the participants were information seekers. Some participants highlighted the usefulness of literature, books, leaflets and photographs to refer to and read at their own pace.

Some of the individual concerns raised around medical support were accessibility because of distance which led to feelings of isolation, and the need for overall coordination over different types of surgery. Two participants expressed a wish for additional follow up appointments or counselling post-surgery.

### **2.3 BRCA support group and other women with lived experience**

Around half of the participants attended a support group for BRCA mutation carriers. The group contained women at all stages of their journey and was “helpful” and “inspiring” as it was “upbeat and “positive”. Important factors seemed to be the support from each other and commonality with others going through the same experience. It made the women realise that they were not on their own and facilitated coping. Some participants wanted to help others like they had been helped. The group was experienced as normalising and reassuring, and positive coping role modelling took place:

Emma: “It’s just such a good group because you see them and you think mmm they’re just normal people don’t you (laughs) and they’ve all come through the surgery or they are waiting for the surgery and you think yeah they’re just normal and they’ve got normal lives and they do normal things.”

Positive reassurance from others was seen as helpful, but not to the expense of over optimism and ignoring the consequences of PBM.

### **3 Focus on experiencing surgery and impact on self**

This superordinate theme helps bring together a series of themes that captures the participants’ descriptions of their experience of the surgery and their views of themselves. It was clear for the majority of participants that PBM impacted on their sense of self in varying ways.

#### **3.1 Importance of reconstruction**

It was important for the majority of the participants to visually look the same as they did before surgery and to be “normal”. The meaning of this for the participants varied, for example for Jessica, this was so that she doesn’t have to explain anything to others, and for Amy she was proud of her breasts and shape as a woman. As such, breasts have a meaning in the construction of gender and personal identity (Hallowell, 1998). The majority participants

felt their breast reconstruction was very important, with many stating that they did not think that they would be as happy with the surgery without it.

The importance on reconstruction appeared to vary with age with older participants putting less importance on reconstruction. Charlotte said if she had not had reconstruction: “I don’t think it would have bothered me at all.” However, although Hannah did not have immediate reconstruction as she didn’t initially think that she “needed it”, went on to have reconstruction:

“I thought actually I’ve had enough of them, being really flat chested and wearing prosthesis and I spent a lot a lot of money on nice underwear and things but it’s just not the same, so it’s a big operation but yes I’m glad I done it.”

Although the majority of the participants were happy with how their new breasts looked with clothes on, they were aware that they were “not my own breasts” and that they felt different. They were less confident about how they felt about their new body, which felt “strange” at first with “no feeling” being a “funny feeling” and “it takes time to adjust”. Becky felt that her new breasts were a cushioned “barrier” when she cuddled her children. Over time this feeling appeared to diminish for the women.

Four participants stated that the reconstruction offered the opportunity for positive changes, including removing cyclical breast pain, lifting, reduction in size and improving previous surgery.

### **3.2 Loss of sexual attractiveness**

Breasts are a visual sign of being female and have sexual connotations. Loss of sexual attractiveness following PBM was mentioned by around half of the participants. Feeling feminine by wearing pretty underwear was mentioned by many participants and made them feel more attractive. Sally remembered how at times she still struggles with her body image and confidence:

“I felt like every last ounce was taken. I hate them myself, I still do. I’m hoping it will get, I mean in a nice bra they look lovely. But I know what’s underneath.”

Body image concerns were connected to partner support. Many participants talked about the importance of being in a secure relationship which seemed a protective factor to their sexual attractiveness. A few participants stated that they would not show a new partner their new breasts because they would be afraid of a negative reaction. They were concerned about seeming less physically attractive because of their mastectomy and resulting mood changes, one participant worried if her husband “is still going to love me because it’s different”. Some participants gave accounts of others relationships that had broken down and suggested the need to consider the impact of PBM on partners and additional support needs.

### **3.3 Impact on self from negative reaction of others**

Some participants spoke of adverse responses from other people about PBM:

Becky: “...saying you know she doesn’t have cancer, I don’t know why she’s done it, what an extreme measure to take and so on, that just makes me really angry”

For some of the participants telling others about PBM was met with a strong emotional response of shock and horror which fuelled their own frustration and distress. A few participants disclosed that they felt unsupported by medical professionals in the community or on the ward, who either had little knowledge of the procedure or presumed it was an “elective” surgery as they were “not ill”, which left them reluctant to talk about how they felt and resulted in feelings of isolation.

Nicola felt that people should take time to listen to the reasoning of why she had the surgery before passing judgement, as the good result she had externally hides the emotional struggle within:

Nicola: “So some people, there was very few ... they see me as somebody who has got a lovely pair of boobies but I actually want to get my scars out and get my boobies



out and say really? Really? What you see on the outside is what I make you see, not what you see on the inside.”

### **3.4 Adjusting to surgical results**

The impact of the surgery on the body was something that many participants took time to adjust to, and this an emotional impact which affected the women in a variety of ways. For some of the participants coping with the PBM had an emotional impact which they were not prepared for. For some, PBM evoked memories of previous bereavements. A few of the participants described the surgery as a traumatic event, “harrowing”, “frightening”, “debilitating” and as if they had been “run over”. At first some women were shocked by the “alien” “ugly” surgical results. Sally: “... it is a huge shock to the system, not just physically. I would say emotionally I’ve struggled harder than physically.”

The recuperation from surgery took longer than many participants expected. Amy expressed the surprise that many had felt: “I just thought I’d have the surgery and just carry on as normal. I didn’t think about how my body would feel afterwards.”

Despite this, many of the participants said that they were “fine” in what appeared to be acceptance based coping, Hannah: “Basically I just carried on”. Many of the participants used problem focused coping such as focusing on sorting out “small things”, which as part of a wider goal enabled them to cope. For example Marie set herself targets each day and felt positive when she achieved them “that’s how I got through it really”.

Although this did not affect their belief that they had a good end result, a few of the participants wished that they had taken more time to research the different types of breast reconstruction and the consequences of the surgery. The physical consequences of the PBM varied within the participants from an “odd thing now and again” to some participants who experienced post-operative pain or complications which was a constant reminder of their experience. This hindered coping.

## Discussion

The aim of this study had been to add to the knowledge base by exploring the lived experience of PBM for women with a known faulty breast cancer gene. Three superordinate themes were identified by the IPA (1) focus on reduced risk of cancer; (2) focus on relationships; (3) focus on experiencing surgery and impact on self. Some aspects of these themes have been found in previous research following a PBM. These will now be discussed in the context of theory. Suggestions of how this can be applied to clinical practice are also discussed.

