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Men's Experiences of Having Breast Cancer: A Comparison with Women's Experiences

Caroline Ann Sime

**Submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy at the University of Glasgow**

**Medical Research Council.
Social and Public Sciences Unit
2012**

Abstract

Background: In the UK, men with breast cancer account for 1% of all new cases of breast cancer with only 341 men receiving this diagnosis throughout the UK in 2008 (Cancer Research, 2010b). There is a lack of research on all aspects of men with breast cancer in large part due to the rarity of the disease. However it is the psychosocial effects of receiving a breast cancer diagnosis, and the subsequent support available to men, that has in particular been ignored. To date, no study compares men's and women's experiences of having breast cancer. Furthermore, breast cancer is arguably at the most extreme 'female' end of a spectrum of illnesses that men can experience, and is likely to pose particular challenges for men's identities, which may have profound implications for their use of health services, attitudes to treatment and living beyond their cancer diagnosis. The aim of this study therefore is to compare men's and women's experiences of having breast cancer and what effect, if any, having a 'female' cancer has on a man's identity.

Methods: The data on men's experiences of breast cancer derive from interviews with 19 men with breast cancer in which semi-structured questions and prompts explored: what prompted them to seek help for their breast symptom; their own reactions to having breast cancer; the reactions of family, friends, colleagues and health professionals; their experience of treatment; the embodied effects of treatment and living beyond their breast cancer diagnosis. These data were collected using the methods employed by researchers at the Health Experiences Research Group in Oxford, see www.healthtalkonline.org, so that a) they could contribute towards a new module on men's experiences of breast cancer, and b) they could be compared with existing interviews on women's experiences of breast cancer.

The transcripts of 23 interviews with women who had breast cancer were made available for secondary analysis. The interviews with men with breast cancer were undertaken in such a way that direct comparison was possible. Analysis of both collections was undertaken using the framework approach to compare the men's and women's experiences of having breast cancer.

Findings: The findings demonstrated both similarities and differences between men's and women's experiences of having breast cancer. First, the help-seeking

practices of the men and women were found to be similar. The men were largely ignorant that men could get breast cancer, but this did not prevent some from attending their doctor. In turn, knowing that women can get breast cancer did not ensure women sought help for their breast symptom straight away. Help-seeking was found to be a complex process for both men and women that shared some push/pull elements that influenced their help-seeking.

The disclosure practices of the men and women were found to be similar and changed over time. Men used 'strategic announcing' to educate other men of the risk of breast cancer in men. The women in this study changed their disclosure behaviour to either protect their families from their illness, or themselves from negative encounters with people. The men also described feeling they *had* to disclose their illness when treatment side effects made them look ill, whereas some women described using aids such as wigs and prostheses to conceal changes in their appearance.

Contrasting experiences of healthcare were reported by men and women. The women were often given a treatment choice, could access information at different points throughout their treatment and had a variety of support networks. In contrast, the men were given few choices in their treatment, little or female-specific information, and reported limited sources of support. The men recounted negative experiences in the clinic and ward setting. They were mistaken as supporters not as the patient, experienced suspicion from female patients and were not given adequate resources to manage their treatment. In contrast, most women had positive experiences during their treatment and felt supported within the healthcare environment.

There was some evidence to suggest the effect on their closest relationships was similar for men and women with breast cancer. Most married men and women suggested their relationships had remained good and in some cases improved, adapting to physical changes and expressing their affection in other ways. The wives of men with breast cancer played a key role during their experiences of help-seeking, disclosure, offering support and retrieving information.

Most of the men in this study appeared to successfully renegotiate their masculine identities to incorporate their breast cancer experiences. Some men

felt their new role was to educate and 'spread the word' that men can, and do, develop breast cancer. A renegotiated traditional male stereotype was constructed including traditionally female characteristics to present an identity that enabled the men to cope with negative experiences within their communities and the healthcare setting.

Conclusions: There are similarities in the experiences of men and women with breast cancer. However, a lack of awareness men can develop breast cancer and the rarity of the disease has led to the development of female specific services and treatment. Greater social awareness and gender-sensitive healthcare is necessary to improve the experiences of men with breast cancer.

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Acknowledgements

First, I would like to thank my supervisors, Kate Hunt and Katie Buston, for giving me the opportunity to undertake this PhD, who guided, taught and encouraged me throughout and for that I will be eternally grateful. It was a privilege to undertake such interesting research that would not have been possible without the financial support and resources provided by the Medical Research Council. I would also like to thank DIPEX, and in particular Sue Ziebland and Suman Prinjha for providing me with the secondary data for this study and advising me throughout.

Special thanks are owed to Helen Sweeting who very kindly read my thesis and giving detailed and insightful comments, Mary Robins for always accommodating my library requests, Carol Nicol for computing services, Catherine Ferrell, Elaine Hindle and Julie Watson for their help during data collection, and Samantha Bird and Nicola Durkin for their patience and help when I often broke the photocopier and needed help with administrative tasks. Special thanks to Carol Emslie who always knew when a coffee was needed and offering support and advice.

I would also like to thank fellow students Alison Teyhan and Jane Hartley - I could not have survived this without you, and over the years roommates, Kalonde, Emily, Catherine, Laura, Gillian, Nicola S, Nicola BD, Neil and Jemma have all made the experience enjoyable. My friends and colleagues in the Out of Hours District Nursing service have also supported and encouraged me throughout, accommodating my shift requests and being there for me when I have struggled.

I will always be indebted to the men who participated in this study. It was a privilege, and knowing together we have contributed to the production of another resource for men with breast cancer is incredibly satisfying.

Most of all, I would like to thank my husband, Andy, and children Megan, Ruaridh and Robbie, for putting up with me over the last four years, and sacrificing precious family times to allow me to work. "Poor Andy" has been a source of comfort, love and encouragement throughout. Words are inadequate, but I love you all and dedicate this to you.

Author's Declaration

“I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.”

Signature

Caroline Ann Sime

1 Introduction

This qualitative PhD focuses on the comparison of men and women's experiences of having breast cancer. Approximately 1% of all new cases of breast cancer in the UK are men. That is, 300 men a year diagnosed versus almost 46,000 women (Cancer Research UK, 2010b). Thus, breast cancer in men is a rare disease. There are few qualitative studies on men and their experiences (Brain et al., 2006, France et al., 2000, Iredale et al., 2006, Naymark, 2006, Pituskin et al., 2007, Williams et al., 2003, Donovan and Flynn, 2007), and none identified compared men's experiences with women. The aim of this study is to explore men's experiences of having breast cancer, an archetypically 'female' disease, and compare them with women's experiences to draw out how the experience of the same illness may be similar or different between men and women.

This introductory chapter will outline why there is a need for research in men with breast cancer before setting out the aims and research questions of this study. There is a brief description of the methods used (which will be expanded upon in chapter three). In this study interviews with 19 men with breast cancer were undertaken and interviews with 23 women with breast cancer were made available for secondary analysis by DIPEX, (Database of Individual Patients' Experiences) an organisation that undertakes high quality, methodologically sound research (Herxheimer et al., 2000). Similar methods were used in the data collection of both men and women interviews to ensure comparability and to enable the contribution of the men's interviews to the production of a new 'module' on men's experiences of having breast cancer for the DIPEX website, Healthtalkonline.

1.1 Breast Cancer Research and Where Men Fit In

Many qualitative and quantitative studies of breast cancer have been conducted and the knowledge base is huge. However, few of the quantitative studies include men with breast cancer, and none of the trials include men in significant enough numbers to provide an evidence base on the effects which treatment has on a man's body. Similarly, the majority of qualitative studies are based on women and their experiences. Men tend to be diagnosed with more advanced breast cancer than women and have lower survival rates than women (Giordano

et al., 2002). However, once male breast cancer is age and stage matched with female breast cancer, standardised survival rates between men and women in the UK and Europe are comparable (Sant et al., 2003). A recent study by Moller et al (2010) compared survival rates of women between 1996-2004 in England, Norway and Sweden. They found that there were nearly 1,000 deaths that could have been prevented each year in England if breast cancer had been diagnosed at an earlier stage. The report authors concluded that early detection of breast cancer should remain a priority for breast cancer services. Men were not included in this study, but it may be assumed that if men were diagnosed at an earlier stage, their survival rates would also improve. However, for men with breast cancer there is very little evidence on which to base any action that may help improve detection rates and subsequent treatment.

The experiences of men with breast cancer before, during and after diagnosis and treatment are also under-researched. To date there have been seven papers found on men's experiences of breast cancer (Brain et al., 2006, Donovan and Flynn, 2007, France et al., 2000, Pituskin et al., 2007, Williams et al., 2003, Naymark, 2006, Iredale et al., 2006) and four of these are reporting the results from a multi-staged study (France et al., 2000, Iredale et al., 2006, Brain et al., 2006, Williams et al., 2003). Furthermore, only one of these papers explores the effects breast cancer has on a man's masculinity (Donovan and Flynn, 2007). However, similar to the other studies undertaken on men's experiences of breast cancer, Donovan and Flynn (2007) do not compare men's experiences with women's therefore it is not known how their experiences are the same, or different.

1.2 Aims, Research Questions and Methods

1.2.1 Study Aims

To help our understanding and knowledge of breast cancer in men the main aim of this study is to explore men's experiences of having a rare and neglected cancer from first noticing a change in their breast, disclosure of their cancer, active treatment and the legacy their cancer and treatment has on their bodies and intimate relationships. The study also aims to compare men's experiences with women's experiences. These issues are addressed through the following three research questions.

1.2.2 Research Questions

What are men's experiences of having breast cancer?

The first step was to explore men's experiences of finding a change in their breast, diagnosis, treatment and living beyond their diagnosis.

How do men's experiences of having breast cancer compare with women's experiences of having breast cancer?

Are men's experiences of having breast cancer similar to women's experiences and if not, what are the differences and why do they occur?

What effect, if any, does having a 'feminine' cancer have on a man's identity and masculinity?

Finally, the study will conclude by addressing how successfully the men construct their masculine identities following a diagnosis of a 'female' disease.

1.2.3 Methods

Narrative interviews were completed with nineteen men with breast cancer with semi-structured questions and prompts used to explore their experiences of diagnosis; their own reactions to having breast cancer; the reactions of family, friends, colleagues and health professionals; who they did or did not disclose their diagnosis to; their experiences of treatment; and finally the impact treatment had on their body image and intimate relationships. Secondary analysis of interviews with women who had experienced breast cancer was undertaken and analysed using framework analysis in order to identify similarities and differences between the men and women's experiences of having breast cancer.

1.2.4 DIPEX and Healthtalkonline

Based at the University of Oxford's Department of Primary Health Care, DIPEX (Database of Individual Patients' Experience of Illness) is a registered charity whose primary aim is to provide a resource for people to access excerpts of interviews with people about their experiences of illness and health, treatment choices, and information regarding support groups and resource material

(Herxheimer et al., 2000). These are available online via the website Healthtalkonline (see www.healthtalkonline.org).

There is a wide range of illness experiences that have been collated into different 'modules' on the healthtalkonline website. The modules produced so far cover well researched areas such as women's experiences of breast cancer, and under-researched areas such as pelvic pain (Herxheimer et al., 2000). Each module has video, audio and written extracts of interviews with people about their experiences of various aspects of their illness. A module is a collection of approximately 40 interviews of a maximum variation sample. A maximum variation sample has a broad range of people with different characteristics to ensure a wide variety of experiences are captured (Coyne, 1997, Marshall, 1996). The interviews follow a narrative approach and are analysed thematically for emergent themes (Herxheimer et al., 2000). To ensure validity in the findings, a steering group of healthcare specialists, academics, lay people and the voluntary sector working within the specific field review the interviews and support the module production by ensuring that themes emerging reflect the reality of what they see day to day.

The interviews with men with breast cancer were undertaken in such a way that direct comparison was possible with the women's interviews. The men's interviews were also video recorded and will contribute to the production of a male breast cancer module for the Healthtalkonline website in the future.

1.3 Thesis Outline

The study will be presented within this thesis over the next seven chapters as follows:

Chapter Two will outline the literature on men with breast cancer. First, the aetiology of breast cancer in men will be presented before the existing qualitative studies are discussed. A brief summary of the aetiology of breast cancer in women and overview of the qualitative work will then follow. An introduction to the gender literature will then follow, exploring the role masculinities has on men's health and healthcare use.

Chapter Three describes the design and methodology of the study. This will include a justification for the methods chosen and a description of how they were undertaken, data collated, analysis and the ethical and researcher considerations.

Chapter Four is the first of four findings chapters. This chapter explores men's and women's help-seeking behaviour when they first become aware of a change in their breast. The findings focus on the men's knowledge of male-specific breast cancer; interpretation of their symptoms; the role that others played in their help-seeking behaviour; and their approaches to help-seeking. The findings for the women follow before discussion of these findings.

Chapter Five explores the disclosure patterns of the men and women. The focus is on whether men and women told others about their breast cancer diagnosis. The findings describe how and when disclosure occurred, the reactions from others and the role the men's sick bodies played in their disclosure behaviour.

Chapter Six features the experiences of the men and women during active treatment, that is, their experiences of the hospital at diagnosis and initial treatment such as surgery, chemotherapy and radiotherapy. This chapter also includes the experiences of treatment decision-making, information and support needs during treatment.

Chapter Seven examines the lasting effect that breast cancer and its treatment has physically on men and women's body image, sexuality and the enduring effects on marital relationships.

Chapter Eight discusses the findings in relation to the wider masculinities literature presented in chapter two. It also provides a conclusion to this study and the implications the findings have on future research on men with breast cancer and on wider gender-related policies in healthcare.

2 Setting the Context

The purpose of this chapter is to introduce the literature that has informed the foundations and development of this PhD study. First, to understand breast cancer as a disease and its psychosocial impact, it is necessary to briefly describe the aetiology of breast cancer, putting the disease into a social context before exploring the existing literature on men's and women's experiences of breast cancer. I will then introduce the social constructionist theory of gender, focusing on masculinities, men's health behaviour and gender and healthcare. The literature in this chapter is relevant throughout the thesis. In each subsequent findings chapters, topic-specific literature relevant to the findings is presented in greater detail. The literature is presented in this way to provide structure to the findings of this study and enable the reader to consider the relevant literature directly with the study's findings.

2.1 Breast Cancer in Men

2.1.1 Aetiology

Breast cancer in men is rare and accounts for approximately 1% of the total breast cancer diagnoses made in the UK each year. In 2008 341 men were diagnosed with breast cancer (Cancer Research UK, 2010b). Men, on average, are ten years older at diagnosis than women (Agrawal et al., 2007) and are more likely to have invasive tumours at diagnosis. This has been linked to poorer survival rates for men compared to women (Nahleh, 2006). However, once survival has been age and stage matched, men and women have similar survival outcomes (Marchal et al., 2009, Sant et al., 2003).

Breast cancer in men and women share common risk factors. For example family history and genetics, obesity and the use of hormone therapy are risk factors for both sexes (France et al., 2000). In particular, Anderson et al (2010) suggest that there are many similarities between breast cancer in men and breast cancer in post-menopausal women, most tumours are oestrogen sensitive and more likely to be linked to environmental and lifestyle exposures. Although the risk is small, obesity doubles the risk of men developing breast cancer due to the increase in production of naturally occurring oestrogen (Fentiman et al., 2006, Ottini et al., 2010). Similarly, hormonal treatments to treat prostate cancer and prostate

cancer itself have also been found to increase the risk of breast cancer in men due to the high levels of oestrogen involved (Ravandi-Kashani and Hayes, 1998, Weiss et al., 2005).

There are differing incidence rates between men with particular genetic mutations, between ethnic groups and men with chromosomal disorders (Sasco et al., 1993, Korde et al., 2010). Giordano et al (2002) found in their review that 15-20% of men diagnosed with breast cancer reported having a family history ('family' could include siblings, mother, aunts but it is not defined within this review), and it has been estimated that approximately 10% of men with breast cancer have a genetic predisposition, most commonly associated with the BRCA 2 gene (Haraldsson et al., 1998, Weiss et al., 2005). There is, as yet, no evidence to link the BRCA 1 gene with breast cancer in men (Giordano et al., 2002). The effects of lifestyle on a man's risk of developing breast cancer are unclear although certain occupational and environmental factors such as chronic exposure to heat, radiation, exhaust fumes and aromatic hydrocarbons which are present in cigarette smoke have been linked to increasing the risk of breast cancer in men (Fentiman et al., 2006, Agrawal et al., 2007, Ottini et al., 2010, Weiss et al., 2005). The role of alcohol in men's risk of developing breast cancer is also unclear (Fentiman et al., 2006).

The evidence provided for the aetiology of breast cancer in men relies on much conjecture from limited studies and small sample sizes, often referring to the evidence of breast cancer in women and using that to theorize possible causes in men. In both women and men, increasing age, family history, obesity and use of hormone therapy have been identified as risk factors for breast cancer.

Reproductive history of women alone can increase their risk of breast cancer. Lifestyle choices and habits pose a risk to both men and women, though the evidence base is poorly developed for men.

2.1.2 Men's Experiences

Literature searches identified seven papers exploring the experiences of men with breast cancer (France et al., 2000, Donovan and Flynn, 2007, Iredale et al., 2006, Naymark, 2006, Pituskin et al., 2007, Williams et al., 2003, Brain et al., 2006). Five of these describe studies undertaken in the UK (Brain et al., 2006, France et al., 2000, Iredale et al., 2006, Donovan and Flynn, 2007, Williams et

al., 2003), one in Canada (Pituskin et al., 2007) and one including men from several different countries as well as Australian healthcare workers (Naymark, 2006). The strengths and limitations of each paper will be discussed before turning to their findings.

France et al's (2000) study aimed to describe the psychosocial effects having a breast cancer diagnosis had on men. Six men took part in this exploratory study, which was designed to identify themes to be explored in a larger study (Williams et al., 2003, Iredale et al., 2006, Brain et al., 2006). Unstructured interviews were carried out, with the use of prompts to explore areas of interest which included the men's feelings towards their diagnosis, how they and their partners dealt with these feelings, and what support they were given. The themes identified from the data were: diagnosis, attitudes towards men with breast cancer, body image, causal factors, information, treatment and support. The small sample size and recruitment from one regional hospital limits the generalisability of the results to the wider population. Furthermore, there is no description of the sample given in the paper so the reader does not know the age of the participants or their socioeconomic status. The authors note that some partners were present during the interview process. However, it is unclear how many partners were present and whether and how this may have influenced some of the men's responses.