The findings in this study suggest a number of social cognitive models have potential relevance to help us to understand individual response and adjustment to PBM. In line with the health belief model, the participants had perceived both the severity and susceptibility to breast cancer as high and were motivated by the outcome of the perceived benefits of the PBM to reduce their risk. However, this was not straight forward as the consequences of the PBM had an emotional impact, which some participants were not anticipating. The self-regulation model has resonance as the participants' appeared to be active problem solvers (Leventhal, Diefenbach, & Leventhal, 1992). Women may find a meaning to their experience by attributing the genetic mutation as the cause, and the PBM then is seen as worthwhile (Park, 2010). By understanding and making meaning of their experience, they have a sense of control over the illness and their bodies. This need for control has been found in previous studies (Babb et al., 2002). Some participants made conscious efforts to restore self-esteem to restore equilibrium. This was demonstrated by Marie who set herself goals during recovery and Claire who used downward comparisons. This allows better adjustment to the stressful event (Collie & Long, 2005; Taylor, 1983). Counter to a previous study loss and suffering was not found to be central to the participants' experiences (Lloyd et al., 2000). Based on the findings a hypothesis could be that women who make their decision following predictive

genetic testing had found a meaning to their experience which went some way to counter the loss. This could be a topic to be explored in further studies.

In line with previous studies, the surgery resulted in a reduction in worry (Claes et al., 2005; Hatcher, Fallowfield, & A'Hern, 2001). All of the participants were “glad” that they had the PBM. For many of the participants the PBM resulted in relief, but this was not felt as strongly for all the women. Variations may be tentatively accounted for by women with personal experience of cancer experiencing more relief, for some participants relief was tempered as PBM was seen as one part of a continued journey to reduce risk, or some women felt cancer related distress for their family that was difficult to separate from their experience of PBM (Wasteson et al., 2011).

Coping research explores the way in which people respond to stressful events. The cognitive adaptation theories discussed above emphasise how people are motivated to return to normality, and other theories can be drawn on that consider positive consequences following stressful events (Ogden, 2012). This is not to suggest that women must benefit from the experience, or minimising the individual experience of loss and grief, rather to consider positive reappraisal coping and this may affect mood (MacBrayer, 2007). Benefit finding was identified as a sub-theme and found in the accounts of the participants, which suggests positive psychological change following PBM (Tedeschi and Calhoun, 2004). Some participants perceived enhanced personal relationships, greater appreciation for life, sense of increased personal strength, a valued change in life priorities and goals, and increased awareness of the body. Benefit finding may be representative of the participants reconstructing past experiences to be more congruent to their current state, and reporting gains retrospectively may be a way of coping (Stanton, Danoff-Burg, & Huggins, 2002). However, this model can only be tentatively applied here.

The positivity that the participants showed in the face of the unpleasant procedure of PBM was striking. The findings from this study support previous findings that focusing on distress may lead to an incomplete and potentially misleading picture of adjustment to illness (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Culturally, subjective norms and interpretations of what it means to be diagnosed with cancer include the imperative to think positively about their situation which places the patient as an active participant with a responsibility to do what they can to regain health. This preoccupation with control can mean that the unpleasant nature of the intervention are minimised in preference for the belief that things will turn out well (Willig, 2012). It seems important to keep an open dialogue as the consequences could be that any negative consequences to the PBM are not discussed, so not to risk losing social support or empathy.

In line with previous qualitative findings the importance of social support was central in the participants' accounts of their experience and importance, and there were potential difficulties of eliciting support and understanding from others (Lloyd et al., 2000). The experience of the participants was closely linked to those around them. The importance of a supportive relationship with a partner seemed to be a benefit to psychological functioning, emotional adjustment and coping. This perceived social support from friends and family are of paramount importance for long-term adaptation (den Heijer et al., 2011, 2012). The support group was important for many of the participants. Hannah was one of the participants who had felt isolated before she found the support group. Previous research suggests the support group has a role in building self-esteem, reducing isolation and reducing stigma (den Heijer et al., 2011). Talking to other women who had already had surgery was also valued (Patenaude et al., 2008). The high level of satisfaction with social support that the majority of the participants experienced may have resulted in greater benefit finding.

The findings in this study support previous findings of positive and negative impacts on identity following PBM. Some participants felt that not having reconstruction would have threatened their self-identity. For many participants at first their reconstructed breasts felt “different”. The participants had to adjust to their bodies post-surgery, and this can be seen as both incorporating new attitudes to the self and perceptions of that self by others. Some women spoke about others lack of understanding which seemed threatening to the cognitive adaptation they have made to the PBM and resulted in anger. Previous research discusses a risk of loss of self and a restricted life following illness and social isolation due to physical limitations or fears of others response to their new state (Charmaz, 1991). Although Sally felt positive about her PBM, when faced with post-operative complications she struggled. She avoided social situations, and lost confidence due to changes to her physical shape. This resulted in changes in her self-identity and it took time to reconstruct her self-identity. This can also be illustrated by Nicola’s story, as she described her scars as “war wounds” and spoke about radically displaying her breasts to disprove assumptions of viewed as “lovely” by others. Scars can be seen as a visible challenge to conventional ideas of beauty and for Nicola seemingly become a ‘sign’ of her experience, not just a body part but as a whole reconstructed self-identity as a woman who had reduced her risk of breast cancer, but not without consequences.

Loss of sexual attractiveness was experienced by around half of the participants. This appeared to be closely related to concerns about body image and has also been found in previous studies (for example Hopwood et al., 2000). Many participants spoke of the importance of a secure relationship with their partner and their affirming responses can help maintain sexual attractiveness. However, not only is the self –identity threatened, there are heightened awareness of the importance of a supportive relationship to be able to cope with the PBM. More research would be required as this is a small sample.

### **Limitations of the current study**

This study can only shed light on a small part of what is a complex and individual experience. As such it is an exploratory study offering interesting information in the accounts of PBM regarding the impact of the surgery. There is a weakness in using accounts due to retrospective bias, and interviewing women in particular contexts including hospital may have influenced responses to interview questions including willingness to disclose sensitive information. Consideration should also be made of the limitations what can be generalised from an individual experience both across the group and more widely to other women, and of the variation associated with the different lengths of time after surgery for the participants. In addition, all the participants were recruited from one unit. The study included three women who had a personal history of cancer as well as unaffected women. There were practical limitations of available time for a clinical doctoral thesis, and with more time, the researcher would have added participants' voices to the analysis stage. As this did not take place this has meant that there is a gap between the participants' accounts and the researcher's interpretation of meaning (Willig, 2012).

As the women in this study had chosen PBM they may be a highly motivated group and it may have been helpful to compare their experiences with women who chose not to have the surgery. How do women who choose not to have PBM deal with the perceived risk? One finding was that PBM was just a part of the participants' journey with many feeling that they would do anything possible to reduce their risk. More research would be beneficial into what the cut-off point would be to make people feel like they have done all they can to reduce risk. Another consideration for future research may be to explore partners' reactions and how they cope, in view of meeting couples' support needs.

## **Clinical Implications**

A number of suggestions will be made in view of the findings in order to be more sensitive to women's needs post-surgery. PBM was perceived as a health intervention that reduced the risk of cancer, many participants positively reframed their experience and believed in returning to 'normal' life. If coping strategies are to succeed it is important for clinicians to know what the participants' goals are, and their meaning of 'normal' in order that support can be appropriately targeted to improve quality of life. Adequate training is required in eliciting women's concerns. In clinical practice, similarly to the methodology of IPA, it is important to keep a person centred approach and consider the meaning for the individual in their wider social context. Another aspect of this is the need to consider that for many of the participants PBM is one part of their journey and to consider joined up services and clinical coordination.

Social and psychological resources are important in coping following PBM. The participants' coped by use of relationships with medical professionals, family life and other women. Therefore the social resources that women have available should be assessed and access to new resources encouraged, facilitating coping and adaptation (den Heijer et al., 2012). It may be helpful for professionals to suggest ways of coping that others have found to be helpful. Previous literature of follow up after hospital admission suggests that acceptance coping (accepting how things were) was associated with lower levels of distress, and problem-focused (problem solving) was associated with high positive mood (Stanton, Danoff-Burg, & Huggins, 2007). As situations are dynamic and multi-dimensional, therefore coping responses need also to be varied (Kyngäs et al., 2001). The participants in this study used all sorts of active coping efforts including problem-focused; making use of social support resources, seeking information from health professionals, support from others in a similar situation and emotional support from families, setting behavioural targets to cope and

get through things and planning how to resolve their difficulties, appraisal focused; reframing things positively, acceptance and social comparison coping. This would suggest that psychological interventions to encourage a variety of active ways of coping such as cognitive behavioural therapy, or acceptance based approaches may be helpful for some. The unexpected negative impact of PBM for some women should not be underestimated particularly for those with post-operative complications (Metcalf et al., 2004; Josephson et al., 2000; van Oostrom et al., 2003). The findings support previous studies that suggest psychological support should be routinely offered to women after PBM.

### **Conclusion**

PBM is a relatively new intervention to manage the risk of developing cancer. This study has explored the experience of PBM and the psycho-social impact on current life experiences in order to better understand the needs of women post-surgery and how they might be best supported after surgery. The findings suggest an impact on a number of psychological and social levels. Three themes were suggested to convey the lived experience of participants, a focus on the reduced risk of developing cancer; a way of taking control for survival. It is suggested that cognitive adaptation theories are helpful in explaining how people are motivated to return to normality and coping research can be applied in assisting adaptation to the stressful event. Relief was felt following surgery by many participants. The data suggested that positive psychological consequences may follow this stressful event and that there may be benefit finding which facilitated coping.

The second focus for the women was on relationships and coping by use of relationships; family life, seeking support from medical professionals and other women in a support group and with commonalties of experience. Social support is known to be an important factor influencing good outcomes.



The third focus was on experiencing surgery and impact on self. The importance of reconstruction was highlighted, a feminine physical shape an important part of self-identity. For some participants surgical changes resulted in perceived loss of sexual attractiveness. Some women received negative responses from others that impacted on their sense of self. Many participants had an adjustment period to the surgical results.

Some suggestions were made on how to apply this clinically in order that support can be appropriated targeted.

## References

- Babb, S. A., Swisher, E. M., Heller, H. N., Whelan, A. J., Mutch, D. G., Herzog, T. J., & Rader, J. S. (2002). Qualitative evaluation of medical information processing needs of 60 women choosing ovarian cancer surveillance or prophylactic oophorectomy. *Journal of Genetic Counseling, 11*, 81-96. doi: 10.1023/a:1014571420844
- Becker, M. H., & Rosenstock, I. M. (1987). Comparing social learning theory and the health belief model. In W. B. Ward (Ed.) *Advances in Health Education and Promotion*. Greenwich, CT: JAI Press.
- Brandberg, Y., Sandelin, K., Erikson, S., Jurell, G., Liljegren, A., Lindblom, A., Lindén, A., von Wachenfeldt, A., Wickman, M., & Arver, B. (2008). Psychological reactions, quality of life, and body image after bilateral prophylactic mastectomy in women at high risk for breast cancer: A prospective 1-year follow-up study. *Journal of Clinical Oncology, 26*, 3943-3949. doi: 10.1200/jco.2007.13.9568
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Claes, E., Evers-Kiebooms, G., Decruyenaere, M., Denayer, L., Boogaerts, A., Philippe, K., & Legius, E. (2005). Surveillance behavior and prophylactic surgery after predictive testing for hereditary breast/ovarian cancer. *Behavioral Medicine, 31*, 93-105. doi: 10.3200/bmed.31.3.93-106
- Collie, K., & Long, B. C. (2005). Considering 'meaning' in the context of breast cancer. *Journal of Health Psychology, 10*, 843-853. doi: 10.1177/1359105305057318
- Contant, C., Wersch, A. V., Menke-Pluymers, M., Wai, T. J., Eggermont, A., & Geel, A. V. (2004). Satisfaction and prosthesis related complaints in women with immediate

- breast reconstruction following prophylactic and oncological mastectomy. *Psychology, Health and Medicine*, 9, 71-84. doi: 10.1080/13548500310001637760
- Cordova, M. J., Cunningham, L. L., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: a controlled comparison study. *Health Psychology*, 20, 176-185. doi: 10.1037/0278-6133.20.3.176
- Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma and the construction of meaning*. Buckingham: Open University Press.
- den Heijer, M, Vos, J., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Tilanus-Linthorst, M., Menke-Pluymers, M. B. E., & Tibben, A. (2012). The impact of social and personal resources on psychological distress in women at risk for hereditary breast cancer. *Psycho-Oncology*, 21, 153-160. doi: 10.1002/pon.1879
- Frost, M. H., Schaid, D. J., Sellers, T. A., Slezak, J. M., Arnold, P. G., Woods, J. E., Petty, P.M., Johnson, J. L., Sitta, D. L., McDonnell, S. K., Rummans, T. A., Jenkins, R. B., Sloan, J. A., & Hartmann, L. C. (2000). Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. *JAMA: Journal of the American Medical Association*, 284, 319-324. doi: 10.1001/jama.284.3.319
- Gergen, K. J., & Gergen, M. M. (1988). Narrative and the self as relationship. In L. Berkowitz (Ed.) *Advances in Experimental Social Psychology*, 21. New York, NY: Academic Press.
- Hatcher, M. B., Fallowfield, L., & A'Hern, R. (2001). The psychosocial impact of bilateral prophylactic mastectomy: Prospective study using questionnaires and semi-structured interviews. *British Medical Journal*, 322 (76). doi: 10.1136/bmj.322.7278.76
- Hallowell, N. (1998). "You don't want to lose your ovaries because you think I might become a man". Women's perceptions of prophylactic surgery as a cancer risk management