Based on the findings of France et al's (2000) study, a multi-phased mixed methodology study was designed and findings were reported over three papers (Iredale et al., 2006, Brain K et al., 2006, Williams et al., 2003). The first paper by Williams et al (2003) reported the findings of the first phase of the work which involved a series of focus groups including two groups of men with breast cancer (n=5; n=4); one group of women with breast cancer (n=13) and one group of healthcare professionals (n=5). The men were recruited from a regional oncology unit in South Wales and the women from a local support group. The healthcare professionals included were breast surgeons, breast care nurses and oncologists. The topic guide differed for each group. The areas covered in the two patient groups were patient experiences, diagnosis, information and support. The topics covered in the healthcare group were perceived differences between men and women, patient interaction, information and gender-specific resources. Using thematic analysis four themes were identified: diagnosis,

disclosure, support and gender-specific information. The limitations of this study include the small number of focus groups and the possible sample bias resulting from participants self-selecting.

The second paper by Williams et al (2003) reports the findings from phases two, three and four of the study. During phase two a retrospective cross-sectional questionnaire was distributed throughout the UK by regional genetic departments and breast consultants. It was publicised through the media. It is unknown how many men with breast cancer were aware of this study, but 171 completed and returned a questionnaire to the researchers. Ten men were excluded from the study as the length of time since their diagnosis exceeded the time limit of ten years. The questionnaire collected demographic and clinical data from the 161 eligible men. Psychological measures were used to gauge general distress, cancer-specific distress and coping. The mean age of participants was 67 years. Most were married or living with someone (n=125, 78%) and had at least a secondary school education (n=102, 64%). Approximately half the sample (n=87, 55%) were still having treatment at the time of taking part in the survey. Of the 161 men, 92 (57%) agreed to be interviewed and participate in phase three of the study (Williams et al, 2003). It was decided that 30 interviews were sufficient to reach data saturation. A selection of the willing participants was chosen with the aim of representing a range of ages, time since treatment, and geographical spread. The topic guide for the interviews was not discussed in the paper, although the main areas of discussion in the focus groups were patient experiences, diagnosis, information and support. Phase four consisted of re-convening the initial focus groups of men (n=7) and women (n=10) in order to report back the findings and develop recommendations for future treatment of men with breast cancer. This study found men with breast cancer had differing healthcare experiences to women, were treated differently by healthcare staff and had limited information and support available to them.

The study has several limitations. Recruitment was conducted by breast consultants, which may have resulted in selection bias in terms of to whom they chose to give information about the study. It is unknown how many men were contacted or what methods were used to contact them. The retrospective nature of the questionnaire may have resulted in recall bias, particularly as the

inclusion criteria included men who had been diagnosed up to ten years previously.

The last paper from this multi-phase study by Brain et al, (2006) presented the findings of the psychological measures that were completed within the questionnaire described above. The measures used were: The Hospital Anxiety and Depression Scale (HADS), which measures anxiety and depression; the Impact of Event Scale (IES), which measures cancer-specific distress; the Body Image Scale (BIS), which measures body image changes in people with cancer; and COPE, which measures a variety of ways of coping with breast cancer. Stress levels and information and support needs were also measured. The results showed that men who had had a mastectomy (81% of the sample) or men who had experienced co morbid disease (proportion not reported) had significantly higher depressive symptoms and IES scores. Men who were single or living alone and those who would have liked to attend a support group had higher IES scores than married men. Overall, cancer-specific anxiety was reported more frequently than symptoms of anxiety and depression.

While all the measures used in Brain et al's (2006) study are validated tools, the heterogeneous sample, in terms of age and time of diagnosis, means a range of experiences are represented in the results. The impact and distress a breast cancer diagnosis had on a younger man was found to be greater than for older men. Time since diagnosis was not found to be related to the anxiety and depression of men either diagnosed ten years or two months prior to the survey. Around half of the sample (n=79, 49%) were experiencing treatment side effects; their distress and anxiety may have been higher than those who did not report any treatment side effects.

The Canadian study by Pituskin et al (2007) used a narrative approach when interviewing twenty men who responded to an invitation to participate in a study to describe the experiences of men with breast cancer. One hundred and twenty eight men were identified via the Alberta Cancer Board Cancer Registry. Each man was sent an information pack. Thirty one invitations were returned as undeliverable, and twenty men sent back signed consent forms. The average age of the men interviewed was 63 years; sixteen were married and average time since diagnosis was seven years (range 1-16 yrs). The themes identified in the

analysis were diagnosis, disclosure, coping, support, information and body image were identified. There were additional themes found in the younger men's interviews. They discussed slow referrals from their GP and feelings of a changed outlook on life following their treatment for breast cancer. The sample in this study was mainly white men and the province in which the study was sited had publicly funded healthcare (unlike other Canadian provinces that do not). Length of time since initial diagnosis may have resulted in problems with recall, and it is unclear from the paper how many men had had a mastectomy versus a lumpectomy.

Naymark's (2006) study aimed to explore men's experiences of having breast cancer and the effects having a feminine cancer had on the information, support, treatment and research practices available to men. She recruited six men diagnosed with breast cancer from Australia, England and America, and another group of five Australian breast cancer healthcare personnel including doctors, nurses and psychologists. In-depth, structured interviews were carried out. The interviews with the healthcare personnel were used to challenge and cross-reference the responses from the men with breast cancer. The main themes discussed in the findings were: the uncertainty of optimal treatment for men with breast cancer; shock at diagnosis; dissatisfaction at support services and available information; altered body image; and rejection of support services. The methodology used in this study limits the ability to generalise the results. It is unclear why participants were recruited from three countries. Each country has a unique healthcare system and it is unclear how the author compared these systems or concluded they were similar. The international mix of participants precludes any generalisation to a wider population. In addition, the men were recruited from international cancer organisations and may therefore have been particularly proactive in raising awareness of men with breast cancer. There are no details in the paper regarding how the interviews were carried out or the characteristics of the participants.

Finally, Donovan & Flynn's (2007) phenomenological study explored the lived experience of men with breast cancer from a gender perspective. Five men were recruited and data collected using in-depth, semi-structured interviews. A further ten men living overseas contributed contextual data via email correspondence. The content of the topic guide was not detailed in the paper

nor was the format of questioning via email. The findings presented were thematically discussed as: living with breast cancer; a contested masculinity; concealment of diagnosis and interactions with healthcare. There is no discussion on the recruitment process for either group, or whether potentially different experiences between the groups may have influenced the findings. It may have been that the men recruited via the internet were self-selected and searching for answers following more problematic experiences than the five men interviewed. While the theoretical framework used for this study is based on lived experiences, the focus was only on the gendered aspects of what the men experienced. The focus on masculinity is not counterbalanced with any comparison to women's experiences and the effect breast cancer has on femininity. Therefore what may be an effect of having breast cancer has been problematised as a male issue.

2.1.2.1 Help Seeking

The studies reported a range of help seeking behaviour. France et al (2000) found that none of the participants (n=6) in his study knew that men could get breast cancer. Five of the men reported delays of three months to two years in seeing their GP. Only one man said he sought medical advice in the first week of noticing a change in his breast. Pituskin et al (2007) also reported that most of the men in their study (n=18/20) did not know that men could get breast cancer, however all said that they sought prompt medical advice once they recognized something was wrong. This finding is supported by the survey results that found most of the men (n=135, 84%) reported their symptoms to their GP within three months of noticing a change (Iredale et al., 2006). However, in Iredale's survey there was a higher proportion of men reporting prior knowledge that men could develop breast cancer (n=64, 40%) than in any other study, and this knowledge may have prompted more men to seek medical help promptly.

Two studies (Williams et al., 2003, France et al., 2000) repeated that wives or partners played a significant role in the help seeking behaviour of the men with breast cancer. Williams et al (2003) reported that none of the men participating in their focus groups said they delayed seeing their GP. They suggested their wives were key to this, insisting they see their GP and pushed for a referral to specialist services when GP's appeared reluctant to do so. France et al(2000) found that two of the six men interviewed also reported that their wives insisted

they either got a second opinion or were referred on after their GP dismissed their symptoms as nothing to worry about.

2.1.2.2 Diagnosis

In all six studies common emotions at diagnosis were shock and disbelief. Pituskin et al's (2007) participants said they knew of public health campaigns in their region of Canada which promoted breast awareness in women, but did not know that men were also at risk as it was not mentioned in any of the campaigns. In France et al's (2000) study five men reported feeling shock at being told they had breast cancer and four of the men believed breast cancer to be a disease that only affected women. Donovan & Flynn (2007) found that the men they interviewed felt disappointed at being diagnosed with something only women should be diagnosed with. They wondered why it had happened to them.

Williams et al's (2003) study included a focus group with healthcare workers who discussed differences in the reactions between men and women at diagnosis. The staff described the men's reactions to their diagnosis as stoical and said they immediately asked about practicalities such as treatment options. This was in contrast to the perceived reactions of women being more emotional. The staff in turn said they reacted differently to men and women, and described their response as being more practical and less emotional with men during the process of diagnosis.

2.1.2.3 Disclosure

Within the studies disclosure was often discussed in relation to immediate family and close friends separately from extended family and other friends and colleagues. There is little evidence within these studies that the men reported disclosure of their diagnosis to close family caused them any concern. However, there were some men who encountered problems when telling their wider associates about their breast cancer diagnosis. All the participants in Williams et al's (2003) study said they told everyone they had been diagnosed with breast cancer. Eighty per cent (n=129) of the men surveyed by Iredale et al (2006) reported telling partners and close family their diagnosis, although disclosure to wider associates was not as prevalent with only 37% (n=60) of men telling extended family and work colleagues. The follow-up interviews revealed that some of the men did not want to tell many people about their breast cancer

diagnosis because they did not want sympathy, or to be stigmatised as a man with an apparently feminine disease (Iredale et al., 2006). Similarly, Naymark (2006) reported that although none of the men hid their diagnosis some encountered problems when disclosing their diagnosis to extended family members and friends. Some men reported their friends distanced themselves as they were unsure how to support a man with breast cancer. Some men speculated this was because breasts were considered to be a feminine issue and people could not relate to breast cancer in a man. France et al (2000) found that while most men did not have any problems telling others, one man discussed feelings of embarrassment while telling friends he had breast cancer. He said he experienced negative responses from others who questioned his masculine identity and called him “soft” (p.345). Pituskin et al’s (2007) findings showed that while some men felt reluctant (4/20) to share their diagnosis with others, most did not have any issues, saying that they felt it was their duty to raise awareness that men get breast cancer. This finding was also supported by Donovan & Flynn (2007) who reported contrasting findings from within their sample. They found that some men said they concealed their diagnosis from others and changed their behaviour to facilitate this, whilst others felt it was their duty to share their diagnosis and show that a “normal” man could have breast cancer. Some men described this action as “coming out” (p.467).

2.1.2.4 Body Image

Mastectomy was the primary treatment for the majority of the men that participated in the studies. In this context, body image was another theme that emerged (France et al., 2000, Iredale et al., 2006, Williams et al., 2003). Men discussed coping strategies that included keeping their chests covered, for example by stopping activities such as public swimming. About half of the men (11/20) in Pituskin et al’s (2007) study said they had no problems regarding their body image (five did not discuss this area). Some were philosophical and said they were lucky to be alive, rationalising that having cancer was not their fault. One man felt proud of his scar as it reminded him of the challenge he overcame. Four men said they had a negative body image, with one man feeling embarrassed resulting in concealment of his scar. The survey of men’s experiences of breast cancer also found that 16% (n=26) of the sample had similar feelings of embarrassment but during the interviews this embarrassment

was related to their altered body image. They felt something was “missing” from their bodies, causing emotions of loss and disfigurement (Iredale et al., 2006).

All of Naymark’s (2006) participants discussed breasts as being central to a woman’s sexuality, playing down the effect a mastectomy had on them as men. They did not feel they looked any different, the effects of mastectomy being less on their masculine bodies. In contrast, the participants in Donovan & Flynn’s (2007) study reported feelings of altered body image that affected their own feelings of masculinity. They felt scrutinised by others as being less of a man having had a mastectomy. It is unclear why there should be contrasting findings. One explanation may be the different aims of each study and unclear methodologies.

2.1.2.5 Information and Support

All of the studies highlighted the lack of information available specifically for men with breast cancer. Similar to Pituskin et al (2007), Naymark’s (2006) participants reflected that national health promotion activities did not inform men that they could get breast cancer, and the participants in France et al (2000) and Pituskin et al (2007) studies said they did not receive enough information about their disease or treatment. Iredale’s survey revealed that the men used a variety of sources to access information (Iredale et al., 2006). Almost all (n=148, 92%) received verbal information, mostly from healthcare personnel, with 71% (n=114) receiving written information in leaflet and booklet form, although most of these resources focused on women and there was little content the men could relate to. Twenty per cent (n=32) used the internet, where a small number (n=19, 12%) saw photographs here of a mastectomised body prior to their surgery. However, over half of the men (n=90, 56%) wanted more information, such as seeing a photo of a male mastectomised body, and more information on side effects of treatments. Similarly, Donovan & Flynn (2007) found that the men they interviewed had a lot of breast cancer information, but little of it was relevant to them as men with breast cancer. They reported that they were not advised about male-specific side effects such as impotence whilst taking hormonal treatment. One suggestion the authors make to improve the availability of information was small sections relevant to men within the female literature (Williams et al., 2003). Including these sections would remove the need for separate leaflets.

Access to, and support from the breast care nurse was perceived differently across the studies. France et al (2000) found that two of their six participants were introduced to the Breast Care Nurse, although these nurses had made it clear to the men that they had no experience of looking after a man with breast cancer. Most of the men felt they had not missed out on support from the breast care nurse and attributed this to strong spousal support, as well as support from female friends who had experienced breast cancer. Only one man felt his anxiety about post-operative complications may have been alleviated had he had access to information and professional support. Similar findings were presented in other studies which found that the men's main source of support was from their partners, although they did meet their breast care nurses and valued their support (Pituskin et al., 2007, Williams et al., 2003). None of the married participants in Pituskin et al's (2007) study said they wanted to attend a support group at any point through their treatment or after its completion. However, this finding appears to relate to attending support groups that include women. There was conflicting evidence with regard to support from another man with breast cancer. William et al(2003)reported all men in their study felt it would be useful to meet and talk with another man, although they did not want to attend a mixed support group. Similar findings were reported by Iredale et al (2006) in their survey. They reported a lack of interest in talking to men with other forms of cancer, or to women who had breast cancer. However, 19% (n=31) of participants had spoken to another man who had breast cancer and a further 27% (n=43) would have liked the opportunity. In contrast, none of the six participants in France et al's (2000) study had wanted to meet with another man with breast cancer.

2.1.2.6 Hormonal Treatment

Iredale et al (2006)reported that 78% (n=126/161) of the men surveyed had hormonal therapy as part of their treatment for breast cancer. Hormone therapy is used to block the metastatic spread of breast cancer in tumours that are biologically sensitive to oestrogen, a common characteristic of tumours in men. However, the prescribing of hormone therapy was often described as problematic by the men in the studies. Most found that the men said there was not enough information about the effect of treatment on their body, how long it should be taken for, and how effective it was for them (France et al., 2000, Naymark, 2006, Pituskin et al., 2007). In addition, some men reported confusion

at the pharmacy, with questions as to who the drug was for as it was so uncommon for this medication to be dispensed to a man (France et al., 2000). Furthermore, Donovan & Flynn (2007) suggest that the use of hormonal therapy in men and the resultant erectile dysfunction “contest[ed] the foundations and legitimacy of masculinity” (p.467) as the men in their study said they struggled to come to terms with their loss of libido. This was the only study to address the loss of sexual function as an assault on a man’s masculine identity. However there is no discussion of ways in which the men may have renegotiated their identities or the ultimate survival benefit that taking the treatment has.

2.2 Women with Breast Cancer

2.2.1 Aetiology

Breast cancer is the commonest cancer in women in the UK, accounting for 31% of all cancers in women. In 2008 47,693 women were diagnosed with breast cancer in the UK (Cancer Research UK, 2010b). In 2007 approximately 12,000 women died as a result of their breast cancer in the UK, accounting for 16% of all female mortality from cancer, although mortality rates have been declining in the UK since the 1980’s (Cancer Research UK, 2010b). Breast cancer can be diagnosed in a woman of any age, but risk of developing breast cancer increases with age, and most cases (approximately 80%) of breast cancer occur in women over the age of fifty years.

There are several factors that increase a woman’s risk of breast cancer including: hormonal and reproductive factors, obesity, alcohol, and physical inactivity (Cancer Research UK, 2010a). In developed countries early age at menarche, older age at first birth, reduced parity, lack of breast feeding, and late menopause have all been linked to an increased risk of developing breast cancer (Mc Pherson et al., 2000). In addition the use of oral contraceptives and hormone replacement therapies (HRT) have been shown to increase the risk of breast cancer for up to five years after being discontinued before the risk returns to the same levels as women who have never used hormone therapy (Beral, 2003). Lifestyle issues such as diet and obesity, alcohol intake and levels of physical activity have all been explored for associations with breast cancer. Obesity in post-menopausal women (Reeves et al., 2007) and increased alcohol consumption (Baan et al., 2007) have all been found to increase risk of breast

cancer, while participating in physical activity offers some protection (Chan et al., 2007). The evidence linking diet to breast cancer is not conclusive although fat consumption is considered to increase risk (McPherson et al., 2000).

Approximately 10% of all female breast cancer is attributed to a genetic mutation (McPherson et al., 2000). A woman's risk of breast cancer is doubled if a mother or sister is diagnosed with breast cancer. Most women with a family history, however, will not go on to develop breast cancer (Pharoah et al., 1997, Pharoah PD et al., 1997). There are two main genes that account for most genetically linked breast cancer: BRCA 1 and BRCA 2. They have also been linked to ovarian, colon and prostate cancer. Women with a genetic mutation are more likely to have a strong family history of breast cancer and to be diagnosed at a younger age than the general population (McPherson et al., 2000).