- option. *Psycho-Oncology*, 7, 263-275. doi: 10.1002/(sici)1099-1611(199805/06)7:3<263::aid-pon307>3.0.co;2-q
- Hallowell, N. (2000). A qualitative study of the information needs of high-risk women undergoing prophylactic oophorectomy. *Psycho-Oncology*, 9, 486-495. doi: 10.1002/1099-1611(200011/12)9:6<486::AID-PON478>3.0.CO;2-Y
- Hamilton, R., Williams, J. K., Bowers, B. J., & Calzone, K. (2009). Life trajectories, genetic testing, and risk reduction decisions in 18-39 year old women at risk for hereditary breast and ovarian cancer. *Journal of Genetic Counseling*, 18, 147-159. doi: 10.1007/s10897-008-9200-1
- Hefferon, K., Grealy, M., & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: A systematic review of the qualitative literature. *British Journal of Health Psychology*, 14, 343-378. doi: 10.1348/135910708X332936
- Hodgetts, A., & Wright, J. (2007). Researching clients' experiences: A review of qualitative studies. *Clinical Psychology & Psychotherapy*, 14, 157-163. doi: 10.1002/cpp.527
- Hopwood, P., Lee, A., Shenton, A., Baidam, A., Brain, A., Lalloo, F., Evans, G., & Howell, A. (2000). Clinical follow-up after bilateral risk-reducing ('prophylactic') mastectomy: Mental health and body image outcomes. *Psycho-Oncology*, 9, 462-472. doi: 10.1002/1099-1611(200011/12)9:6<462::aid-pon485>3.0.co;2-j
- Hoskins, L. M., & Greene, M. H. (2012). Anticipatory loss and early mastectomy for young female BRCA1/2 mutation carriers. *Qualitative Health Research*, 22, 1633-1646. doi: 10.1177/1049732312458182
- Hoskins, L. M., Roy, K., Peters, J. A., Loud, J. T., & Greene, M. H. (2008). Disclosure of positive BRCA1/2 mutation status in young couples: The journey from uncertainty to bonding through partner support. *Families, Systems & Health*, 26, 296-316. doi: 10.1037/a0012914

- Howard, A. F., Balneaves, L. G., & Bottorff, J. L. (2009). Women's decision making about risk-reducing strategies in the context of hereditary breast and ovarian cancer: A systematic review. *Journal of Genetic Counseling, 18*, 578-597. doi: 10.1007/s10897-009-9245-9
- Josephson U., Wickman M., & Sandelin K. (2000). Initial experiences of women from hereditary breast cancer families after bilateral prophylactic mastectomy: A retrospective study. *European Journal of Surgical Oncology, 26*, 351-356. doi: org/10.1053/ejso.1999.0897
- Kyngäs, H., Mikkonen, R., Nousiainen, E. M., Ryttilähti, M., Seppänen, P., Vaattovaara, R., & Jämsä, T. (2001). Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care, 10*, 6-11. doi: 10.1046/j.1365-2354.2001.00243.x
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16*, 143-163. doi: 10.1007/bf01173486
- Lloyd, S. M., Watson, M., Oaker, G., Sacks, N., Rovere, U. Q. D., & Gui, G. (2000). Understanding the experience of prophylactic bilateral mastectomy: A qualitative study of ten women. *Psycho-Oncology, 9*, 473-485. doi: 10.1002/1099-1611(200011/12)9:6<473::aid-pon490>3.0.co;2-t
- Low, C. A., Bower, J. E., Kwan, L., & Seldon, J. (2008). Benefit finding in response to BRCA1/2 testing. *Annals of Behavioral Medicine, 35*, 61-69. doi: 10.1007/s12160-007-9004-9
- MacBrayer, E. K. (2007). My life as a mutant: The BRCA1 experience. *Professional Psychology: Research and Practice, 38*, 571-575. doi: 10.1037/0735-7028.38.6.571

- Meiser, B., Tiller, K., Gleeson, M. A., Andrews, L., Robertson, G., & Tucker, K. M. (2000). Psychological impact of prophylactic oophorectomy in women at increased risk for ovarian cancer. *Psycho-Oncology*, *9*, 496-503. doi: 10.1002/1099-1611(200011/12)9:6<496::AID-PON487>3.0.CO;2-Z
- Metcalfe, K. A., Semple, J. L., & Narod, S. A. (2004). Satisfaction with breast reconstruction in women with bilateral prophylactic mastectomy: A descriptive study. *Plastic & Reconstructive Surgery*, *114*, 360-366.
- National Institute for Health and Clinical Excellence. (2006). *Familial breast cancer (Clinical Guideline 41)*.
- Ogden, J. (2012). *Health psychology* (5<sup>th</sup> ed.) Berkshire: Open University Press.
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychology Bulletin*, *136*, 257-301. doi: 10.1037/a0018301
- Patenaude, A. F., Orozco, S., Xiaochun, L., Kaelin, C. M., Gadd, M., Matory, Y., Mayzel, K., Roche, C.A., Smith, B. L., Farkas, W., & Garber, J. E. (2008). Support needs and acceptability of psychological and peer consultation: Attitudes of 108 women who had undergone or were considering prophylactic mastectomy. *Psycho-Oncology*, *17*, 831-843. doi: 10.1002/pon.1279
- Reid, K., Flowers, P., & Larkin, M. (2005). Interpretative phenomenological analysis: An overview and methodological review. *The Psychologist*, *18*, 20-23.
- Rosenstock, I. M. (1974). The health belief model and preventive health behaviour. *Health Education Monographs*, *2*, 354-386.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.

- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray, K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Methods* (pp. 218-240). London: Sage.
- Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. *Psycho-Oncology*, *11*, 93-102. doi: 10.1002/pon.574
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, *38*, 1161-1173.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, *9*, 455-471. doi: 10.1002/jts.2490090305
- Trivers, K. F., Baldwin, L. M., Miller, J. W., Matthews, B., Andrilla, C. H. A., Lishner, D. M., & Goff, B. A. (2011). Reported referral for genetic counseling for BRCA 1/2 testing among United States physicians. *Cancer*, *117*, 5334-5343. doi: 10.1002/cncr.26166
- van Oostrom, I., Meijers-Heijboer, H., Lodder, L. N., Duivendoorn, H. J., van Gool, A. R., Seynaeve, C., van der Meer, C. A., Klijn, J. G. M., van Geel, B. N., Burger, C. W., Wladimiroff, J. W., & Tibben, A. (2003). Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: A 5-year follow-up study. *Journal of Clinical Oncology*, *21*, 3867-3874. doi: 10.1200/JCO.2003.10.100
- Wasteson, E., Sandelin, K., Brandberg, Y., Wickman, M., & Arver, B. (2011). High satisfaction rate ten years after bilateral prophylactic mastectomy-A longitudinal study. *European Journal of Cancer Care*, *20*, 508-513. doi: 10.1111/j.1365-2354.2010.01204.x

Willig, C. (2012). *Qualitative interpretation and analysis in psychology*. Maidenhead: Open University Press.



## **Appendices**

### **Appendix A: Ethics documentation**

#### **Ai Letters of ethics and NHS Trust approval**

Ai1 NHS Health Research Authority

Ai2 Royal Devon and Exeter NHS Foundation Trust

Ai3 University of Exeter Psychology Ethics Committee

#### **Aii Consent form**

#### **Aiii Letter to GP informing participants participation in the study**



## Health Research Authority

### NRES Committee South West - Exeter

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13 July 2012

Miss Katharine Jones  
 Trainee Clinical Psychologist  
 Psychology, University of Exeter  
 Washington Singer Laboratories  
 Perry Road  
 Exeter  
 EX4 4QG

Dear Miss Jones

**Study title:** The Psycho-social Impact of Elective Bilateral Risk Reducing Mastectomy for Women deemed at High Risk of Developing Breast Cancer

**REC reference:** 12/SW/0128

Thank you for your letter of 3 July 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each NHS organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		
Evidence of insurance or indemnity		11 July 2011
Interview Schedules/Topic Guides	1	02 April 2012
Investigator CV		02 April 2012
Letter from Sponsor		30 March 2012
Other: CV - Dr Janet Smithson		02 April 2012
Other: CV - Dr Phil Yates		02 April 2012
Other: NHS Lone worker Policy		01 March 2012
Participant Consent Form	2	15 May 2011
Participant Information Sheet	3	29 June 2012
Protocol	1	23 December 2011
REC application	3.4	01 April 2012
References or other scientific critique report		13 January 2012

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known, please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/SW/0128** Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

*Denise Sheehan*

pg Dr Denise Sheehan  
Chair  
NRES Committee South West - Exeter

Enclosure: "After ethical review – guidance for researchers" (SL-AR2)  
Copy to: Dr Michael Wykes (m.c.wykes@exeter.ac.uk)  
Miss Gyan Ling, Royal Devon And Exeter NHS Foundation Trust (g.ling@nres.nhs.uk)

Royal Devon and Exeter   
NHS Foundation Trust

Miss Katharine Jones  
8 South View  
Broadmayne  
Dorchester  
Dorset  
DT2 8LI

Royal Devon and Exeter  
Hospital (Wenford)  
Harrack Road  
Exeter  
EX2 5DW

Tel: 01392 411511

**GENERAL MANAGEMENT**

**Direct dial:** 01392 406933  
**Direct Fax:** 01392 403012  
**Email:** Research@rdel.nhs.uk

**Ref:** VL/MC/R&D/CG

18<sup>th</sup> October 2012

Dear Miss Jones

**Study Title:** Experiences of Bilateral Risk Reducing Mastectomy

**R&D Ref:** 1304771

**MREC Ref:** 12/SW/0128

I have reviewed the Trust R&D file for your study and I note that this study received ethical approval from the South West - Exeter Research Ethics Committee dated 13<sup>th</sup> July 2012. I am happy to give approval on behalf of the Royal Devon & Exeter NHS Foundation Trust.

The documentation approved for use with this study is as follows:

- |  |                  |                                  |
|--|------------------|----------------------------------|
| • <i>Protocol</i>                      | <i>Version 1</i> | <i>23 December 2012</i>          |
| • <i>Participant Information Sheet</i> | <i>Version 3</i> | <i>29<sup>th</sup> June 2012</i> |
| • <i>Participant Consent Form</i>      | <i>Version 2</i> | <i>15<sup>th</sup> May 2012</i>  |

**Research Governance**

As an NHS researcher, you are required to abide by the Research Governance Framework for Health and Social Care, which details the responsibilities for everyone involved in Research.

More information about all these responsibilities can be found on the Department of Health Research and Development web pages at:

<http://www.dh.gov.uk/rpolicies/guidance/Researchanddevelopment/A-Z/Researchgovernance/index.htm>

If you have received an Honorary Contract or Letter of Access in order to conduct the above research at this Trust, it is important that you check the termination date on these documents and if applicable contact the R&D Office to extend the document end date.

The duration of the Trust Approval extends to the date specified in the IRAS application form. Action may be taken to suspend Trust Approval if the research is not run in accordance with the Research Governance Framework. Research must commence within 6 months of Trust R&D Approval.

With best wishes for a successful study

Yours sincerely

  
Dr Vaughan Lewis/Mr Martin Couper

**JOINT MEDICAL DIRECTORS**

Cc: R&D Study File  
Ms Sandra Cookson – Breast Care Nurse Specialist  
Dr Phil Yates & Dr Janet Smithson – Academic Supervisors

Trust approval N11V101638/10

Chairman: Linda Birt Chief Executive: Angela Parker OBE

VZK856



Psychology Research Ethics  
Committee

Psychology, College of Life  
& Environmental Sciences

Washington Singer Laboratories  
Perry Road  
Exeter  
EX4 4QG

Telephone +44 (0)1392 724611  
Fax +44 (0)1392 724623  
Email Marilyn.evans@exeter.ac.uk

**To: Katharine Jones**  
**From: Cris Burgess**  
**CC: Phil Yates**  
**Re: Application 2012/506 to Ethics Committee**  
**Date: 30 October 2012**

The School of Psychology Ethics Committee met recently and your NHS Local Research Ethics Committee application and approval were reviewed. In line with our procedures, your project is now de facto approved.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (<http://www.ex.ac.uk/admin/academic/datapro/>). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Cris Burgess', with a horizontal line underneath.

Cris Burgess  
Chair of School Ethics Committee

**Aii Consent Form****DOCTORATE IN CLINICAL PSYCHOLOGY**

College of Life and Environmental Sciences  
 Washington Singer Laboratories  
 Perry Road  
 Exeter  
 UK EX4 4QG

Telephone +44 (0)1392 724695  
 Fax +44 (0)1392 724623  
 Email kj248@exeter.ac.uk  
 Web www.exeter.ac.uk/psychology

REC reference: 12/SW/0128

**CONSENT FORM (version 2, 15.5.2012)**

Title of Project: Experiences of Elective Risk-reducing Mastectomy for Women at a High Risk of Breast Cancer

Name of Researcher: Katharine Jones

Please  
 initial  
 box

1.I confirm that I have read and understand the information sheet (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3.I agree to my GP being informed of my participation in the study.

4. I agree for my interview to be recorded.

5.I agree to take part in the above study.