2.2.2 Women's Experiences

Moynihan (2002) asserts there is an extensive evidence base available that explores experiences of breast cancer in women. The literature more specifically related to the findings is covered in greater detail in each subsequent chapter. The search for literature for this PhD used several databases and checking bibliographies of papers. Databases searched and search terms for this and subsequent chapters are listed in Appendix 1. The men and women in this study were aged over 50 years, and when searching I specifically looked for studies using older men and women (or post-menopausal women). However many studies used a wide age range within their samples and it was not always possible to solely focus on older men and women. I also used review and data syntheses papers where possible. A brief overview of women's experiences of breast cancer follows. The papers identified for this section, when possible, draw on the literature available on older women's experiences of breast cancer.

2.2.2.1 Help-seeking

Approximately 80% of breast cancer is found symptomatically by women themselves (Bish et al., 2005), despite the UK having a national breast screening programme for women aged 50 -70 years (Forrest, 1986). Although most women seek help promptly, a significant minority (20-30%) delay seeking medical attention for at least three months, and some for much longer (Richards et al., 1999a). This has been found to have a significant effect on their chances of

survival. In women with breast cancer, a delay of three to six months can significantly reduce survival (Ramirez et al., 1999). Women may use denial or normalise symptoms as a way of delaying seeing their GP (Lugton, 1997), lack knowledge of breast symptoms that indicate cancer (Ramirez et al., 1999) or have a fear of treatment and surgical outcomes (Grunfeld et al., 2002b).

2.2.2.2 Diagnosis

Diagnosis of breast cancer in women is a significant event. It has been described as life-changing, instilling fear and vulnerability into women and making them confront their own mortality (Kralik et al., 2001, Carter, 1993). One study explored the meanings and shared experiences of thirty women diagnosed with breast cancer in an American hospital (Boehmke and Dickerson, 2006). The women reported their lives changing overnight when they received their breast cancer diagnosis, causing emotional distress and anxiety. Similar findings have been reported elsewhere (Kralik et al., 2001, Longman et al., 1999).

2.2.2.3 Disclosure

Women with breast cancer have been found to use various disclosure strategies. Telling others about their breast cancer has been described as an effective coping strategy (Pistrang and Barker, 1992) and most women share their diagnosis with at least one person (Henderson et al., 2002). Not all women disclose their illness. Several studies (Harrison et al., 1995, Figueiredo et al., 2004b, Henderson et al., 2002) found a proportion of women chose not to tell other people their diagnosis. Non-disclosure in these women was found to be associated with poorer levels of emotional well-being.

2.2.2.4 Body Image

Changes in women's body image following a breast cancer diagnosis have been well documented. The potential loss of a breast forces women to re-evaluate their body and female identity (Manderson and Stirling, 2007). Mastectomy has been shown to be emotionally distressing regardless of any reconstruction that may be done (Piot-Ziegler et al., 2010). Some studies however, suggest that the effect mastectomy has on some women's body image has been over-stated and many women prioritise regaining their health and survival over body image concerns (Meyerowitz et al., 1988, Langellier and Sullivan, 1998). In addition, some studies found it was not the mastectomy that altered a woman's body

image, but the adjuvant treatment that she required, in particular chemotherapy and the resultant hair loss experienced (Richer and Ezer, 2002, Browall et al., 2006).

2.2.2.5 Information and Support

The predominant theme to emerge from women's experiences of having breast cancer was the role of family and informal support (Browall et al., 2006, Landmark et al., 2002, Landmark and Wahl, 2002, Howard et al., 2007, Richer and Ezer, 2002, Overcash, 2004, Crooks, 2001). Richer and Ezer (2002) discussed two coping strategies that described the way women coped with breast cancer. They interviewed ten women at least five times during their chemotherapy treatment. They found that some women compartmentalised their cancer from their everyday activities to enable them to get on with their lives whilst undergoing treatment. Similar findings were reported by Overcash (2004) and Crooks, (2001). The second coping strategy which Richer & Ezer (2002) identified, was the embracing of their breast cancer by the women, using available "lifelines" from family and friends to confront their diagnosis and come to terms with it using their support. Browall et al (2006) found that while some women reported their families struggled with their diagnosis, other social networks were useful in helping them to get information and advice about how to manage their diagnosis and treatment.

Women with breast cancer can use a variety of sources for information. They require different information at different times during their treatment and beyond (Rees and Bath, 2000). They are given information by hospital staff (Husain et al., 2008) and can access information from the internet (Ziebland et al., 2004), and friends and family (Clarke et al., 2006).

2.2.2.6 Hormonal Treatment

There is a huge evidence base on the efficacy and side effects of using hormonal therapies in women with breast cancer. Hormone therapy for the treatment of breast cancer has many uncomfortable and some potentially serious side effects. Physical side effects include fatigue, hot flushes, vaginal dryness and loss of libido (Janz et al., 2007, Ganz et al., 1999, Foster et al., 2009). Use of hormonal therapies also raise the risk of gynaecological cancers, stroke and osteoporosis (Turner and Jones, 2008).

2.3 The Sociology of Gender, Masculinities and Femininities

In recent years in the UK, life expectancy has increased for both sexes, although life expectancy for men is consistently shorter than for women. For example, life expectancy for males born in 2004-6 is 76.9 years, compared with 81.3 years for females (ONS, 2008b). The burden of disease is also greater in men in the UK. Men have a significantly higher risk of developing and dying of cancer (White et al., 2009), coronary heart disease (BHF, 2009), and suicide rates are consistently higher for men at age standardised rates of 17.5 versus 5.4 per 100,000 for women in 2008 (ONS, 2010). One explanation for this is that men are more likely to adopt unhealthy behaviours such as smoking (although rates among men are declining and converging with women) and drinking alcohol to excess (ONS, 2008a). White and Johnson (1998) point out that national trends do not explain an individual's personal experience of health and ill-health. Situating the focus on men's health within sociological theory, we can explore the experiences of men with breast cancer, and the societal pressures to conform to the masculine 'norm'. Using a sociological approach it is also possible to explore how men with breast cancer construct their masculine identity once diagnosed with a disease that predominantly affects women.

2.3.1 Gender

In its simplest description, gender is not something that 'we are' but it is something that 'we do' (Robertson, 2007). This is in contrast to biological sex, which is pre-determined by the genetic makeup of an individual. Oakley (1972) attempted to define the distinction between sex and gender:

'Sex' is a word that refers to the biological differences between male and female: the visible difference in genitalia, the related difference in procreative function. 'Gender' however is a matter of culture: it refers to the social classification into 'masculine' and 'feminine'.

(Oakley, 1972 p.16)

Oakley (1972) goes on to explain that biology can usually be used to categorise people as male or female, but not as 'masculine' or 'feminine'. Gender is not associated with a rigid duality that presumes men and women each have one stereotypical personality type (Courtenay, 2000a). Gender is fluid, interchangeable and socially constructed (Connell, 1995). It is "something that

one does, and *does* recurrently, in interaction with others (West and Zimmerman, 1987 p140). As individuals we adopt certain gender characteristics to conform to the society that we live in (Chapple and Ziebland, 2002). This leads to the construction of gender stereotypes which reinforce shared beliefs of what men and women should be, that in turn puts greater pressure on individuals to adopt certain gendered behaviours (Courtenay, 2009). Gender stereotypes create a false binary between what is seen as being 'masculine' and 'feminine' that "artificially, and inappropriately, divide people into two camps" (Annandale and Clark, 1996). Gender is not merely split into two separate entities of masculinities and femininities but is a complex, interchangeable, socially constructed notion that can change according to each society's beliefs and power relations between men and women, but also between different groups of men and women. Gender is constructed through everyday activities such as language, work and recreation (Courtenay, 2000a). Paechter (2003) suggests describing the day to day practice of masculinities and femininities in a social context as taking place in "communities of practice." She describes these communities as places where people share common attitudes and behaviours that are learned by new members, which in turn reinforces and embeds the practice within the community.

2.3.2 Masculinities and Femininities

Connell's (1995) seminal work on masculinities helps us in understanding the complexities of masculinities and their multiple dimensions by describing a hierarchy of masculine traits with hegemonic masculinity as the ideal, most powerful form of masculinity. Most men aspire to, but few manage to enact a hegemonic form of masculinity which dominates all other forms of masculinities (Connell and Messerschmidt, 2005). However, in spite of these masculinities being less powerful than hegemonic forms of masculinity, the least powerful men remain more powerful than women, just by being men (Kimmel, 1994). Connell (1987) asserts that there are no femininities that are hegemonic. He states:

"All forms of femininity in this society are constructed in the context of the overall subordination of women to men. For this reason, there is no femininity that holds among women the position held by hegemonic masculinity among men."

(Connell, 1987 p.187)

Hierarchies of masculinities and femininities can be explored further by understanding what characteristics are considered to be 'masculine' and 'feminine'. In a follow-up study to Broverman et al's (1972) original study exploring the social desirability of traditional gender role stereotypes, Seem and Clark (2006) surveyed university students (n=89) to assess socially desirable traits in men and women. They found that the most desirable traits in women were centred round caring attributes such as being affectionate, compassionate, loving and considerate to others. In contrast the most desirable traits found in men were independence, competitiveness, adventurousness and enjoyment of a challenge (Seem and Clark, 2006). These stereotypically desirable traits were also reported by Street et al (1995) who carried out a large (n=2,990) cross-sectional study of undergraduate students. However, Seem and Clark(2006) report that there were additional characteristics endorsed for women that were traditionally considered to be exclusively 'masculine'. The traits were being strong, independent and enjoying a challenge. They contend that this marks a change in gender roles, but not a change for the better. Women are expected to remain feminine yet exhibit masculine traits of independence. There was no change to the stereotypical masculine gender role.

2.4 Masculinity and Illness

It has been suggested that 'the doing of health is a form of doing gender', not because it is linked to the male or female body, but because it is linked to the 'social and cultural interpretations of masculine and feminine selves' (Saltonstall, 1993) i.e. the cultural stereotypes that are reproduced in everyday lives. The study of men's experiences of ill-health may assist in the understanding of how men construct their identities while coping with illness.

Traditionally the men's health research agenda has focused on diseases of the male reproductive organs, and there is a growing body of evidence of men's experiences of having prostate and testicular cancer (Banks, 2004). Men with prostate cancer appear to be an ideal comparison group for men and women with breast cancer. Both usually affect older people and treatment includes surgery, radiotherapy, chemotherapy, and hormonal treatment. In recent years there have been a number of studies that have explored men's experiences of prostate cancer (Chapple and Ziebland, 2002, Kelly, 2009, Hedestig et al., 2003,

Fergus et al., 2002, Broom, 2004, Oliffe, 2005, Bokhour et al., 2001, Clark et al., 2003). These studies offer an insight into how men cope with a life threatening disease, how it affects their masculinity and how ongoing treatment can further challenge their masculinity, particularly with the use of hormone therapies. Prostate cancer is the most common cancer in men in the UK and in 2008, 37,051 men were diagnosed with prostate cancer (Cancer Research UK, 2011). It is not surprising that men's experiences of having prostate cancer are an area of interest to researchers. Fergus et al (2002) suggests that a fully functioning penis and sexual performance are central to a man's idealised masculinity. Bokhour et al (2001) asserts that the treatment for prostate cancer assaults a man's sexual function and threatens his identity, reducing him to subordinate and marginalised forms of masculinity. Men taking hormonal treatments may notice their breasts enlarging, and experience hot flushes and mood swings. Hormonal treatments also 'shrink' the penis and testes, and urinary symptoms such as frequency and leaking can reduce a man's control over his bodily functions. All of this can have a direct impact on a man's embodied masculinity (Oliffe, 2006).

One qualitative study of 15 men who had been undergoing hormonal treatment for 6 months to 3 years following a diagnosis of prostate cancer, found their interviewees expressing grief over loss of their perceived masculinity (Navon and Morag, 2003). Once seen as the head of the family, as provider and protector, they felt that they had lost the attributes that maintained their ability to carry out this role, and were reduced to needing the help and support of their family. Another study (Chapple and Ziebland, 2002) that explored men's experiences of having prostate cancer (n=52) reported that the men felt asking for help and becoming dependent on others was emasculating, and found the physical changes caused by the hormonal treatment to their bodies (hot flushes, breast enlargement) unacceptable and a reinforcement of their loss of masculinity. Furthermore, the men experienced excessive physical fatigue that meant many of them could not meet the physical demands of their jobs. Their domestic duties were either left unfinished or their wives had to take on more responsibilities and duties. For many men, work is a major source of status and identity. They are traditionally the providers for their families and this status is challenged if they have to give up work. Many worried about the financial implications of their illness for their wives and children (Chapple and Ziebland,

2002). Their hopes and plans for their future retirement might also be disrupted leading to an uncertain financial future (Harden et al., 2006).

Studies have explored other illnesses in relation to masculinity, particularly coronary heart disease (CHD), an illness commonly stereotyped as a 'male' disease (Emslie et al., 2001), and depression often seen as a 'female' disease (Curry and O'Brien, 2006, Adams et al., 2008). One study (O'Brien et al., 2007) that explored whether depression, CHD and prostate cancer each presented different challenges to a man's masculinity involved fifty nine men in fifteen focus groups and nine men interviewed individually. O'Brien and colleagues found that the men with depression were more secretive about their illness due to social pressures they encountered and preconceived notions that they could not share problems with other men for fear of being ridiculed. This was in contrast to the men with heart disease. Their illness was acute and the men had to come to terms with being diagnosed with a life threatening disease that often brought their working lives (a traditional masculine activity) to a sudden end. However, this group could rebuild their masculine identity once the acute phase of their illness was over. Their working life may have gone but they could return to some of the activities that helped them restore their masculine identity. The men with prostate cancer were faced with an illness that often required long term treatment and side effects that permanently removed other aspects of their masculine identity such as their loss of sex drive, but this was often countered with a realisation that without treatment their lives were at risk.

O'Brien et al's (2007) study has parallels with men with breast cancer. Like men with CHD, a breast cancer diagnosis may come as a surprise, and like prostate cancer it threatens their life if left untreated. Furthermore, men with breast cancer may wish to conceal their diagnosis for fear of being ridiculed by other men and having their masculinity challenged (Donovan and Flynn, 2007, France et al., 2000, Naymark, 2006).

2.5 Gender and Healthcare

The emergence of the men's health research agenda [a term that describes the "creation of public policy, research and popular media discourse" (Schofield, 2010 p240)], and the development of gender-sensitive healthcare have followed

in the footsteps of the women's health movement (Schofield, 2010). The men's health research agenda suggests it is not only women's health that is disadvantaged by the current healthcare structure, men are also disadvantaged (Doyal, 2001, Banks, 2004). The emergence of the men's health research agenda led to the development of a binary concept of men's health and women's health working in opposition to one another based on biological difference (Schofield et al., 2000, Connell, 2002). However this over-simplification of men and women's health ignored other variables such as age, ethnicity and socioeconomic status (Doyal, 2000, Moynihan, 2002, Schofield, 2010). Furthermore, this binary suggested that men and women are homogenous groups, perpetually working in opposition to one another (Schofield et al., 2000).

In recent years there has been a concerted effort to move away from a binary concept to a social constructionist stance of gender within healthcare, thus taking into account shared and different health practices amongst men and women within their social context and how they influence one another (Smith and Robertson, 2008). This research has been translated into UK wide policies. The Gender Equality Duty was introduced as part of the Equality Act that became law in 2007. The aim of this act is to promote equality of opportunity among men and women. Gender equality is the "absence of discrimination in relation to opportunities, resources, benefits and access to services" (Payne and Doyal, 2010 p21). This is not to be confused with gender equity, which refers to an *equal* distribution of power, resources and responsibilities. The World Health Organisation clarifies this:

Gender equality means the absence of discrimination on the basis of a person's sex in opportunities, allocation of resources or benefits, and access to services... Gender equity means fairness and justice in the distribution of benefits, power, resources and responsibilities between women and men. The concept recognizes that women and men have different needs, power and access to resources and that these differences should be identified and addressed in a manner that rectifies the imbalance between the sexes.

WHO (2002 p3)

Moynihan (2002) argues that it is imperative 'gender' and a gendered approach to healthcare is adopted within cancer research to understand what it means to be a man or woman with cancer. She contends there is limited research exploring gender within a healthcare setting, and breast cancer in women is

often used as the benchmark for good practice and for describing the well-adjusted patient. Women are expected to be 'expressive' and 'emotional' while men with cancer are often expected to display 'masculine' characteristics of stoicism and resilience whilst being expected to adjust to their cancer diagnosis. Annandale and Kuhlman (2010) agree and suggest that a greater appreciation of gender within healthcare and healthcare research will improve services for both men and women. They do, however concede that, despite the new gender equality policies, there still appears to be a resistance within healthcare to adapt.

2.6 Summary

Existing knowledge of men's experiences of breast cancer is limited. Current studies suggest men have little knowledge about breast cancer in men (France et al., 2000, Pituskin et al., 2007), wives are central to their help-seeking and support (Williams et al., 2003, France et al., 2000), body image is altered following mastectomy (France et al., 2000, Iredale et al., 2006, Williams et al., 2003) and disclosure of their diagnosis is largely unproblematic (Williams et al., 2003). These studies however had small, mostly homogenous samples and at times methodology was vague (Donovan and Flynn, 2007, Naymark, 2006). Furthermore, no study compared men's experiences of breast cancer with women's. Donovan and Flynn (2007) suggest breast cancer in men is distressing, stigmatising, and unparalleled in other disease profiles. There is no comparison however undertaken within this study of other disease profiles, nor illustrated with findings from other disease studies. The remainder of this thesis will present the findings of men's experiences of breast cancer, compared to women's experiences of breast cancer. The data on men's experiences of breast cancer derive from 19 interviews, which I conducted for this study; the data on none were pre-existing (and were collected using similar methods for a Healthtalkonline/DIPEX module in breast cancer in men).

To recap, the aim of this thesis is to explore men's experiences of having breast cancer and to compare men's experiences with women's experiences. These issues will be addressed through the following three research questions:

1. What are men's experiences of having breast cancer?

2. How do men's experiences of having breast cancer compare with women's experiences of having breast cancer?
3. What effect, if any, does having a 'feminine' cancer have on a man's identity and masculinity?

3 Methods

3.1 Introduction

This chapter focuses on the methods chosen to undertake this research and the justifications for using these methods. It will include discussion of: the role of secondary analysis in the thesis, my experiences of recruiting men with breast cancer, and of collecting and analysing interview data from my respondents. This is a qualitative piece of work. I begin the chapter by discussing why it was felt a qualitative approach was best for exploring the experiences of men with breast cancer, and why in-depth interviews using a narrative approach in particular, were chosen as the means to collect data. I will also discuss why a framework methodology was chosen to analyse the data. The inclusion of secondary analysis in the research design, supplementing the analysis of data collected by me, is another feature of the research. I go on to discuss the use of secondary data in this study. I then move on to focus on specific issues around collecting and analysing the data on the men with breast cancer, including sample design and recruitment, the process of interviewing, the analysis of the data, and the meshing of analysis of the primary data with the secondary data. I will end by considering ethical aspects of the study. Throughout my writing in this chapter I aim to be reflexive about my own role in the processes involved in collecting, analysing and writing-up the data.

3.2 Qualitative Research

Qualitative research explores the social world, providing meaning and explanation for complex phenomena, and was best suited to this study's aim to explore the lived experiences of men with breast cancer (Marshall, 1996, Snape and Spencer, 2003). Qualitative data are either generated naturally and collated using participant observation or are reconstructed in focus groups or interviews (Lewis, 2003). Naturally occurring data can be observed, and the researcher may choose to immerse oneself in the world of the respondents. However, this was not a suitable method for this study since men with breast cancer did not live in close proximity to each other, and observation of one man undergoing diagnosis, treatment and living with and beyond cancer would be impractical, intrusive and unacceptable to many. Similarly, the use of focus groups was not suitable for

this study. Focus groups are used regularly to generate ideas which are created through a process of interaction between participants where group consensus is important (Lewis, 2003). The focus of this study is the unique lived experience of each individual, which would have been compromised during the group discussion. Furthermore, organising a focus group would have been logistically very difficult due to the geographical spread of participants throughout the UK. In contrast to focus groups, interviews can be undertaken locally to the participant, sustain a person-centred approach and give the participant the full attention of the researcher to facilitate the re-telling of their experiences of cancer, a life-threatening disease that would require sensitivity to support the individual through the interview (Lewis, 2003). Consideration of these points and the intention to compare the men with the existing data available for secondary analysis led to the conclusion that in-depth interviews would be the most appropriate method for this study.

3.2.1 Narrative Interview

The in-depth interview had two parts. The first part, following DIPEx methods, was a narrative method where the respondent was asked to 'tell a story' of his experiences since first suspecting that something might be wrong (Herxheimer et al., 2000). A narrative approach allows the respondent to tell their story in their own reality, how they perceive what has happened to them. It may or may not be 'factually correct' (Miller, 2003). Central to this approach is the relationship between the interviewer and interviewee, who together collaborate to produce the story that the interviewee wishes told, with the interviewer supporting and offering encouragement (Miller, 2003). The story told may change depending on who it is being told to, and the social context in which it is being told (Miller J and Glassner B, 1997, Greenhalgh et al., 2005). Greenhalgh et al (2005) cite Fontana and Frey (2003) who describe a narrative interview as a "practical production, the meaning of which is accomplished at the intersection of the interaction of interviewer and respondent" (p 444).

During the interview process the relationship between me, a younger woman, and the man being interviewed, facilitated the production of the narrative told, created at a specific time and place. An older woman or male interviewer may have elicited different data. Most interviews took place in the men's own homes, facilitating their comfort, whereas the interviews undertaken in other

unfamiliar venues (a hotel sitting room and serviced offices) may have constructed a different narrative. This however, does not invalidate the narrative constructed during the interview. The narrative was a social construction of the men's experiences they wanted to share with me. I was aware throughout the research process that what was said may not be wholly accurate but what the men constructed as reality. It is impossible for me to know how the narratives may have been constructed had they been carried out by another researcher or at a different time and place. At times in the findings chapters I refer to the men's narratives as reflecting reality and at other times as accounts. However, I was always aware their narratives were socially constructed.

3.2.2 Framework Analysis

Greenhalgh et al (2005) suggests the narrative interview is a "process of accessing deeper truths" and requires the researcher to undertake rigorous, reflexive analysis to gain deeper meaning and understanding from the narratives. In qualitative research there is no 'best' approach for analysis that often involves large, inconsistent volumes of data (Ritchie and Spencer, 2002). Qualitative analysis is "essentially about detection, and the tasks of defining, categorizing, theorizing, explaining, exploring and mapping are fundamental to the analyst's role" (Ritchie and Spencer, 2002 p 309).

In this study, framework analysis was chosen to analyse data from in-depth interviews. Framework analysis is an analytic hierarchy that provides "conceptual scaffolding" (Spencer et al., 2003 p 213) to help the researcher undertake a systematic and rigorous approach to analysis. First the analysis is a deductive process that begins by exploring the initial research questions of the study before an inductive process of including new and developing themes. The data are then collated systematically into a matrix that facilitates an open and transparent account of the analysis undertaken. The main stages of this process are shown in figure 1 (adapted from National Centre for Social Research, 2002). Organising the data in this way allows for within and between case investigation that can be flexible and accommodate new and unexpected data (Spencer et al., 2003). One advantage of this type of analysis is the transparency of the process undertaken, meaning that it can easily be viewed and understood by another researcher (Pope et al., 2000).

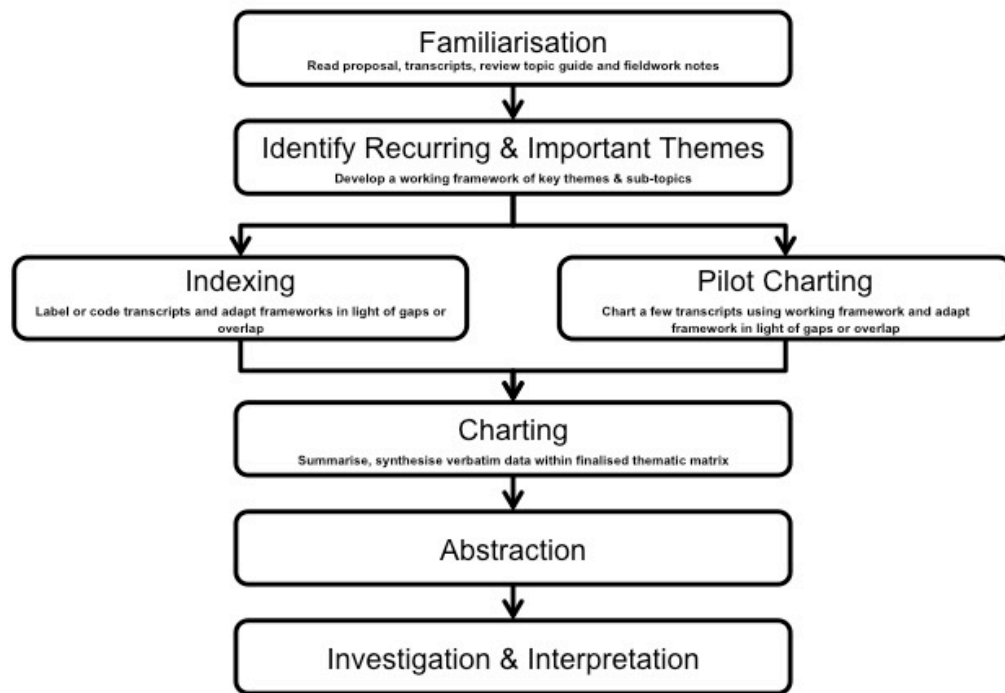


Figure1: Overview of the Analysis Process, National Centre for Social Research, 2002

3.2.3 Secondary Analysis

As was outlined in the introduction, one of the objectives of the PhD was to compare the experiences of men with breast cancer with those of women with breast cancer. In order to do this, transcripts of interviews with women, focusing on their experiences of having breast cancer, were made available to me by DIPEX, for secondary analysis. There were many advantages of using secondary analysis in this study. There was good quality data available from DIPEX (Bryman, 2004); the secondary analysis of the women's interviews brought a new perspective to the original interviews (Lewis, 2003); and it saved time and money when resources were scarce (Corti and Thompson, 2004).

Doing secondary analysis raises particular ethical considerations. Archived data should always adhere to the ethical and legal guidelines that were in situ when the data were archived. If anonymity was requested and agreed to by the primary research team, this anonymity should be protected at all times (Corti and Thompson, 2004). Included in this is the consideration of copyright ownership and the researcher must ensure that the interviewee has signed

copyright over to the primary researchers so that their words are the property of those interviewing and may be archived for future use (Corti et al., 2000).

DIPEX has rigorous procedures in place to protect the participant and control what is used on their website and for secondary analysis by gaining consent from the participant. DIPEX also follows a strict protocol before asking a respondent to sign over copyright (Appendix 2). To do this, DIPEX sends the final transcript back to the interviewee to seek agreement about what they give permission to appear on the website. For example, the interviewee may want some sections removed that he/she feels are too personal to appear in a public domain, or may cause offence to close contacts. Once they have agreed what can be used, the participant signs copyright over to the research institution so that the agreed data can be used on the Healthtalkonline website, and for academic use including teaching purposes and for secondary analysis. This process is also followed for any video clips that may be used. For participants that request anonymity on the website, an actor is used to read out their account or their accounts are presented in text only form.

In the early stages of the PhD study it was envisaged that another two comparison groups would be included in the secondary analysis: men with prostate cancer (a male-specific cancer) and men and women with colorectal cancer (a non-gendered cancer). Transcripts from these groups were available from DIPEX. However, due to time constraints it was ultimately decided it would not be feasible to include these other groups. While the inclusion of a comparison of men's experiences of breast cancer with men with prostate cancer would have been an interesting dimension to consider when exploring illness experiences and masculinity, it was decided to use the time available to focus on an analysis which compared men and women's experiences of breast cancer. Before this decision was made, however, I had familiarised myself with the literature on men's experiences of prostate cancer, and with the DIPEX transcripts of the men with prostate cancer, so the work that follows has been informed by my initial, unsystematic, explorations of this area.

Time constraints also ruled out a comparison with men with colorectal cancer, though further reading by the time this decision was made was already leading me to question the usefulness of such a comparison in terms of answering my

research questions. Rozmovits et al(2004) found that the formation of a stoma that caused faecal incontinence impacted upon the dignity, independence and sexuality men and women. We had become concerned that these participants had unique and distressing problems that made it an 'untypical' cancer, and not simply an example of a non-gendered cancer that had been the reason for selecting it as a potential comparator.

3.2.4 Ethics

This study had NHS MREC (Multi centre Research Ethics Committee) approval from DIPEX (Appendix 3). Approval had been secured for all future module developments using their current methodology and using tools such as their participant information sheet (Appendix 4), response form (Appendix 5) and consent form (Appendix 6). The only change required for this study was the addition of the MRC logo, and participants were made aware that the study was being carried out jointly by the MRC and DIPEX and interviews would be undertaken by me. Having NHS approval allowed me to recruit via specialist breast surgeons, breast care nurses and GPs who had immediate contact with potential participants throughout the UK.

3.3 Data Collection

The next section discusses how the primary data were collected, before returning to consider the place of the secondary analysis in the research design.

3.3.1 Men with breast cancer

Early in the study design process it was agreed with my supervisors that I would interview approximately twenty men who had breast cancer. It was anticipated this would be an achievable goal within the PhD timescale and generate a manageable amount of data. The objective was to recruit men aged 50 years or older, and at various stages of having breast cancer: e.g. soon after diagnosis, at different stages in their treatment cycle and post treatment. This was to maximise comparability with the women's characteristics (such as being older and post menopausal) and stages in treatment at which they were interviewed. Our aim was, if possible given the low prevalence of breast cancer amongst men, to capture a wide range of men's experiences and personal characteristics

(Marshall, 1996). Due to the relative rarity of men with breast cancer, the study was UK wide to ensure that a maximum variation sample was recruited.

3.3.2 Recruitment

It was anticipated that recruitment would be difficult due to the rarity of breast cancer in men and we therefore decided to use convenience and purposive methods to optimise our chances of recruitment (Marshall, 1996, Ritchie et al., 2003). Specific professional groups (breast care nurses, breast specialists and support workers) were identified as possible leads to men with breast cancer. To disseminate study information more widely I used a variety of advertising methods including newspaper advertisements and internet postings. The importance of using a rigorous recruitment strategy was foremost in the recruitment plan (Bryman, 2004). However, no single treatment centre or specialist was identified as having a particular interest in men with breast cancer. Men with breast cancer were diagnosed and treated within their local hospitals throughout the UK. Furthermore, we did not find one source with the potential to allow access to a large number of men with breast cancer. While our purposive sampling strategy (men over the age of fifty diagnosed within the last five years) was our aim the rarity of the disease and the time it took to recruit meant the reality was we had to consider each man who volunteered.

The aim of making health professionals aware of the study was to generate enough interest to facilitate the transfer of study information to men with breast cancer. A key recruitment strategy was making contact with breast care nurses via the Royal College of Nursing's (RCN) Breast Care Nurses forum. I advertised in their biannual magazine and online forum outlining the study details. I also had a stand at their annual conference handing out flyers and information packs to nurses. The interest generated opened new opportunities to me and I gave presentations about the study to the West of Scotland Breast Care Nurse Group, West Midlands Breast Care Group and the weekly multidisciplinary meeting at the Western General Hospital in Edinburgh. However, one aspect of an over-stretched NHS is that breast care nurses spend most of their time caring for patients at diagnosis and whilst they are undergoing active treatment. There is little routine follow-up and the responsibility is with the patient to contact the nurse if they have any concerns. Many nurses reported some experience of meeting men diagnosed with breast cancer, although few

had recent contact with a man, and it would have been a time consuming task to them to find details of potential participants and relay the study information to them. In addition to this, despite having NHS ethical approval, for each nurse who agreed to distribute information packs I had to submit our ethical and study information to the local Research & Development department for each trust to gain their permission before the nurse could help. At times this required me to gain the approval of the nurse, their line manager, the lead consultant and unit manager. There were many nurses who offered help with recruitment but were not able to because of the time delay gaining approval. Meeting nurses via the RCN group was the most successful method of recruitment and seven men were recruited via NHS contacts. Most of the recruits came from one nurse who was a research nurse in breast cancer and her role included recruitment for local and national studies. Her time was spent at breast clinics which enabled her to meet men who had completed active treatment and pass on information about the study. Although these men were recruited from one NHS trust, their treatment and location of care differed, as did their characteristics and background.

The internet was also a valuable tool to use when advertising the study. The DIPEX (www.healthtalkonline.org), Breast Cancer Care (www.breastcancercare.org.uk) and the British Association of Surgical Oncology, BASO (www.baso.org.uk) websites agreed to post an advert which asked men with breast cancer to contact me directly if they were interested in participating in the study. The Breast Cancer Care website was the only website that generated any recruits, although a number of breast consultants did contact me, saying they were interested in the study, but only one man was recruited via a breast consultant. The Breast Cancer Care website advert was posted directly onto the men's forum page; three men responded directly to the advertisement and another four were recruited via the charity's newsletter that ran the same advert. Some of these men were actively involved with Breast Cancer Care, participating in the development of their literature, volunteering as 'buddies' to other men with breast cancer, and speaking out about their experiences of having breast cancer. However, some men were "lurkers" who did not participate in the forums but read the posts and used the website for information. Initially I was surprised when these men agreed to participate but it soon became apparent during their interviews that their need for information

and desire to meet others in similar predicaments was their motivation for participating.

We learned from colleagues at DIPEX that there was free advertising in the London Metro and Evening Standard, which they had used to recruit for previous modules. Two men were recruited through this method; though it was decided to remove the advert after an interview was arranged with someone (it is not known whether he had breast cancer or not) who posed a threat to me. At first this man appeared to be enquiring about the study and asked pertinent questions. An interview time was agreed between us and was to take place in a neutral location. Before I was due to travel for this interview I received an upsetting email, of a sexual nature from this man. I immediately alerted my supervisors to this. The interview was cancelled. The risk assessment for the study was revisited to ensure we had considered all aspects of my personal safety and an incident form was completed and logged. I was also offered support and counselling from the MRC. In my experience as a District Nurse and in my supervisors' years of undertaking fieldwork we had never encountered such a problem before. We were aware of the importance of the risk assessment and the need for using personal safety measures which were strictly adhered to at all times (see 3.3.5).

We also identified the Maggie's Centres as possible recruitment sources. Maggie's (see www.maggie'scentres.or.uk) is a charitable organisation that has centres, usually situated in hospital grounds, which provide information and support for anyone with cancer. I visited centres in Glasgow, Edinburgh, Dundee, Fife and London and Professor Hunt visited the Oxford centre to deliver information on my behalf. While staff within each centre expressed support for the study, few reported meeting a man with breast cancer. Only one man was recruited via a Maggie's Centre. He was a single man, isolated from his family, who used the centre in order to obtain complementary therapies and assistance from the welfare officer.

3.3.3 An unexpected challenge to recruitment: the language used to talk about men with breast cancer

In the first year of the PhD, the study was referred to as one exploring 'male breast cancer'. This was used in the ethics application form and in the study

materials such as the information booklet. In the first week of recruitment I made contact with a man who had participated in a newspaper article about men with breast cancer. However, he refused to participate in the study because he objected to the use of the term 'male breast cancer'. He said he felt that by using the term we were perpetuating the 'myth' that 'male' breast cancer was somehow different to 'female' breast cancer when in fact biologically it is the same disease. On reflection it was decided that to spare any possible offence to other potential participants the information booklets would be reprinted using the term 'men with breast cancer'. It was also decided to include questions in the topic guide in order to explore how those interviewed felt about the term 'male breast cancer'. Some did, indeed, agree that the term 'male breast cancer' was not appropriate. For example, Andy (MBC73) shared similar thoughts to the man who refused to participate. He said, "There is no difference" between breast cancer in men and women, it is the same disease and should be reflected in the language used. However, most of the men felt it raised awareness that men could get breast cancer and was an effective way to describe their illness to others. For example, Michael (MBC85) said "It is what it is, isn't it? It's breast cancer. There's, there's no point in pussy footing around, I mean it's cancer of the breast isn't it, in the man?" One man discussed using the term 'chest' instead of 'breast' for men, a topic that was being discussed in the media at that time. Henry (MBC93) reflected that men "don't even have breasts, we have chests! And nobody ever calls it chest cancer."