---

Name of participant

Date

Signature

---

Name of person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file.



**DOCTORATE IN CLINICAL  
PSYCHOLOGY**

College of Life and Environmental Sciences  
Washington Singer Laboratories  
Perry Road  
Exeter  
UK EX4 4QG

Telephone +44 (0)1392 724695  
Fax +44 (0)1392 724623  
Email [kj248@exeter.ac.uk](mailto:kj248@exeter.ac.uk)  
Web [www.exeter.ac.uk/psychology](http://www.exeter.ac.uk/psychology)

[NAME AND ADDRESS]

RESEARCH STUDY : Experiences of Prophylactic Bilateral Risk-reducing  
Mastectomy for Women with a High Risk of Breast Cancer.

We are writing to inform you that your patient\_\_\_\_\_ [NAME AND ADDRESS] \_\_\_\_\_  
has agreed to take part in the above research project.

Please find enclosed the Participant Information Sheet that gives the details of this  
study. If you have any questions, or wish to obtain more information about this  
research, I will be happy to discuss these with you.

Yours Sincerely

Katharine Jones  
Trainee Clinical Psychologist  
University of Exeter  
Email: [KJ248@exeter.ac.uk](mailto:KJ248@exeter.ac.uk)



## Appendix B: Participant Information Sheet

Project title: Experiences of Elective Bilateral Risk-reducing Mastectomy REC reference: 12/SW/0128    Version 3: 29.6.12
--

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

One of our team will go through the information sheet with you and answer any questions you have.

Talk to others about the study if you wish (such as family, friends or GP). (Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Ask us if there is anything that is not clear.

### Part 1:

#### Summary of the study

The aim of the study is to explore the experiences of women are BRCA1 or BRCA2 carriers who had a high risk of developing breast cancer and have had risk-reducing surgery, and are living and coping following this experience. The study is being completed as part of the lead researcher's doctoral study and with the aim of improving the processes for women who may consider such surgery in the future.

#### Why have I been chosen?

You have been chosen because you have had risk-reducing surgery. Twelve women will take part in the study.

#### Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. Refusal to take part or withdrawal at any point in the process will not affect the care you receive.

#### What will happen to me if I take part? What will I have to do?

Taking part in this study will involve meeting with the lead researcher at a location we have agreed for approximately one hour to answer some questions in an interview. Your travel expenses will be repaid for public transport or car parking fees as appropriate to the location that we have agreed. Before the interview you will be asked some questions about yourself (including age, ethnicity, number of children and history of cancer in your family). The interview will be recorded.

#### What are the possible disadvantages of taking part?

Being part of this research will involve you giving up your time to answer some questions about your experience. There is a risk that talking about these stressful events may cause emotional distress and it may be necessary to stop the interview. You can choose to stop the interview at any time. You can arrange follow up appointments with your Consultant or others if you wish to do so.

#### What are the benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the treatment of women who are at high risk of developing breast cancer and are considering risk-reducing surgery.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

**Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

**If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.**

**Part 2:****What if relevant information becomes available?**

Sometimes we get new information about the treatment being studied. If this happens, your researcher will tell you and discuss whether you should continue in the study. If the study is stopped for any reason, we will tell you.

**What happens if I don't want to continue with the study?**

If you do not wish to continue with the study your details and any identifiable data collected would be withdrawn from the study. Data that is not identifiable may be kept.

**What if there is a problem?**

We want you to feel comfortable with what happens during this study. If you are unhappy or unsure about anything that happens during the study at any time, you should speak to the researcher who will do their best to answer your questions. If you feel unable to do this, or are not satisfied with our response to your concerns, the normal NHS complaints procedures will be available to you, or via Research and Knowledge Transfer at the University of Exeter (details below).

**Harm**

The University of Exeter acts as a sponsor for the study as outlined in the Department of Health's Research Governance Framework for Health and Social Care (second edition, 2005). The University will ensure the appropriate insurance and indemnity are in place for the study.

In some circumstances, such as a situation where you need to prevent serious harm to other people, it may be necessary to disclose confidential information. In this type of situation, the researcher needs to consider whether it is in the public interest to disclose the information, and will seek appropriate advice and support as necessary.

**Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the NHS will have your name and address removed so that you cannot be recognised.

The data will be stored securely in a locked filing cabinet on NHS premises and only the researchers have a key. The custodian for the data will be the lead researcher. Only authorised members of the research team will have access to identifiable data. If authorised members of the team use email, it will be secure and encrypted. The interview recording will be allocated a code that is known only to the researchers, and will not be stored with identifiable information. The recording will be destroyed after it is transcribed and checked.

The transcripts of the interviews will be given a code and anonymised. Transcripts will be kept for four years in case of challenge of validity and then will be securely destroyed. The

anonymous transcript will be seen by the researchers and peers from the clinical doctoral training course during analysis of the data to review the emerging themes and to check, and to ensure the quality of the research. In keeping with qualitative methodology, direct quotes from respondents may be used in the final report, but these will be anonymised.

Participants have the right to ensure that the interview transcript is accurate and to correct any errors. Your transcript can be sent to you if you request this so that you can check for accuracy.

### **Involvement of the General Practitioner (GP)**

Your GP will be informed of your participation in this study with your permission.

### **What will happen to the results of the study?**

It is intended to publish the work in an academic journal. Upon request, the lead researcher will provide you with details of any publication or an information sheet about the results of the research, which will be available from September 2013. All your personal details will remain confidential and secure. When the research is written up it will only include anonymised information. All names will be changed.

### **Who is organising the research?**

The research is organised by Katharine Jones, trainee clinical psychologist (the lead researcher) employed by the University of Exeter and Taunton and Somerset NHS Foundation Trust. The researcher receives no extra payment for this research, which is conducted and submitted as part of her clinical doctoral training.

### **Who has reviewed this study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Exeter Research Ethics Committee.

You will be given a copy of the information sheet and of the signed consent form to keep.