The language used to describe men with breast cancer was not considered an issue that would be problematic before fieldwork had begun due to the extensive use of the term 'male breast cancer' throughout the medical literature. The upset to the man who refused to participate was unforeseen and was a difficult period in the early stages of fieldwork. Changes to the materials used and a meeting between the man and Professor Hunt alleviated any distress caused, and on reflection enriched the data collected during subsequent interviews. Furthermore, it highlighted the lack of research in men's experiences of having breast cancer as the term 'male breast cancer' has been used extensively in the existing literature.

I am unsure how many men were made aware of the study and decided not to participate. This is primarily due to my reliance on other people facilitating the

distribution of study information to men with breast cancer. However, I am aware no response forms were returned from one hospital consultant who said she had sent out three information packs. I had also sent four packs out directly to men and none were returned. I did not get any specific feedback from anyone suggesting reasons for their non-participation (except from one man discussed earlier). One possible explanation may be some men are embarrassed to have had breast cancer and do not want to talk about it. One contact requested a pack for her partner who had previously had breast cancer. She was interested in the study and knew information was limited for men with breast cancer. However she was doubtful that her partner would participate because she said he did not like to talk about his experience. During the interviews some men talked of their need to move on in their lives when treatment finished and put their illness behind them. It may be that some men did not want to reflect on painful past events. The participants acknowledged their desire to move on from their illness, but felt it more important to improve information available for men with breast cancer and felt their participation in this study would do this. Another possible explanation for non-participation may have been the request (which could be refused) to video the interview for future use on the DIPEX website. Clear explanation about its use was in the information pack stating the right to refuse the interview being video-recorded. Indeed, two men who did participate declined to have their interviews video recorded. However, it may have been that this assurance was not enough for some men and they did not feel confident their anonymity would be preserved.

3.3.4 The interviews

The first part of the interview, the narrative, generated good data. One man struggled to talk about his experiences at any length and wanted to be directed with questions. The other men talked through their experiences from being diagnosed to the present day without any prompts and with a variety of detail within each narrative. The second part was semi-structured questions asked in order to cover areas of interest and gain clarification of meaning. The aim of these questions was to ensure a degree of standardisation across the interviews in the topics covered, to explore important areas that were not brought up in the initial narrative and to clarify any areas of ambiguity from the narrative. The preliminary topic guide was developed from the themes evident in the existing literature on men's experiences of having breast cancer and dominant themes

emerging from a small sample of the women's data. Six randomly selected female transcripts had been analysed to help develop the topic guide for interviewing men with breast cancer. This complemented knowledge of the existing literature on men. An iterative process further developed the topic guide following each interview and reflecting on any new areas of interest that emerged (see Appendix 7). The topic guide was structured to revisit areas in a chronological order, although it was flexible to adapt to each individual interview (Legard et al., 2003). The themes explored with the men were:

- Diagnosis
- Treatment
- Level of information and support offered to the men and where this came from
- Disclosure of diagnosis to family and wider contacts
- Their reaction to the breast cancer diagnosis
- The reaction of others to their diagnosis
- Impact on identity and masculinity

With the participants' agreement, the interview was video taped and digitally audio recorded. The video recording was necessary for future use in the production of the DIPEX module on men's experiences of breast cancer. As discussed, two men declined to have their interview video taped so their interview was recorded with the camcorder switched on with the cap over the lens to obtain a back-up audio recording.

It was anticipated that the interviews would be a one to one with the interviewee and me. However, early in the fieldwork four wives sat in the same room and listened to their husband. One man wanted his wife in the room so that she could be part of the experience. Although she was reluctant to do this, she eventually agreed to sit in and actively participated in the narrative to confirm and assist her husband with his narrative. I did not ask her to leave as

her husband had wanted her to participate. In the other cases, the wives would enter the room once the interview was under way and being a guest in their home I felt unable to ask them to leave. On reflection, I think possible reasons for the wives wanting to be present were that they had played an important role in their husband's experience of having breast cancer and viewed the interview as an extension of their joint experience. However, in one interview the wife appeared to be interested in what her husband was saying, as though she was hearing his story for the first time. She also challenged him on some of his answers to my questioning that made him change his answer. For example, whilst discussing body image he told me he was not bothered about showing off his chest in public. His wife countered that he used to be, and he modified his answer to include being upset immediately following his surgery, but now five years on had come to terms with his mastectomised body. We decided to introduce some strategies to discourage the wives' involvement when organising the interview. I would ask the participant if there was somewhere quiet where we would not disturb their wife, and I offered to organise an alternative location if that was not possible. This was intended to set the expectation that it was a one to one meeting without causing any offence. It was a successful strategy in all but one of the remaining interviews.

One interview was undertaken with a deaf participant who could lip read and talk. However, the sound quality of the recording was poor and I had to check it using the video recording. At the time of the interview, communication felt satisfactory, from my point of view. However, it was not until I was checking the transcript that I realised how many cues I had missed from him and at times when communication was difficult during the interview we had both misinterpreted each other. On reflection it would have been useful to email him the topic guide, or the areas we were interested in, to alleviate some of the pressure we both apparently felt in trying to ask and answer some of the questions.

3.3.5 Researcher Safety

As the researcher I had to ensure my own safety whilst undertaking fieldwork, and had systems in place to call upon if help was needed (Lewis, 2003). The participants were spread across the UK, so travel arrangements were made and logged with one of my supervisors (Professor Hunt) and the unit's survey team. A

fieldwork risk assessment identified any areas of concern and systems were put in place to eliminate as much of the risk as possible. Safety in the interviewee's home was paramount and while I was undertaking the interviews I used the lone worker telephone system that required me to log in before an interview, and log out once the interview was complete. Interviews usually lasted between one and two hours so I would set the alarm for a call back after two hours. If I had not logged off within that time period I would have received a phone call from the service to ensure my safety. If I had not answered there was a series of escalation points that would have been triggered until as a last resort the police would have been informed and the address given for the interview location. On one occasion the interview ran over the allotted time and I was phoned to ensure I was safe. After ensuring my safety I renegotiated the end time of the interview and continued until the interview was complete. As an experienced District Nurse, I was accustomed to meeting people in their homes and discussing sensitive issues and on reflection did not feel under any threat or upset at any point whilst interviewing the men.

3.3.6 Reflections on Interviewing Men

I felt my past experience as a District Nurse enabled the interviews with men with breast cancer to be undertaken with relative ease and sensitivity. There has been discussion within the literature that men can be inhibited and cautious in their disclosure about health during interviews which ultimately affects the quality of data collected (Oliffe and Mroz, 2005). However, on meeting each man I felt I worked hard to gain their trust, talking to them and sharing some information about myself and the study and built up a good rapport before the interview began. I felt the men were at ease with me (particularly when the interview took place in their own home) at the start of every interview. In addition, because of my nursing experience, I did not feel uncomfortable discussing delicate issues such as facing death or the potentially embarrassing side effects of treatments such as impotence. As the interviews progressed I realised that if I said at the outset I was comfortable discussing any issues the men wanted to they would often discuss sensitive issues, such as their experiences of erectile dysfunction, spontaneously and in their own words. Furthermore, the men were given control of the interview when starting the narrative part of the interview, thus allowing them to choose what they told me and when. All the interviews bar three were undertaken in the men's homes and

as such most were in their own environment which appeared to facilitate a relaxed atmosphere that supported the relationship between myself and the interviewee (Olliffe and Mroz, 2005). The three interviews not carried out in their homes were more difficult to manage effectively. One was carried out in a local hotel that had a quiet seating area we used without interruption. The other two were done in meeting rooms that had been booked specifically for the interviews. Tea and coffee were provided and setting up the video camera allowed me time to chat to the participant without any pressure to start the interview immediately. I do think these interviews were not as good in quality as the others, although one was my first interview and I was nervous, and one was with the deaf man discussed earlier. The third interview in the hotel was the longest interview and took two and a half hours to complete. This man said he had not discussed his experience of breast cancer in such detail before and felt better for doing so.

It is difficult to say whether being interviewed by me, a woman, had any effect on the interview or the quality of data that I was able to collate. There is some evidence (Williams and Heikes, 1993) to suggest that men being interviewed by women are more cautious in their language to ensure that no offence is caused. It is impossible to say if this was the case in this study since I was the sole interviewer. In contrast, healthcare is considered a feminine issue. Talking to men about their experience of illness may have been facilitated by my presence without having their masculine identity being challenged by another man. The only reference that was made to me was that I was a lot younger than them and there were often jokes about their sons being single. However I did not feel that this affected the interview and their older age gave them a sense of power and control over the interview as they imparted their knowledge and experiences. At first I worried that my younger age and knowing I was a student would deter them from speaking freely to save me from any embarrassment. I was conscious that the quality of rapport I managed to build with the men during the interview would affect the data I collected and in the first few interviews I would convey my qualifications as a nurse. My aim was to reassure the men that I was experienced in talking about illness and also to assure them that not only was I bound by my ethical duties as a researcher but also by my nursing code of conduct, which I thought, they would be more familiar with. My first interviews were read by Sue Ziebland, Research Director of DIPEX, the Health Experiences

Research Group and she recommended that I did not share with the men my nursing background. She felt that by doing so it may inhibit some men from talking about their NHS experiences, particularly if they were not good or they may see it as an opportunity to complain to me. It is important to share some information about yourself with participants (Miller and Glassner, 1997) but it is also important to ensure that what you do tell them is relevant and will facilitate the interview. I did not openly tell the men about my background thereafter and I do not think the quality of interviews was affected. Once I had gained confidence in my interview technique I soon realised that making them feel at ease and creating a positive relationship early in the interview gained their confidence and trust to discuss their experiences at length.

The digital recording of the interviews was sent to a transcribing company used by MRC Social and Public Health Sciences Unit for many years, who transcribed the full interview. I listened to the interviews and checked the transcription to ensure it was accurate and corrected any mistakes. The data were stored in a secure environment in accordance with the guidelines set out by the Data Protection Act (1998).

3.4 Characteristics of the Men and Women Interviewed

3.4.1 Characteristics of the Male sample

We successfully recruited nineteen men aged 51-78 years from across the UK. At the time of interview three were unemployed; twelve were retired and four were in employment (all full-time, except one who worked part-time). Three men were single, one divorced and the remaining fifteen were married. One man was South Asian and the rest of the sample was White British. Most of the men had been diagnosed with breast cancer within the last five years, however two men (MBC67 and MBC87) had been diagnosed eight and ten years before interview respectively. We decided that their narratives were relevant to the other men's experiences and were included in the study. All the men had had a mastectomy and all had experiences of hormonal therapy (usually tamoxifen) but four had to stop taking this therapy before the completion of treatment due to intolerable side effects. Depending on the characteristics of their tumours, the men reported having different treatment regimes with and without chemotherapy and radiotherapy (see Appendix 8 for full details).

3.4.2 Characteristics of the Female Sample

The original collection included forty eight women with breast cancer interviews. These included pre-menopausal women of younger age (less than 50 years) that did not meet the criteria in this study, and their transcripts were removed from the sample. Three interviews with post-menopausal women who had been diagnosed twenty years earlier were also removed. It would have been difficult to compare these women's experiences with the men's current experiences. There were 23 interviews with women aged over 50 years who had been diagnosed with breast cancer up to 10 years previously. Of those, two were 70 years or older; four aged 60-70 years and 17 aged 50-60 years. Most were White British, but African Caribbean, African and Indian women were represented in the sample and reported a variety of occupations from unemployed to professional. They were geographically spread throughout the UK and time since diagnosis ranged from less than one year to ten years. Nine women were diagnosed via the National Screening Programme (Forrest, 1986) and fourteen women found a symptom that they reported to their GP that led to their breast cancer diagnosis. One woman originally diagnosed at screening later found a lump in her breast and was diagnosed with another primary breast cancer. The women reported more varied treatment plans involving hormone therapy, chemotherapy and radiotherapy, but the biggest contrast to the men was the difference in surgical procedures. Almost half of the women (n=10) had a mastectomy and the remainder (n=13) had lumpectomies (see Appendix 9 for full details).

3.4.3 Similarities and Differences between the Men & Women

Within the male and female samples there was a variety of different biological types of breast cancer diagnosed that accounted for the different treatment plans between individuals. Two women were diagnosed with relatively rare types of breast cancer (inflammatory and Paget's disease) that were not represented within the male sample. There were two major differences between the men and women. First, the majority of the men were married (15/19). Thirteen women were married, and the remaining ten were either divorced or single. Second, more women (13/23) reported having professional jobs compared to the men (7/19). Twelve men reported having manual jobs compared to four women, however there is no information available for the occupation of six women.

3.5 Analysis

Nineteen interviews with men and twenty three interviews with women were included in the analysis. The women's interviews provided high quality data, collected by the same methods that could be directly compared to the men's. However one disadvantage of using secondary analysis is the difference in research aims for the original research to the current research. In this study a few of the women's interviews were frustrating to read, as cues from the participant which I would have liked to have followed up were missed and data that could have enhanced my research was not obtained. For example, one woman talked about the loss of her youth when she had to stop taking HRT and vaginal dryness became a problem. She talked about buying a lubricant several times yet the researcher did not ask her about the effect this dryness had on her sexual life that she appeared to be indirectly referring to. There was little discussion of sexuality within the women's interviews, which could be compared to the men's experiences. Despite this, each interview produced large quantities of data to be analysed and interviews from both the men and women were analysed using the same method of framework analysis.

Analysis was an iterative process that commenced after the first interview. Subsequent interviews and analysis took place side by side. This allowed new and emergent themes to be incorporated into the interviews (Bryman, 2004). An example of this was the incorporation of questions on the terms used to describe breast cancer in men following discussions with the first man I had contact with. First, each interview was read and reread to familiarise myself with the data and notes were made on paper copies of initial thoughts and themes that had been identified. The first few interviews were summarised with my thoughts on the emerging themes noted in a notebook. After consultation with my supervisors who read these early interviews, a coding strategy was agreed that incorporated the areas of interest included in the topic guide and the new, emerging themes (Appendix 10). The coding strategy was reviewed after each interview and adapted to include emerging themes.

The interviews were then uploaded into NVIVO 7, a qualitative data analysis computer software programme that assists in the organisation and analysis of the data. Using the coding strategy, the transcripts were coded within NVIVO

into themes. The interviews provided a large amount of data and this initial coding into broad themes broke down the data into more manageable sections that could then be further analysed. It is possible to do further analysis within the NVIVO software however, at this stage framework templates were developed for each code.

The framework facilitated the organisation and classification of data into emerging themes whilst remaining close to the raw data and its meaning. A framework was created for each major theme to emerge from the data. For example, I created frameworks for help-seeking, disclosure, experiences of healthcare and living beyond a cancer diagnosis. Within the framework each participant was given a row and each emerging sub-theme a column. Using help-seeking as an example, the first participant (MBC76) said he delayed seeking help. The first sub-theme was 'delayed seeking help'. Within this cell I summarized the key points from his transcript: 'He delayed seeking help for six weeks. He attributed the lump in his breast to recent activity at the gym'. If the man or woman said they did not delay seeking help their cell was left blank and a new sub-theme was created to summarize their narrative. Occasionally quotes were inserted into the framework that captured interesting or significant moments in the data. As new themes emerged from the data, I reviewed the coded transcripts to ensure I had not overlooked any relevant data, thus continuing the iterative process.

An iterative process was used when analysing the men's and women's data for comparability. The men's interviews were analysed first before continuing onto the women's data. The women's frameworks had identical sub-themes. If new sub-themes emerged from the women's data the men's data were re-analysed to incorporate the emerging theme. Using the same sub-themes for both sets of data provided an identical structure between the men's and women's data. This facilitated a direct comparison between sets.

Once the charting of the codes was complete, the charts were used to find associations and interpret the original data to provide meaning and understanding. Throughout the fieldwork it was easy to become fixated on unusual and interesting narratives, sometimes misinterpreting them as the norm. The framework approach soon highlighted this misinterpretation because it was

possible to visualise all the data in sub-themes with ease. To further assist the analysis at this stage I often mapped out the themes from the framework to help visualise the data to look for associations. As I did so I would jot down the respondents beside the themes. This visual representation of the framework would highlight the common threads that sometimes challenged my own understanding of what the dominant themes were. An example of this was the emerging theme of aggression from the men's data. During the first five interviews three men discussed the effect the breast cancer treatment had on their mood, their struggle with mood swings and uncontrollable anger. There is nothing in the literature to suggest that other men with breast cancer have reported this. My perception at the end of fieldwork was that this would be a major finding of this study. However, the synthesized data in the framework highlighted that instead of being a common finding it was only reported by five men and was not present in the majority of the men's narratives. While it is an interesting finding, the emphasis that I had placed on it was not supported by the analysis.

The coding strategy included eighteen themes, each including numerous sub-themes. I had immersed myself in the volumes of data, spent many hours reading and rereading transcripts, synthesizing the data and producing intricate frameworks. It is not possible to present all the findings in one thesis so it was agreed that the most appropriate structure was to focus on the main themes emerging from the data. These were help-seeking, disclosure, their experiences during active treatment and the lasting effects of their treatment on their bodies and relationships. Focusing on these four themes takes you, the reader, through the men's journey from their first symptom awareness to beyond their treatment.

3.6 Ethics

Ethical approval is a mandatory requirement for undertaking any research project. To meet the University of Glasgow guidelines for studies undertaken by students, an ethics application (appendix 11) was submitted and approval granted by the Law Business and Social Science (LBSS) Ethical Committee (appendix 12). Having NHS ethical approval in association with DIPEX allowed me to recruit via specialist breast surgeons, breast care nurses and GPs who had

immediate contact with potential participants throughout the UK. As discussed earlier, simply having MREC approval did not allow me to recruit directly and it was necessary to submit individual applications to each trust and gain approval before I could proceed. At times this was an extremely frustrating and difficult process. No trust appeared to have the same process, and the ethical approval we had was interpreted differently by each trust. For example, one trust refused us permission to recruit through their service because they interpreted our ethical agreement to be out of date. It was not out of date but the methods used had been agreed three years earlier and were under review at the time of my fieldwork. Eventually this was clarified after the intervention of Sue Ziebland, the Research Director of DIPEX. By the time this was done fieldwork had been completed.