### **Where do I get further information?**

#### **1. General information about research and specific information about this research project.**

General information about taking part in research can be found on the University of Exeter website: <http://tiny.cc/gwycew>

You can contact me and I will try my best to help with general and specific research queries:  
Katharine Jones (Trainee clinical psychologist)  
Psychology (D.Clin.Psy), Washington Singer Laboratories  
University of Exeter EX4 4QG  
Email: [Katharine.jones@nhs.net](mailto:Katharine.jones@nhs.net)  
Telephone: 07595 030382

#### **2. Advice as to whether you should participate.**

You may want to talk to your family or friends. You could talk to me, or ask to talk to the field worker who will try their best to answer your questions;

- **Exeter centre:** Sandra Cookson, Breast Care/Reconstruction Nurse Specialist  
Breast Care Unit, Wonford Hospital, Exeter EX2 5DW. Telephone: 01392 402707  
#6537  
Email: [SandraCookson@nhs.net](mailto:SandraCookson@nhs.net)

### 3. Who you should approach if unhappy with the study.

If you have a concern about any aspect of this study, you should ask to speak to the lead researcher or field worker (details above) who will do their best to answer your questions. If you are not satisfied with our response to your concerns, and if you wish to complain formally about the research study, you can do this via Research and Knowledge Transfer at the University of Exeter. Details can be obtained from Dr. Michael Wykes (01392) 722351 or email [M.C.Wykes@exeter.ac.uk](mailto:M.C.Wykes@exeter.ac.uk)

If you wish to make a complaint about your care, a member of the patient advice and information service (PALS) will be able to support and advise you about making complaints and the options for resolving complaints;

Exeter: PALS is available weekdays 9.30am - 4.30pm. To contact this service:  
Visit the health information centre in the main entrance at the RD&E at Wonford Hospital.  
Telephone (01392) 402093 or call extension 2093 from any hospital phone.  
Email: [rde-tr.PALS@nhs.net](mailto:rde-tr.PALS@nhs.net)

### 4. Support

If you had any concerns during the study and would like more support you should contact the lead researcher, the field workers above, or your GP. Should you wish, follow up appointments can be arranged with your Consultant or Breast Care Nurse, or with Anne Searle, Genetic Counsellor, Heavitree Hospital, Exeter. Telephone: 01392 405728. Or alternatively, to discuss further psychological support, you can ask to speak to Elaine Vickers, Clinical Psychologist, Breast Care Service, Royal Devon & Exeter Hospital. Telephone: 01392 676376. Email: [Elaine.Vickers@nhs.net](mailto:Elaine.Vickers@nhs.net).

#### Support agencies that may be able to help:

- Participants from the Exeter area can contact The FORCE Cancer Charity Patient Support.  
Telephone: 01392 406151
- Breast Cancer Care; Information and support for anyone affected by breast cancer  
<http://www.breastcancercare.org.uk/> Free Helpline: 0808 800 6000
- Breakthrough Breast Cancer <http://www.breakthrough.org.uk/> Freephone Information Helpline: 08080 100 200
- The National Breast Cancer Hereditary helpline offers those worried about their family history access to full information on all the options currently available, referrals where appropriate, and full peer support. Telephone: 01629 813000
- The Samaritans are available 24 hours a day and provide confidential support.  
Telephone: 08457 90 90 90. Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Thank you for reading this information sheet and for considering whether to take part in this study.

Katharine Jones (Lead Researcher)  
Trainee Clinical Psychologist, University of Exeter

Sandra Cookson (Field Worker)  
Breast Care Nurse

## Appendix C: Semi-structured Interview Schedule

### Interview Schedule

- **Introduction and discuss Participant Information Sheet**
  - Opportunity to ask questions
- **Consent Form to be completed**
- **Demographics**
  - Age
  - Marital status
  - Number and ages of children
  - Ethnicity
  - Educational level
  - Occupation
  - Family history of cancer

### Onset of Awareness of High Risk Status for Developing a Cancer

- How old were you when you were aware that you might be at a high risk for developing a cancer in the future?
  - How did this experience make you feel?
  - What did you do?
  - How did you cope?

### Genetic testing

- Did you take a genetic test?
- Could you tell me about how you decided to take the test?
- How did this experience make you feel?
- Did your understanding of cancer change as a result of the test?
- What did you do?
- Did the test inform any intervention?
  - If so, how?

### Prophylactic Surgery

- Some people might say the decision to have prophylactic surgery was a difficult decision to make, some people may say that they find it empowering. Do either of these explanations mean something to you?
  - What influenced your decision to undergo surgery?
  - Do you feel that you had a real choice?
- When did you have surgery?

- Did you have reconstructive surgery?
  - If so, at the same time or how long after surgery?
- Can you briefly describe your prophylactic surgery?
  - How did this experience make you feel?
  - How effective do you feel the intervention was for managing your risk of cancer?
- Does the surgery make you feel differently about your understanding of cancer?
- Does it make it easier or harder to cope knowing that you have undergone surgery? How?
- Were there positive things about the surgery? Not so positive things?

### **Help and support**

- What type of help and support did you receive?
- What types of help and support would you have liked to have received?
  - How could it have been improved?
- Was there anything that wasn't helpful?
- How did the help and support that you received from medical professionals compare with your understanding of cancer?
  - Do you agree with what they said?
- Did you feel that professionals wanted to hear your views?
  - How did that make you feel?
  - Did you feel listened to and understood?

### **Post Surgery**

- Was there anything about the experience that you would change?
- Did your feelings about the surgery change over time?
  - How do you feel about the experience now?
- What things can you observe about yourself that are different now from before surgery, that you believe is directly related to the surgery?
- How do you feel about your body and self now?
- Do you feel your feelings of sexual attractiveness were affected by the operation?

### **Social context**

- Who have you told about your prophylactic surgery?
- What was their reaction?
- How did this make you feel?
- Did you expect them to be more/less supportive/understanding?
- Are there some people you haven't told? If so, why?

- Have you accessed any other sources of help (e.g. info on the internet, support groups)?

### **Concluding remarks**

- Do you feel that there is anything that I should have asked about or that I left out?
  - If you had one thing you wanted to tell other women in a similar situation, what would it be?
  - If you had one thing you wanted to communicate to the general public about your experience, what would it be?
  - How did the interview feel for you?
- 
- **Thank-you for taking part in the research**
  - **Debrief and give travel expenses if appropriate**

**Appendix D: Extended Method****Di: Plan of Dissemination of Results**

The final report will be made available to the NHS Trust. A version of the report will be made available to participants who have expressed an interest in receiving one. Invitations will be given to the participants to a research presentation of the results. The results will be discussed in a presentation to the Breast Care team at a NHS Hospital and to a research conference at the University of Exeter for colleagues and interested parties. Opportunities to present findings at other relevant local or national conferences will be explored. It is planned that the research will be submitted for publication.



**Dii: Reflexivity statement**

Reflexivity involves understanding the role of the researcher and the relationship with the data in shaping the findings (Willig, 2012). This statement hopes to demonstrate my approach. I am a 39 year old female trainee clinical psychologist training in the South West of England. I am White British. I have a partner and I do not have children. This study has been developed as part of my completion of professional doctoral training.

I think that a few things attracted me to this study, one of which is an interest in women's health, and in exploring society and history from a female perspective. My initial engagement with the data was an attempt to step into my participants' shoes and my interpretative stance to be empathic. Although I have not personally experienced cancer, I lost both of my Grandmother's to cancer when I was in my teens. Consequently, cancer has always been something that has been openly talked about in my family. This, along with my clinical psychology training and experience, may have led to my presupposing that people are willing and able to talk about one's experience and that people are able to reflect on their experience and engage with it when they are in the interview. On reflection this has led to my contributions during the interview in using reflective techniques (summarising and reflecting back to ensure I have understood) and in encouraging participants to reflect on their experience further rather than tell the story of how it was then (Willig, 2012).