Over and above the formal procedure of completing an ethics form and applying for ethics permission, the way in which the research was conducted was important to me. I recognised, as a nurse with many years experience, the importance of treating the men I would be interviewing with respect and dignity, and of them getting something out of the interview process, as well as me collecting the data I needed in order to complete the PhD. I gave a lot of thought to exactly how respondents were approached and to how I interacted with them during my contact with them. I ensured I maintained eye contact as much as possible and tried to give reassuring cues when I could. This proved more difficult than I anticipated. I was aware of the need for me to be quiet on the video recording that would eventually be used on the internet, and on reflection I replaced reassuring noises with nods of my head.

I would outline what would happen during the interview. Before each interview, participants were offered the opportunity not to proceed if they had changed their mind. No one changed their mind and all signed a consent form before the interview started. It was important in the recording process for the men to feel at ease and if possible ignore the camera, but this was difficult when I had to regularly check the recording equipment and adjust for any changes in their position during the interview. It was also imperative that I did not take their consent for granted. Consent was not a 'done deal' once the interview had started (Usher and Arthur, 1998) and was considered an active, dynamic action that could be withdrawn at any time, particularly when personal experiences

were being shared. None of the men interviewed withdrew their consent during, or after their interview.

One ethical dilemma I had was where my duty of care as a nurse lay during the interviews. The Nursing and Midwifery Council's (NMC) Code of Conduct requires all qualified nurses to act in a professional manner, and maintain and promote the dignity and wellbeing of their patients at all times. However these men were not my patients and I was not there in any healthcare capacity. Some men discussed physical problems for which I had the knowledge to enhance their wellbeing, and felt at ease offering them advice. An example was one man who felt his mastectomy scar was very red and thick; this is known as a keloid scar. I knew it could be treated using a silicone patch to improve the appearance, and I was able to advise him to see his GP regarding this. However, it was the emotional support that some men were lacking that was a concern and I felt conflicted in what I could offer them as a researcher and the duty of care I had towards them as a nurse. An example of this was effective rapport I had managed to build with a few of the men that were keen to keep in touch regarding the study progression. However I also felt they had appreciated telling me their story and discussing their experiences in a way many of them reported they had never done before. My ethical responsibility (as a researcher and a nurse) was to ensure they accessed appropriate, local support which some did. Although, my role as a nurse would be to follow up these men, offering support myself and coordinating their care, this was not my role as a researcher, and letting go of this responsibility I felt for these men was difficult for me.

A reflexive approach was adopted at every stage in the study (Mason, 1996). I reviewed and reflected on my actions to ensure that I was doing no harm to others or myself. I anticipated that some of the content of the interviews would be distressing for the participant to recount, and for myself to hear. During the interviews there were a few times the interviewee became upset, but none that broke down or gave me any reason to think they were too upset to continue. Most of the interviews required some travel and expense and going to places I had never been before and had little knowledge of. Before the incident with the man who threatened my safety I had no concerns about travelling and undertaking the interview in the men's houses. However after the incident I did become much more aware of my surroundings, I quickly established who was in

the house and where I was sitting in relation to the doors. Another concern for me was flying. I do not enjoy flying and would take a train wherever possible or drove the Unit car. I had to fly many times to the interviews and this caused me more anxiety than undertaking the actual interviews in unknown locations.

On reflection there was one man who was upset after his interview. He was surprised at the depth of questioning into his breast cancer experience and commented that he had not thought about it since he was given the 'all clear'. He compared his breast cancer experience to his (deceased) brother's pancreatic cancer. During his reflection on why he had survived and his brother had not he became upset and asked to move onto another question. Although he became upset, I felt he had control of the interview and I felt there was a mutual understanding of what he was prepared to talk about and how much I could explore. I offered him the support information leaflets but he refused to take the information. After the interview we spent time discussing his artwork and the therapeutic effect that it had on his wellbeing. After each interview I wrote to the interviewee and thanked them for their participation. At this time I reiterated that if he wanted to access any support services I would send him the information.

3.7 Conclusion

The choice of narrative interviews allowed the men the opportunity to discuss their experiences as they recalled them, and in a way they were comfortable telling to me, and to talk about what was important to them. To ensure we had consistent and comparable data I followed up the narrative with semi-structured questions. This worked well with all the participants. Possible hurdles that we anticipated when interviewing men, such as their resistance to discuss sensitive issues at all or with a female interviewer, were unfounded. The interviews provided detailed narratives of men's experiences of having breast cancer and once compared to the women's experiences we focused on the four main themes that will now be presented in the findings chapters. The first chapter explores help-seeking and diagnosis, and then future chapters will focus on disclosure, experiences of healthcare and finally living beyond a cancer diagnosis.

4 Help-seeking of Men and Women with Breast Cancer

4.1 Introduction

This chapter presents findings in respect of the men and women's help-seeking behaviour following the discovery of a breast symptom. First, I give an overview of relevant literature on help-seeking. This will include exploring the process of help-seeking, what influences help-seeking, and whether men's and women's help-seeking are comparable.

I then present the findings from my own analysis, starting first with the men. The findings focus on the men's knowledge of male-specific breast cancer; interpretation of their symptoms; the role that others played in their help-seeking behaviour; and their approaches to help-seeking. The findings for the women follow. Not all the women in the sample had found a symptom of breast cancer; some were diagnosed via the National Breast Screening Programme (Forrest, 1986). These women discussed their prior knowledge of breast cancer and their accounts have been included in the findings. The accounts of the women who found a symptom of breast cancer will then be discussed focussing on their knowledge of breast cancer; interpretation of their symptom(s); the role others had and their approaches to help-seeking. The chapter concludes with a discussion of the findings in relation to the existing literature.

Within this chapter, the focus is on what is sometimes referred to as 'patient delay' (as opposed to 'provider delay') (Facione, 1993). Macdonald et al (2006) highlight the problematic use of the term 'delay' within the literature. Delay can be used to describe a time delay or denote advanced disease at presentation. It also implies that someone makes a conscious decision *not* to see their doctor. In women with breast cancer there is evidence to suggest that women can improve their chances of survival by reporting any changes in their breasts promptly to their doctor (Richards et al., 1999b). This is considered to be within three months of first noticing a breast cancer symptom which is the general cut off between 'early' and 'delayed' presentation (Bish et al., 2005). Research has shown that a delay of three to six months can significantly reduce survival

compared to a delay of less than three months (Richards et al., 1999b). However, throughout the literature the use of the term 'delay' is widespread and its definition varies from study to study. For example De Nooijer et al (2001b) reported delay in help-seeking as waiting over a month to see a doctor. Unless otherwise stated 'delay' within this thesis will refer to any time delay regardless of the clinical significance it may have.

4.2 Models of Help-Seeking

The process of help-seeking can be broken down into the actions that someone takes when they become aware of a symptom of ill-health (Smith et al., 2005). Help-seeking is not a straightforward or simple process, it involves complex behavioural interactions that may be influenced by external factors such as the cultural context, the role of others and access to healthcare (Unger-Saldana and Infante-Castaneda, 2011, Andersen et al., 1995, Facione, 1993). There are several psychological models that have been developed to aid our understanding of help-seeking (Andersen et al., 1995, Facione, 2002a), including one model developed specifically to explain why some women delayed seeking help for breast cancer symptoms (Andersen et al., 1995, Bish et al., 2005, Facione, 2002a). However, none of these models situate help-seeking behaviour in a social context, and focus solely on the patient's behaviour. A recent model suggested by Unger-Saldana and Castaneda (2011) does take social and healthcare dimensions into consideration. This model was developed in Mexico using a grounded theory analysis of interviews with women with breast cancer symptoms. The authors found that a delay in help-seeking was a result of personal attributes, social networks and available healthcare. Personal attributes include socioeconomic status, cancer knowledge and beliefs. Social networks include social interactions that provide information, emotional and decision-making support. The healthcare dimension included the availability and accessibility of services (in Mexico this was often described as poor). Unger-Saldana and Castaneda (2011) propose that help-seeking is a complex process that goes beyond the individual. Social interactions and healthcare availability should be considered in help-seeking behaviour to highlight the socio-cultural dimensions that influence help-seeking.

Aside from the help-seeking models, there have also been a number of studies using qualitative methods which have explored the lived experiences of people with illness to investigate what influences someone to seek help. Illnesses explored include cancer (Gascoigne et al., 1999a, Chapple and Ziebland, 2002, Smith et al., 2009, van Osch et al., 2007, de Nooijer et al., 2001b, Corner et al., 2006, Howell et al., 2008, Scott et al., 2006), heart disease (White and Johnson, 2000, Galdas et al., 2007, Galdas et al., 2010) and depression (Emslie et al., 2007a, Moller-Leimkuhler, 2002, O'Brien et al., 2007). There have also been several literature reviews (O'Mahoney and Hegarty, 2009, Macdonald et al., 2006, Smith et al., 2005, Mitchell et al., 2008) and syntheses of studies on help-seeking (O'Mahoney and Hegarty, 2009, Macdonald et al., 2006, Smith et al., 2005, Mitchell et al., 2008). The key themes identified within this literature have been identified as knowledge and symptom interpretation; the role others play in help-seeking; and fear and perception of (cancer) risk. This literature will now be presented.

4.2.1 Knowledge, Symptom Awareness and Interpretation

The qualitative synthesis undertaken by Smith et al (2005) found similar dimensions of help-seeking behaviour amongst the studies despite the different sample sizes and types of cancer being investigated. Knowledge of the disease, and recognition that a symptom may be attributed to cancer were found to be important motivators for help-seeking behaviour (Macdonald et al., 2006, Smith et al., 2005, MacLeod et al., 2009, Mitchell et al., 2008, Facione, 1993, de Nooijer et al., 2003, O'Mahoney and Hegarty, 2009). Misinterpretation of symptoms or a lack of knowledge was found to be a significant cause of delay by Mitchell et al (2008), although MacDonald et al (2006) found the exact effect which misinterpreting symptoms had on delay to be inconclusive.

The severity of symptoms has also been shown to influence help-seeking behaviour. Patients were more likely to seek help for a symptom considered serious, such as pain or bleeding (MacLeod et al, 2009). In turn, vague symptoms led to an increase in length of time to seek help (Smith et al, 2005). Similar results were reported by De Nooijer et al (2001b). They undertook a qualitative study of twenty three men and women with cancer of various sites (breast, testicular, colon and skin). They found that those with a specific symptom, such as bleeding or a lump, perceived it to be serious and reported greater anxiety

that led to an earlier consultation. This was in contrast to those who described non-specific and vague symptoms, who were less concerned about their symptom(s) and took longer to consult. Howell et al's (2008) study of thirty two participants aged over 65 years diagnosed with lymphoma found that vague and intermittent symptoms such as fatigue and lumps in unusual places, together with lack of pain did not raise suspicions of serious disease. Many of the participants said their first response was to find a plausible explanation in terms of their own knowledge and experience. Similar results were found in participants (n=17) who were eventually diagnosed with oral cancer (Scott et al., 2006). However in this study most of the participants believed their symptom would disappear and when it did not, approximately half sought medical help within a month of finding their symptom.

4.2.2 Role of Others

Mitchell et al (2008) found good social support to be an important factor that reduced delay in help-seeking. Other people influenced help-seeking by participating in the decision-making process. They discussed and appraised symptoms with the individual and offered an opinion on help-seeking (De Nooijer et al, 2001b; Howell et al, 2008; Scott et al., 2006). Smith et al's (2009) quantitative study that investigated what factors influenced people to consult their GP with symptoms of lung cancer (n=360) found that people who lived alone took longer to see their GP than those who lived with someone. They attributed the early help-seeking of those living with someone to their partners noticing symptoms and prompting them to see their GP. Furthermore, partners also appeared to play a role in approving help-seeking behaviour.

4.2.3 Fear and Perception of Risk

Fear has been shown to have both a negative and positive influence on people's help-seeking behaviour (Mitchell et al, 2008; O'Mahoney & Hegarty, 2009; De Nooijer et al, 2001b; MacDonald et al, 2006). Recognition of symptoms and their association with cancer could lead to a fear that encouraged prompt help-seeking. However, fear associated with potential cancer symptoms could also lead to embarrassment, fear of treatment and fear of death which could delay help-seeking (De Nooijer et al, 2001b).

In two studies fear did not emerge as a theme (Howell et al, 2008; Scott et al, 2006). The authors attributed this to a lack of knowledge about the cancers investigated (lymphoma and oral cancer) and the vagueness of their presenting symptoms. In these studies cancer was not seen to be a possible cause of their symptom and therefore those people were not fearful of a cancer diagnosis. Whether one considers oneself as being at risk of cancer can operate in a similar way. Smith et al's (2009) study of people with lung cancer (n=360) investigated how quickly they attended their GP after they had initially noticed their symptoms. They found that, despite smoking being an established cause of lung cancer, smokers (n=110/31%) did not think themselves to be at risk of lung cancer and did not consult their GP any sooner than non-smokers. Smith et al (2009) suggest that smokers may attribute symptoms such as breathlessness and cough as 'normal' for a smoker and therefore not as indicative of illness. Similar findings were reported by Corner et al (2006). Their sample of twenty two men and women recently diagnosed with lung cancer all reported having their symptoms for four months or more because they attributed their symptoms to old age and the ageing process, not to cancer.

4.3 Are There Gender Differences in Help-Seeking Strategies?

Previous research has linked men's and women's help-seeking behaviour to traditional ideals of what is masculine and feminine (Galdas et al., 2010), including the notion that the 'ideal' woman has caring qualities required to nurture a family, and the 'ideal' man is independent, self-reliant and hard working (Seem and Clark, 2006). These characteristics may be reflected in the help-seeking behaviour of men and women (Pill and Stott, 1982, Emslie and Hunt, 2008, Ang et al., 2004). First, women are seen as the caretakers of the family - monitoring health and organising healthcare when it is required - but looking after a family can be detrimental to a woman's health. Women may not seek help for themselves when they are ill but rather prioritise the needs of others before their own. Pill and Stott's (1982) qualitative study of forty one working class mothers found that "the good mother is one who 'keeps going' and copes with the multifarious demands that her family make of her... the responsible mother 'carries on' and it is quite clear that this is seen as her duty" (p.50). By contrast, women are often perceived by men and health professionals as frequent healthcare users for themselves and their families, including their

husbands (Tudiver and Talbot, 1999, Seymour-Smith et al., 2002, Chapple and Ziebland, 2002, Gascoigne et al., 1999a).

Traditional male characteristics are considered barriers to help-seeking. A paper by O'Brien et al (2005) on men's experiences of help-seeking in relation to constructions of masculinity summarises the key features of men and their help-seeking. O'Brien undertook fourteen focus groups, some of which were with men who had experienced prior health problems (e.g. prostate cancer, coronary heart disease and mental health problems) and found that many participants talked about their reluctance to seek help. They said they did not want to bother the doctor and that they would tolerate, ignore or monitor minor symptoms. This was particularly relevant to the younger men. The role of a wife or partner was highlighted as crucial to some men's help-seeking behaviour; some said their partner would encourage them to see their doctor. However, men who had experienced a serious illness said they had changed their help-seeking practices and saw reasons to attend their doctor more readily. The authors suggest this is because their masculine identity had been challenged through illness, and that an apparently greater readiness to seek help could enable them to reconstruct or protect more valued aspects of their masculine identities. In a similar vein, George and Fleming (2004) (who interviewed twelve men who had attended an early detection centre for prostate cancer in Northern Ireland) reported that these men fully endorsed attending for screening because they believed an early diagnosis gave them the best chance of curing their prostate cancer. However the men also differentiated themselves from women and their help-seeking behaviour. They said women knew their bodies better and were more willing to discuss health problems with other women.

Another study investigating the help-seeking practices of ten men (age range 28-44 years) who had been diagnosed with testicular cancer suggested that they were reluctant to seek help when they were unsure of the seriousness of the symptom they had found (Mason and Strauss, 2004). They did not want to waste the doctor's time with minor ailments, and said they should be independent, not think about health problems, and deal with issues themselves. Some men felt embarrassed accessing information and thought asking for help might lead to ridicule. Similarly, some of the 52 men interviewed for a study on prostate cancer said it was not 'macho' to seek help for health issues (Chapple and

Ziebland(2002). Furthermore, some felt it was easier for women to seek help as they had prior experience of attending the doctors for reproductive issues and on behalf of their children. On further analysis Chapple & Ziebland (2002) also found that the men found their symptoms 'embarrassing' to ask for help with. They suggest that the western social construction of masculinity is detrimental to men's help seeking because men are not allowed to display weakness without it being detrimental to their masculine status.

White and Johnson (2000) investigated men's help-seeking for chest pain through participant observation in an acute medical ward of twenty five men who had been admitted following an episode of acute chest pain, supplemented by in-depth interviews. They reported that the men had been reluctant to seek help immediately and had attempted to normalise their pain. They were unsure what was wrong and attributed the pain to everyday occurrences, such as pulling a muscle or indigestion. It was only when symptoms worsened that they decided further investigation was needed. However, it has been suggested that this reluctance to seek help for chest pain may relate to a westernised construct of masculinity (Galdas et al., 2007). When comparing the help-seeking behaviour of white, Indian and Pakistani men (n=36) admitted to a coronary care unit, Galdas and colleagues found that the Indian and Pakistani men endorsed prompt help-seeking because they valued different masculine ideals. These men valued their role as provider for their families, having wisdom and taking personal responsibility for their health. They did not view their chest pain as weakness, but as a legitimate reason to seek help.

There is little research that compares the help-seeking behaviour of men and women. However two studies have compared the help-seeking of men and women with chest pain (Galdas et al., 2010, Moser et al., 2005). Galdas et al (2010) interviewed eleven men and nine women about their help-seeking when they experienced symptoms of a heart attack. They found that although some men and women discussed their help-seeking in gender stereotypical ways (i.e. men as reluctant, stoical help-seekers and women as prompt, health aware nurturers of the family) there were some men and women that discussed their help-seeking outwith these gender stereotypes. For example, some women described stoical, reluctant help-seeking behaviour and some men said that they readily sought help and described feelings of vulnerability. Galdas et al

(2010) found that help-seeking was not based solely on a person's gender identity but was also affected by their social context. The presence of another person, the time of day and the location were all influential factors in their help-seeking. Galdas et al (2010) warn against the "binary conceptualisation" (p.22) of gender and emphasise the fluidity of the construction of gender. These findings are reflected in Moser et al's (2005) survey (n=194) which examined differences in the reasons men (n=98) and women (n=96) gave for delayed help-seeking for chest pain. They found that there was no difference in the length of time it took men and women to seek help but they delayed for different reasons. Women were more likely to delay than men if they were older, had a previous history of heart attack and did not want to bother or upset anyone. These findings contradict the stereotype of women's apparent readiness to seek help that is often implicitly or explicitly presented as opposite to men's apparent reluctance to seek help. These assumptions can lead to misinterpretation of both men's and women's help-seeking which focuses solely on men's help-seeking as problematic and ignores the barriers to help-seeking that women experience (Hunt et al., 2010).