I hold a belief that it is important to research in this area, and that people are given a choice of preventive treatment. Consequently, my interest in the area means that I may hold beliefs of the positive value of these techniques. The reflective diary was used to document reflections about my personal history and response to the data process.

### **Diii Extended description of data analysis**

Suggested guidelines for analysis were followed as a framework to apply to analysing the data (Smith et al., 2009). The themes and narrative account of the participants' experiences were developed through my interaction with the data, as I attempted to make sense of the participants' personal and social experience (Reid et al., 2005). The first step was to listen to the audio and to read and –re-read the transcripts in a detailed examination to enhance familiarity with the content. The initial level of analysis involved detailed noting of explanatory notes and comments of interest on the transcript. This included descriptions of what was happening for the participants, what mattered to them and more interpretative noting to help understanding of their concerns. The software NVivo was utilised to record themes. Through this process many notes were generated and then a process took place of mapping interrelationships, connections and patterns across each interview. A list of emerging themes was produced for each interview to attempt to produce a statement of what was important for the participant, and subsequently these steps were repeated for each transcript. The focus was necessarily on the key emergent themes across the participants' accounts rather than a detailed analysis of individual cases because of the large sample (Smith et al., 2009). A file of transcript extracts was created to help look at the internal consistency and relatedness of the emerging themes. The themes were then typed into a list and themes were moved around to create clusters of themes, this led to some reconfiguration and relabeling of themes. Patterns were identified between the emergent themes in a process of abstraction and subsumption. The recurrence of themes across cases was measured, which can be considered as a way to enhance the validity of findings of a large sample (Smith et al., 2009). It was helpful to write the themes on post-it notes and use a large space to move the themes around at this point to explore a spatial representation of how the themes related to each other. A graphic representation of the themes was attempted in a temporal

contextualisation but no specific narrative sequence of events appeared to be present post-surgery. Modelling of how the themes related and interacted was considered but this was not possible to complete in the timescale. The themes that represented a similar understanding were grouped to create three superordinate themes and nine constituent themes in a table.

Care was taken to refer back to original transcripts and interview extract file to ensure themes were grounded in the data, in an attempt to retain an idiographic focus on individual stories whilst considering themes for the larger group. The credibility of the developing themes and analysis was discussed and checked with research supervisors, a breast care nurse specialist, and a Clinical Health Psychologist with experience of this client group. Further exploration and clarification of emerging themes were discussed with was gained in peer supervision with other qualitative researchers. A reflective diary was used to demonstrate the influence of the researcher on the study findings (Smith, Jarman & Osborn, 1999). This outlines the researcher's experience of conducting the research as well as their influence on it. Research process issues were discussed in supervision with the research supervisors.

Appendix E: Example of transcript coding (Claire)

P: Um I think I would have preferred to have reconstruction a little bit sooner after the operation, I know I suppose it depends on the surgeon and it depends on your healing and all that so, but I think with me there was, there was a long time before I had the reconstruction and you kind of get used to how they look in a weird way so it was like I was used to my old breasts and then I had something and then they were changed, I've got used to those and now they've changed again and to be perfectly honest they look really odd now that I've had them I mean they are still bandaged up and everything still (I: it's a period of adjustment each time) yes so I think for me it would have been better if I had it closer together rather than a long, you know almost over a year between having my reconstruction. So.

I: So you had your surgery just over a year ago, did your feelings about the surgery change over time so how you felt about the surgery immediately after it, is that different to now or

P: um, no I think if I, if someone had said to me would you recommend someone else doing it I would maybe say to someone take a little more time because I don't think you realize the impact, how it makes you feel, rather than, I know its only physical I mean that's not so bad but its more you know the emotions that go with it sometimes, that you don't always realize. I mean and I didn't, I spoke to Dr name but I didn't speak to anybody else who'd had it. I'd read on the internet, and I think maybe it would have helped if I'd spoken to somebody else and asked them how they felt afterwards because its more, its sometimes worse in your head, you know than it is actually physically.

I: So it may have been helpful to talk to someone who had been through a similar experience?

P: yeah you know because they can tell you it's ok and you will feel like this so yeah I think that might have helped me a little bit so.

I: Ok. Are you able to tell me a little more about the emotional impact of it, how you experienced it?

P: Um, you know I never thought, because I'm quite a practical person you know and I think you know it's not so bad and but I didn't realise that it would make me feel so unattractive even though I was the only one who really saw it my husband said that it didn't really made a difference to him, you know but I suppose you feel less of a woman, you don't feel as pretty or attractive or um, yeah, I don't think I realized that's how I would feel.

I: thank you (pause) are you alright?

P: yeah fine (laughs).

I: Don't answer this if you don't feel able to but, how do you feel about your body and yourself now?

P: Um, oh, (tearful) you know it took a long time after my surgery to feel attractive and I mean I think that the way I was towards my husband, and we just seemed to you know just get that right and then I had the nipple reconstruction and I kind of, I suppose its fresh, I'm sorry, its only been a couple of months (I: its ok) I think the way that I'm feeling at the moment is the way that I felt straight after surgery (I: yeah) because they do look pretty ugly at the moment, because they are all swollen and all bloody still. I've got you know fresh scars and things like that. It's kind of like I suppose one step forward and two steps back at the moment. That's why I think I would have preferred to have it done sooner (I: mm mm) you know get it over and done with so (I: rather than have this difficulty over quite an extended period of time) it is yeah, its just a long time for me to feel ok with myself and then I had the nipple reconstruction and I suppose it looks really

*Handwritten notes:*

- "Odd" Adjustments Reconstruction long time
- reconstruction
- longer term physical changes
- Emotional impact
- Take more time to prepare medical professionals
- Other have had experience
- Reasonable Support from someone = some experience
- "its not so bad" unattractive
- Not prepared
- Husband
- loss of identity
- Reassurance
- Consider self practical, strong?
- Others reaction - supportive partner reassurance
- contrast expressed emotion and "fine" people with understanding me
- Husband
- loss of sexual attractiveness
- Coming to realize physical changes
- re-experiencing surgery - see how scars - physical beauty
- Set it over with.

## **Appendix F: Instructions for authors**

### **British Journal of Health Psychology Author Guidelines**

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

#### 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

#### 2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

#### 3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified

- the word count is within the stated limit for the Journal (i.e. 5000 words)

#### 4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

#### 5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. The 2-3 (maximum) sentences for each point should identify existing research knowledge relating to the specific research question/topic and a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
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