4.4 Studies on Help-seeking in Men with Breast Cancer

Relatively few studies have examined men's help-seeking for breast cancer. However, the literature suggests that most men diagnosed with breast cancer have no knowledge they are at risk of breast cancer (France et al., 2000, Pituskin et al., 2007), although there is conflicting evidence with regards to the impact that this lack of knowledge has on a man's help-seeking behaviour. France et al (2000) found that none of the six men in their study sought help promptly and delays of up to two years were reported. However, Pituskin et al (2007) found that once the men in their sample had realised there was a change in their breast, all twenty had sought medical advice. This is supported by the findings by Iredale et al (2006), whose survey found that 84% of the participants reported seeing their GP within three months of finding a breast cancer symptom.

France et al (2000) also reported that the wives of the men with breast cancer played a key role in their help-seeking. Two men said their wives insisted they get a second opinion or were referred to a specialist after their GP dismissed

their symptoms as nothing to worry about. Williams et al (2003) found that none of the men who participated in their focus group study delayed seeing their doctor because their wives had insisted they should go and seek help.

The number of participants in all of these studies was small and help-seeking was not a specific focus in any. There are also no studies, which directly compare men and women's experiences of having breast cancer to help us understand whether men and women's help-seeking experiences are similar or different.

4.5 Studies on Help-seeking in Women with Breast Cancer

Knowledge of breast cancer risk and symptoms has been found to play a key role in women recognising a symptom that may indicate breast cancer (Burgess et al., 2001). Thirty five per cent of breast cancer cases are in women aged over 70 years (Grunfeld et al., 2002a), but a recent survey found that less than 1% of women questioned (n=1,496) knew that women aged 80 years or older were at greatest risk of developing breast cancer (Moser et al., 2007). Furthermore a significant proportion of women aged over 65 years believe they are less likely to get breast cancer because of their older age (Grunfeld et al., 2002b). However it is not enough for women to know their risk of having breast cancer. They require knowledge of breast cancer symptoms and have to recognise symptoms as a potential threat to their survival (Facione, 1993). Burgess et al (2001) carried out a study interviewing 46 women newly diagnosed with breast cancer to explore what influenced their decisions to seek medical attention for their breast symptoms. They found that the most important stage in the help-seeking process was when the woman initially became aware of a symptom and how she labelled that symptom. If a woman is unaware that the symptom may be cancer, it is dismissed and seeing the GP is delayed, although some women do continue to monitor symptoms, and a further change may prompt them to seek advice. However, despite the high profile of breast cancer, studies (Ramirez et al., 1999 e.g.) have found many women had a lack of knowledge on the range of breast symptoms that indicate cancer, particularly non-lump symptoms (Bish et al., 2005). Although marital status has been found to have no link with delay (Ramirez et al, 1999), some women do, however prioritise their work or family before their own health needs (Burgess et al, 2001). Fear of treatments and

surgical outcomes (for example scarring or losing a breast) has also been shown to delay help-seeking (Burgess et al, 2005).

Help-seeking has thus been shown to be a process that includes symptom acknowledgment and interpretation, intention to act and action. This process is influenced by knowledge of disease; perception of risk and the role others may have in influencing a person to seek help. These areas are discussed in the following sections, which present findings from my analyses of the accounts of help-seeking, first amongst men and then amongst women with breast cancer.

4.6 Help-seeking Process of Men with Breast Cancer

Review of the literature suggests that the first step in any help-seeking process is the discovery of a symptom, or a change is identified. The most common symptoms reported by the men in my sample were a lump in their breast (9/19) or an inversion of their nipple (7/19). Other symptoms which they noted were a growth on the skin (1/19), swollen breast (3/19) and a bruised nipple (3/19). Three of the men reported that they had first noticed changes to their breasts in young adulthood. Angus (MBC86), for example, said from the age of fifteen his breasts were bigger and one had a lump in it. Nick (MBC55) noticed a lump under his nipple when he was in his early twenties that he had squeezed to release pus and blood and Alec (MBC91) had a lump for many years that he was told not to worry about by his GP.

Six men said they had sought medical help promptly while the rest (13/19) delayed for a few weeks or more. It is important to reflect on why these men did not seek help immediately to help understand why some people do delay for long periods of time.

4.6.1 Knowledge, Symptom Awareness & Interpretation

Most (13/19) of the men had no knowledge that men could get breast cancer. Further, two of those men (MBC73 & MBC67) - one who sought help promptly and one who delayed for months - did not attribute their symptoms to cancer throughout the investigations they underwent (mammogram, biopsy). Andy (MBC73) did not consider cancer a possibility even when he was sitting in a

breast clinic surrounded by women. It was not until he was told that he had breast cancer that he reflected on the investigations that he had had:

Until they said, you had no clue...

Not a clue

Not sitting in the clinics with the women...

I felt stupid afterwards, really felt stupid. I'd think, well, I'm in a breast clinic, I've gone through a mammogram, an ultrasound and I still haven't twigged. How stupid am I? But when you've no knowledge, you know? No knowledge whatsoever.

Andy (MBC73)

Another man who delayed for months (MBC93) did not associate breast cancer with men because he did not think of his chest as 'breasts' and had never heard of another man having breast cancer:

...I mean it was only that at the beginning I hadn't realised that men could have it [breast cancer]. You know it was always women have breast cancer. And in fact I - last year at the Carol Service, Breast Cancer Carol Service, I finally told my story, and I started by saying that it was very strange because we always thought that breast cancer was a woman's disease. I said, I don't even have breasts, we have chests! And nobody calls it chest cancer, you know (laughs).

Henry (MBC93)

The six men who had some knowledge that men could get breast cancer recalled acquiring this information from different places. Michael (MBC85) knew "vaguely" after reading an article in the newspaper some years previously, as did Nick (MBC55). Bob (MBC89) had the most knowledge prior to his diagnosis because of his past employment as a health and safety advisor. He was required to assess the environment of work places to ensure no risk factors were present (in the case of breast cancer, excess heat and chemical exposure). Bob knew that although breast cancer in men was rare, it did exist:

What did you know about men having breast cancer before this?

I knew about it, but I thought there was about thirty a year got it but, you know, I'm not sure.

Bob (MBC89)

However, having knowledge that men could get breast cancer did not necessarily mean that a man attributed his own symptom to breast cancer. In fact, only one man (Michael, MBC85) said he was concerned when he noticed his nipple inverting on holiday and decided he should see his GP immediately when he returned from holiday. Michael had prior knowledge that men could get breast cancer. He did not want to upset his wife when there was nothing he could do about it whilst on holiday, so he only told her he was seeing his GP once they had got home. None of the other men initially attributed their symptom to breast cancer. Eric (MBC71) and Bob (MBC89) were unsure what their breast lump was, although neither attributed it to cancer. Nick (MBC55) decided to “monitor” a lump that appeared to be growing rapidly before he saw his GP. Jonathan’s (MBC75) wife had a history of breast cysts and he compared the pain and swelling in his breast to her experience of cysts. He said his lump was “like a cyst, like a spot you get on the face.” He took “no notice of it, just forgot about it” despite having recurrent problems over the following year because he considered it to be nothing more than a cyst.

Two men, Mani (MBC76) and Patrick (MBC81) said they thought that the change in their breast was caused by a muscle strain or recent activity at the gym as they had started exercising just before the symptom appeared. After attributing his swollen breast to recent activity, Mani continued to ignore his worsening symptoms and went on holiday:

...And then one day I notice, on my breast, it is swollen and it is becoming bigger and bigger though I ignored it, before that, said well, perhaps it is one of the muscles and I went on holidays.

Mani (MBC76)

Another two men, Jack (MBC59) and Tam (MBC77), had banged their breasts whilst working and attributed the swelling and pain in their breast to the recent trauma. Tam did not know that men could get breast cancer and did not think anything of the continued swelling he was experiencing:

The first time I got to know I thought it was a bruise. I walked into some timber, and it did swell, but not knowing, I didn’t know at the time men could get cancer, breast cancer.

Tam (MBC77)

Tam's breast remained swollen, and eventually his wife noticed his nipple inverting which alarmed her, and she insisted he saw his GP immediately.

In this sample of men with breast cancer it appears that those with prior knowledge that men could develop breast cancer were not more likely to seek help promptly once they had found a change in their breast. Most of the men said they assumed their symptom to be transient, such as bruising or working out at the gym, although some of the men with knowledge admitted to monitoring their symptom for any change. Most of the men became suspicious when their GP referred them onto specialists, apart from the two men who remained unaware of the possibility of breast cancer and were stunned when they were told their diagnosis.

4.6.2 Fear and Perception of Own Risk of Breast Cancer

Although the literature review suggested that fear was one emotion that could have either a negative or positive impact on help-seeking behaviour, fear was not an emotion discussed by any of the participants in relation to their help-seeking or general experiences. It cannot be assumed that the omission from the men's narratives means that they were not fearful. They did not talk about it during the interview and they were not asked specifically to talk about fear. However, more men reflected on whether they had seen themselves as being at risk of the disease. Five men had never thought cancer would happen to them. For example, Adam said he had "never even thought about the word [cancer]" and Jack (MBC59) thought cancer "don't happen to me" and was surprised when he was diagnosed with breast cancer.

Despite William (MBC83) vaguely knowing that men could get breast cancer, he "certainly didn't think [he] had it [cancer]" when he saw his GP. Patrick (MBC81) also had some knowledge about men having breast cancer, but again he never considered himself to be at risk:

Did you know beforehand that men could get breast cancer?

I probably did vaguely. But it certainly wasn't something that was you know, that I thought that I would ever get, no.

Patrick (MBC81)

Mani (MBC76) could not identify with the men with breast cancer he read about in information provided by the hospital. The men featured in the information were much older and retired from work. Mani was fifty years old when he was diagnosed, working and going to the gym regularly. He considered himself to be fit and healthy compared to the men he had read about.

4.6.3 Role of Others

Most of the men (14/19) were married and all described their wives as supportive. The role the wives played in the men's help-seeking varied, but the men's accounts suggested that all but two wives (MBC89 & MBC85) influenced their husband's behaviour. Bob (MBC89) and Michael (MBC85) said they had both made up their own minds that they needed to see their GP about their symptoms before telling their wives. Michael, as indicated above, did not speak to his wife about his newly discovered symptoms whilst they were away on holiday. He also said he was calm and not concerned about his inverted nipple because it was not causing him any pain and he knew ten days delay would not make a difference to the outcome:

My wife was KO'd [when she was told he had cancer], I knew she would be so that was one of my reasons when [we were on holiday] I said nothing, cause there was nothing you could do about it. I mean I'm a great believer in only worrying about things that you can do something about. At that point in time I couldn't do anything.

Michael (MBC85)

Bob's (MBC89) narrative suggests that he made the decision to seek help independently from his wife although he did discuss his symptom with her after finding a lump whilst washing:

There was a slight lump under the nipple, and I tested the other side, felt round and I thought "that's strange, there's nothing there", so didn't do anything about it but then after having a bath, I went downstairs to tell my wife that I'd found this sort of lump, so I said "I'll go and see my doctor."

Bob (MBC89)

Some accounts suggested that the men had discussed their symptom with their wives to try and understand what it was and what should be done about it, if anything. Eight men said they had been encouraged by their wives to see their GP after sharing their concerns about their symptoms. Andy's (MBC73) wife and

daughter “did a lot of pushing” for him to make time in his busy work schedule to see his GP and Mani’s (MBC76) wife argued that since seeing his GP was free in the UK he should make use of it. He said he wanted to make his wife happy so booked an appointment. William (MBC83) and Patrick (MBC81) had both noticed a change in their breast some time before talking to their wives about it. William had a growth on his skin and had been wondering what to do about it for some months. He eventually asked his wife if he should mention it to the nurse at his next appointment, and Patrick “after a little while” showed his inverted nipple to his wife who “didn’t like the look of it” and suggested he should see his GP.

There were four men who explicitly said their help-seeking was at the insistence of their wives and daughter. All four had dismissed their symptom as insignificant and it was only after the intervention of others that they went to see their GP. Tam (MBC77) had hurt his chest whilst carrying timber from a lorry and dismissed the pain as bruising. Later his wife noticed his nipple was inverting and insisted he saw his GP:

What was the time difference between you first bumping it and then the inverted nipple?

It was... I would say a couple of months, a couple of month

And you didn’t say to your wife then that you had that sort of swelling?

I showed her the swelling

Right

But I thought it was bruised, so my wife saw it, the nipple going inwards, that’s when she told me to go.

And how soon after her telling you to go did you go and see the doctor?

The following day.

Tam (MBC77)

Although Clive (MBC67) “didn’t take a lot of notice” of his inverted nipple, his wife recognised this to be odd and said “you’re going to the doctor’s tomorrow.” George’s (MBC52) wife was “nattering him to go” and said he would not have

seen his GP had his wife had not insisted on it. Jack's (MBC59) daughter realised that something was wrong with his breast when she visited him on his allotment one hot day and he had his shirt off whilst digging. His breast was "yellowy". He described how later that day she searched the internet and had realised that men could get breast cancer. She then phoned him daily until he had made his appointment with the GP:

How soon after your daughter asking "what's wrong with your breast?" did you make your appointment?

Well, it's like I say, we call her the Rottweiler. That was on the Sunday when she noticed it and she started ringing up on the Monday. "Have you been to the doctors?" So eventually I gave in and I went on the Thursday...I had to keep my daughter off my neck.

Jack (MBC59)

These findings suggest that many wives and some daughters of the men who participated in this study played a role in their husband's help-seeking to some degree. Some were there in a supportive role whilst others actively encouraged their husband, or father, to see their GP. This may be due to the women having more knowledge of breast cancer and its symptoms than the men and attributing the symptoms to disease rather than dismissing it. It could equally reflect a lack of an explanation being found that made them decide they should see their GP.

4.6.4 Approaches to Help-Seeking

Four men said they sought medical advice opportunistically for their breast symptoms; they took the chance to ask about the change in their breast while attending the GP for another issue. William (MBC83) did not want to waste the doctor's time seeing him for something that may be trivial. He monitored a growth on the skin of his breast for some months before asking the practice nurse while attending for a blood cholesterol check if he should see his GP about it:

It was actually a good few months I'd been looking at this, you know, and I'm saying, "I wonder if I should be asking about it." I was just a wee bit concerned about that, and then the fact that I was getting my cholesterol checked, I thought, "ah, this is a good", and I said [to my wife] "Do you think I should let the nurse see that?" And she said "yeah", and she [the nurse] had a look at it and I said, "do you think I should get the GP to look at that?" And she said "yeah, I think so."

William (MBC83)

Tony (MBC70) on the other hand was not concerned about his inverted nipple and would occasionally try and prise it back out whilst in the shower. He saw no need to see his GP as it was painless and there was no lump. He saw his GP approximately seven months after first noticing the inverted nipple for his five year work medical. Whilst there his GP asked him if he had concerns he wanted to discuss and he showed him his inverted nipple:

No problems at all getting through my medical, and luckily for me, my doctor who is pretty caring, he turned round and said to me "Is there any other issues you'd like to discuss? Have you got any other problems?" And I said, "Well yeah, I says, have you got any cream you can put on this" and I had an inverted nipple.

Tony, (MBC70)

Two other men (MBC86 & MBC91) who had opportunistically sought help said they had noticed changes to their breasts several years previously. Angus (MBC86) said he first noticed his breasts growing from the age of fifteen and Alec (MBC91) had had a lump next to his nipple for "years." Both men had spoken to their doctor at an earlier date and had been reassured that there was nothing to worry about. It was only when there were more recent changes to their breasts that they thought they would mention it to their doctor when they saw them next. Angus' nipple was starting to invert and, while he was seeing his GP for a sick line for his benefits, he mentioned it as he was heading for the door on the way out:

And it was later on, my nipple started going in on itself, so I went down for an insurance line [laughs] and went by the way...ken, I was nearly walking out the door. I went "oh, by the way doctor", I says, "my nipple's sinking in on itself", ken? And he says "let's look" and he just sat me there, he says, "You're going to a specialist." Right away he said "you're going to a specialist" and that's when I found out. But I believe it was there for 15, 16, but growing.

Angus (MBC86)

Alec had been offered the chance to have his lump removed years earlier but he had been told it was nothing to worry about so had declined the offer since it was not causing him any pain or discomfort. The skin above the lump then became "itchy" and was irritating him. At the next meeting he had with his GP (for an infected toe) he mentioned his concerns regarding the itchy skin and his GP said he would refer him on "to put [his] mind at ease":

But while I was there I'd says to him, I'd says, "by the way doctor" I says, I didn't even know the doctor's name, I says to him... "I've got a wee concern." He says, "what is it?" I says "it's my chest I says, I've thingmy there", and he looked at it and he says, "oh I'll send you for a biopsy" he says "and that'll put your mind ease".

Alec (MBC91)

There were different scenarios presented by these men for their opportunistic help-seeking behaviour. Angus and Alec had previously discussed their symptoms with their GPs and had been reassured there was nothing that required further investigation. They did not request another consultation despite ongoing, worsening symptoms. William had been monitoring his symptom for some months before consulting both his wife and nurse about seeking advice from his GP. In contrast, Tony had not been concerned about his inverted nipple and only raised the issue with his GP during a consultation for something else when given time to discuss anything that was worrying him. All these men had waited months (at least) before seeking help.

4.6.5 Help-seeking Prior to Breast Cancer

While talking about their help-seeking behaviour for their breast symptom, seven men talked about their help-seeking behaviour prior to their breast cancer diagnosis. All seven men said they were normally very reluctant to see their GP.

Four men said they did not like to attend their GPs with what they perceived to be minor and irrelevant symptoms. George (MBC52) said he did not like going to the doctors and felt that his GP was too quick referring people to hospital when they did not need to go. Another man, Jack (MBC59), said he thought that doctors had enough to do with people he considered to be genuinely sick. He said he did not want to waste a GP appointment with minor ailments when it should be for someone who was sick:

I don't know that I would have bothered going [to see the GP].
Because I'm usually very reluctant to go to the doctors cause I think they've got enough on with other people rather than looking at me... I think they've got enough on cause the waiting rooms are always full and so many people are poorly if they go there.

Jack (MBC59)

Two men emphasized the fact that they had not been to see their GP for many years. Clive (MBC67) said attending the GP with his breast symptom, at 65 years old, was his first encounter with his doctor since childhood. Similarly, Tam (MBC77) said he had not been to the doctors for 36 years. Both men appeared to reflect on this point with pride and reinforced it by describing the good health they had experienced throughout their lives until their breast cancer diagnosis.

Another two men, Tony (MBC70) and Michael (MBC85), said they were reluctant health service users. Tony questioned why any man would go to see their doctors with a symptom that was not causing them any pain or interfering with their daily lives. He said he did not go unless he was in pain. Tony reflected that had his GP not given him time to ask questions about any other problem he was having he would have been "one of [the] seventy that died". Michael said he would not normally have made an appointment to see his GP so promptly because his inverted nipple was not causing him any pain or discomfort. However, he said he knew men could get breast cancer and made an appointment quickly when he returned from holiday. To reinforce his usual reluctance to see his GP he then recalled a time when he said he was very unwell. He had been to see his GP who advised him he had a viral infection, but he subsequently refused to return to see the GP despite continuing to lose weight and friends' comments on his sickly appearance. He then underlined his own stoicism by narrating a contrasting story of his neighbour who would make her husband an appointment to see the GP with minor ailments: "[if he had] had

a slight problem with his bald head, it was an emergency. Which I think's a nonsense you know."

Two men referred to the traditional male stereotype of being reluctant help-seekers. Andy (MBC73) said that it was his wife and daughter that eventually "pushed" him into attending his GPs for the lump he had in his breast. He said they had persuaded him in a similar way to the portrayal of men's help-seeking in the newspapers:

You know, you read these things in newspapers where the women do the pushing and the men go eventually...we were busy at work, but I say, I did go when I could but yes, they did a lot of pushing, the girls.

Andy (MBC73)

Another man, Nick (MBC55), made reference to being a "typical Glaswegian" who did not go to the doctors because it was "not a good idea." However, in many ways Nick defied this stereotype. He was born in Glasgow but his family had moved to a rural location when he was young, leaving behind their crowded tenement in the Gorbals (an area of extreme poverty). Nick said he now drank two litres of water a day, avoided caffeine and did not eat anything unless it was organic to help him maintain his health. He had also spent many years investigating alternative therapies including the healing power of crystals and energy fields. Nick also compared his experiences to women's several times during the interview, and when talking about seeking help said he felt women were more aware of their health and at times overused services:

Females are much more open and aware of these things - males aren't, and they're fairly sensitive about going to the doctors, or even believing that they're ill.

Nick (MBC55)

To summarise, all the men who had talked about their past help-seeking behaviour said they did not normally attend their doctor. Two men explicitly talked about the 'reluctant male' stereotype and used it to explain their own help-seeking practices. It helped Andy explain his delay seeing his GP and helped Nick construct a masculine identity in contrast to the way he currently lived.

4.7 Help-seeking Process of Women with Breast Cancer

All the women in this analysis were aged over fifty years, and so would have been invited to routine breast screening; nine women had been diagnosed with breast cancer via the national screening programme. Although these women had not themselves found a breast symptom, their narratives have contributed to the findings on knowledge and symptom interpretation alongside the accounts from fifteen women who had found a change in their breast. One woman, Lesley (FBC70), was first diagnosed via screening services but subsequently developed a second primary breast cancer that she found herself whilst checking her breasts. Most of the symptomatic women (9/15) described their initial symptom as a lump. Four women said they found a thickening of their breast, one woman said the first symptom she became aware of was a pain in her breast (FBC72) and one woman had a lesion on her breast that would not heal (FBC88). The analysis of the women's accounts will be presented in relation to similar themes (knowledge, symptom awareness and interpretation; the role of others and their approaches to help-seeking) as those presented above for the men.

4.7.1 Knowledge, Symptom Awareness and Interpretation

Knowledge of breast cancer was poor amongst the women. The women diagnosed via the screening programme said they had little knowledge of breast cancer prior to diagnosis. One woman (FBC64) had a mammography as part of a research trial she was participating in (and she was unaware of having any symptom of breast cancer at the time); the remaining eight women diagnosed at screening had been invited to attend routine screening at their local centres. Among these women, five women said they knew nothing, or very little about breast cancer. For example, Emma (FBC86) said she knew "almost nothing" and it never crossed her mind to examine her breasts regularly. Another, Abina (FBC96), said that she also knew very little, only what she had read in magazines and even then they only told stories of people:

Did you know much about breast cancer before that?

Nothing, I just know people have it you know. That's what I read in the paper or the magazines...But they don't really give you the real you know low down on it, you've got to really have someone explain it to you, you know.

Abina (FBC96)

Only one woman from the screening group said she had any knowledge of breast cancer. About three or four years before her own diagnosis, Ada (FBC74) had supported a friend from the point of her breast cancer diagnosis until her death two years later. Although she knew little about her friend's cancer she knew a lot about breast cancer in general.

Prior knowledge of breast cancer appeared to have had a greater impact on the help-seeking behaviour of women who had found a symptom themselves. Three women said their prior knowledge of breast cancer had influenced their help-seeking. Two women, Jane (FBC68) and Catherine (FBC52), had sisters who had died of breast cancer prior to their own diagnosis. Jane was unsure what was wrong with her breast when one afternoon it had become hard and engorged for a few hours before it returned to normal. She knew this was unusual and, although she did not know what was wrong, she attended her GP later that day. Catherine's breast had become painful and on examination she found a lump. She phoned her GP first thing the next morning, fearing for her life after her sister had died the previous year. Her sister had delayed seeing her GP and Catherine said she knew how important it was to see her GP immediately. In contrast, Mary (FBC66), who sought prompt help had no prior experience of breast cancer or past problems with her breasts, but had read a leaflet on how to examine her breasts, which she did regularly whilst in the bath. Once she had found a small lump under her arm she made an appointment that day to see her GP.

One reason that some women appeared to have taken longer to consult was a failure to attribute their symptom as a sign of cancer. Two women, Helen (FBC72) and Rashida (FBC98), did not regard their symptom as anything to concern them. Helen had been experiencing pain and itching in her breast and had a discharge from her nipple. It was only when she found a lump in her breast two months after first noticing a change that she contacted her GP. She wrongly thought that at her age she was not at risk of breast cancer:

I'm very angry at myself because I feel I should have known better, but I got up one Saturday morning and showered as usual, and I'd been having very bad indigestion and a pain in my breast that I thought I'd just got to do something about this, this is getting a little bit beyond, and as I put my hand down over my breast, horror I felt a lump...And I just assumed quite wrongly that at 70 oh well it's not relevant now, and it was the least thing from my mind, if it had been anything else.

Helen (FBC72)

Rashida had felt hardness in her breast that she could not explain. She did not realise that she should see her GP until she attended a talk from a breast care nurse at her local centre for women and was given information about breast cancer and what symptoms to be aware of. After the talk she returned home and discussed her symptom with her daughter in law who encouraged her to see her GP.

There were three women who were unsure of their symptom because it did not match the description of other women's symptoms of breast cancer. Jess (FBC60) said she felt something "peculiar" in her breast but did not see her GP until she started having pain in her breast. She knew of women who had had breast cancer and who had described their first symptom as a lump. Jess felt unable to describe the "hardness" in her breast as a lump:

...As I dried myself I could feel in the left breast that there was something a bit peculiar. I'd had other friends who'd had breast cancer and they had told me that there was no doubt at all that they had a lump, but I was in quite a lot of doubt about exactly what I had. Sometimes I could feel it, sometimes I couldn't, and it was very much at the back of the breast, nearer the rib cage.

Jess (FBC60)

Susan (FBC76) said she had been ignoring a lump she had found in her breast for some months. Work had been very busy and she had been travelling outside the UK. On her return she realised that she had been ignoring a lump in her breast. She had always thought of cancer as being hard to touch, but her lump was soft "like a jelly bean." Susan said she had no knowledge of any breast cancer in her family and therefore did not think she was at risk of breast cancer. She dismissed the lump as nothing serious. On reflection she could not understand how someone as intelligent as herself could ignore a potentially serious symptom and found her diagnosis an "unbelievable thing to happen to [her]."

4.7.2 Fear and Perception of Risk

Unlike the men, throughout the women's narratives, fear of cancer and their perceived risk of getting cancer themselves was evident. For example Camilla (see above) said she was "scared" when she found a lump in her breast. Similarly, Helen said she felt "horror" when she felt a lump after misinterpreting other symptoms she had had for some time. Both Camilla and Helen knew that a lump could be a symptom of breast cancer. Awareness of breast cancer in women is commonplace, including knowing other women who have had breast cancer. In this sample, two women had sisters who died with breast cancer, and four women knew someone or had read other women's stories in newspapers and magazines. For example, Abina (FBC96) said she had no detailed knowledge of breast cancer but was aware of women dying of breast cancer after reading their stories in magazines. Marion (FBC64) also said she knew nothing about breast cancer but that she had "always been frightened of [breast cancer]" and questioned whether there would be any woman who was not frightened of it.

Despite the fear of breast cancer, four women said they had not felt that they were at risk of the disease prior to their diagnosis. Layla (FBC82) did not think breast cancer would "affect [her] in any way". Another woman, Amelia (FBC78), said that because she had no family history of breast cancer she did not perceive herself to be at risk. In contrast, Hannah (FBC62) and Jane (FBC68) used their family history to justify why breast cancer would not happen to them. Despite both women having a sister diagnosed with breast cancer (and Jane's sister dying from the disease) they did not think they would get breast cancer. Hannah thought that she would be "okay and [screening] wouldn't be a problem". Jane said she did not think the change in her breast was anything to concern her, and that breast cancer would not happen to her. She said, "...subconsciously you think it won't be me".

4.7.3 The Role of Others

Six women explicitly talked about the role that others had played in encouraging them to seek help. Five (out of thirteen) married women in the sample said they spoke to their husbands and another married woman (Rashida discussed above) had talked to her daughter-in-law.

Similar to some of the men, four of these women had shared their concerns with their husbands and come to a joint decision to seek help. For example, Jennifer (FBC50) and Ada (FBC74) received recall letters from the breast screening clinic. Both women said they discussed the contents of the letter with their husbands and agreed on what they thought this meant for them. Amongst the symptomatic women, Andrea (FBC80) and Jane (FBC68) had asked their husbands to confirm their suspicions after finding changes in their breast. Andrea had delayed seeing her GP while her father had been unwell. She became aware of a sizeable lump in her breast some months after noticing a thickening to her breast. She immediately called her husband to check that he could also feel the lump. When he confirmed he could she immediately made an appointment to see her doctor. Jane did not feel a lump but experienced a sensation she likened to breast feeding - an engorged, swollen feeling in her breast that felt hard to touch. She asked her husband to “come feel this” and “what do you think?” He did not know what was wrong and encouraged her to see the GP.

Rashida (FBC98) did not have a partner, and after attending a breast awareness talk she confided in her daughter-in-law that she was concerned about a thickening she had noticed in her breast. Her daughter-in-law encouraged her to see her GP:

I went home to my daughter-in-law... and I went and told [her]. She said, “Mum you should get yourself examined.” So I went to the doctor’s on Friday.

Rashida (FBC98)

Within the sample there was one woman, Camilla (FBC84), who did not tell anyone about the lump she had found in her breast while in the bath: “I didn’t say anything to my husband, my friends, my family, nobody”. She did not seek help for three or four weeks until eventually she became upset and told her husband who insisted she see her GP. Camilla’s reason for not telling anyone was that she was “scared” and feared her lump would be cancer.

4.7.4 Approaches to Help-Seeking

The men and women talked of different approaches to help-seeking. While some men said they sought help opportunistically, some women said they prioritised the health of their families above their own health and some monitored

symptoms before seeking help. Two women (FBC80 and FBC54) offered their prioritisation of ill-health of others before their own as an explanation for their own delay in seeking help. Margaret (FBC54) had been on holiday when she discovered a thickening of her breast. On her return, her husband had been unwell and she said she was more concerned about him than her own symptom, and only saw her GP once her husband was recovering. Andrea (FBC80) decided to 'wait and see' if the hardness in her breast would disappear. Soon after her father had a stroke that resulted in a long hospital stay and rehabilitation before he was allowed home. Once he was home and settled her thoughts returned to her own health and she was horrified to find a large lump in her breast:

...Previously I had discovered something, I'd felt like a thickening in the breast, about 4 months maybe beforehand, which I wasn't sure about. I thought well I'll check this again next month. And then my father had a stroke...And it wasn't till after I'd got him home you know that he'd got home and he was okay that I found this lump in my right breast. And it was sort of a shock because it was so much bigger than it had been when I found you know, what I thought I'd found a few months earlier, 3months, 4 months earlier.

Andrea (FBC80)

In addition to Andrea, another three women had waited to see if the lump they had found would disappear. Layla (FBC82) said she was reluctant to see her GP normally and preferred to buy over the counter remedies so that she did not "bother him." However when her lump failed to disappear after three weeks of her bathing it and rubbing cream on the area she decided she had to see her GP. Camilla (FBC84) also waited three or four weeks, hoping the lump would go away until she eventually broke down and confided in her husband. Lesley (FBC70) also delayed seeing her GP, despite having had breast cancer before. She delayed seeking medical advice for a lump she had found in the same breast. She "eventually" went to the GP (she did not explain why she delayed).

Jennifer (FBC50) also adopted a "wait and see" approach to her lump. At first she attributed the lump to changes in her hormones because she was prone to lumpy breasts at certain points in her menstrual cycle. When the lump remained after her period she decided to wait another month to see if anything changed after her next period. Soon after, her nipple started to invert and she realised that this was a symptom to see her GP about. She said her perception of a

cancerous lump was small and round like a pea, unlike her bigger, less defined lump.

4.8 Discussion

The data presented here suggest many similarities between the help-seeking behaviour of these men and women who went on to be diagnosed with breast cancer (see box 1). Their behaviours were affected by a variety of factor including knowledge, interpretation of symptoms, the roles of others, perception of risk and their social context.

Similarities Between Men and Women

- Both men and women had poor knowledge of breast cancer.
- Having knowledge of breast cancer did not necessarily prompt men or women to seek help for a change in their breast.
- Both men and women did not consider themselves at risk of developing breast cancer.
- Symptoms were often not attributed to cancer, leading to delay in help-seeking.
- Some men and women said they sought the advice from another person to discuss their symptom and decide what to do.

Differences Between Men and Women

- Some women attributed their prompt help-seeking to having witnessed friends/family experience breast cancer.
- Some men said they sought help opportunistically from the GP whilst attending an appointment for another issue.
- Some men said they were usually reluctant to seek help and did not want to bother the Doctor with what they considered minor ailments.
- Some women prioritised the health of their families before their own health needs and delayed seeking help.

Box 1. Discussion summary for Help-seeking of Men and Women with Breast Cancer

In addition, men used opportunistic opportunities to seek help for their breast symptoms and women described fear as having positive and negative effects on their help-seeking (see figures 2 and 3 for a diagrammatical representation of these push/pull factors). Similar to findings elsewhere (Galdas et al., 2010), the data suggest that the common and contrasting gender stereotypes of men as reluctant help-seekers and women as automatic help-seekers are not supported within this study.

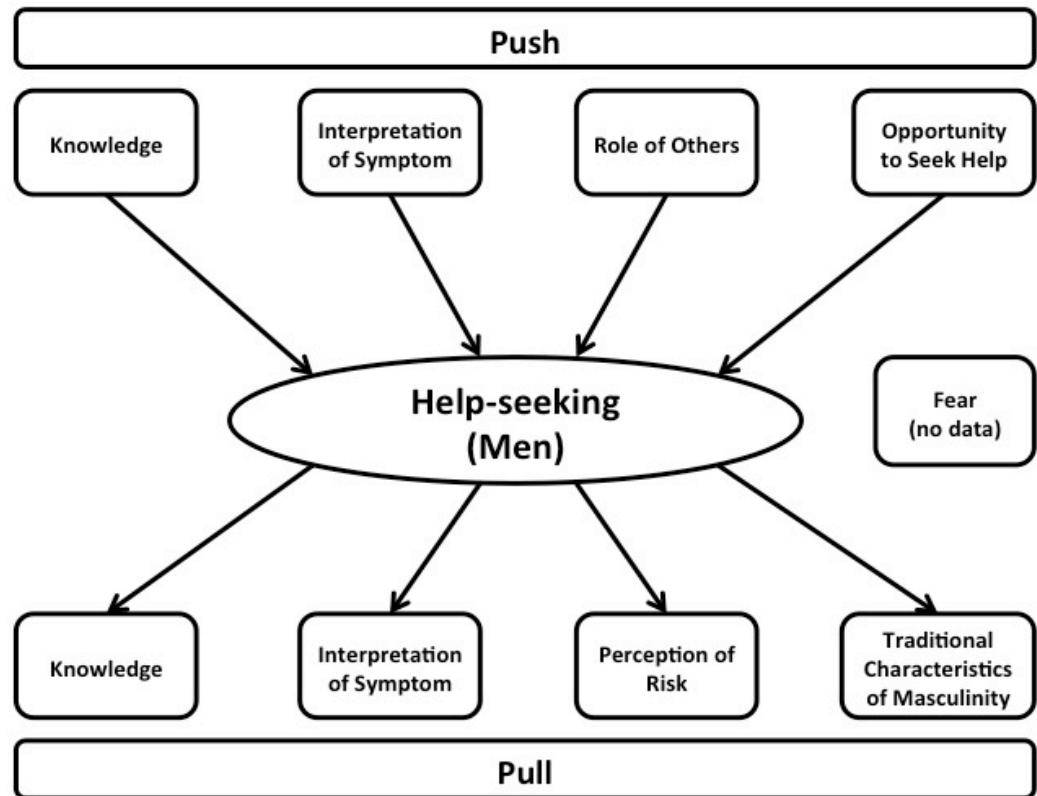


Figure 2: Men's Push/Pull Factors in Help-seeking

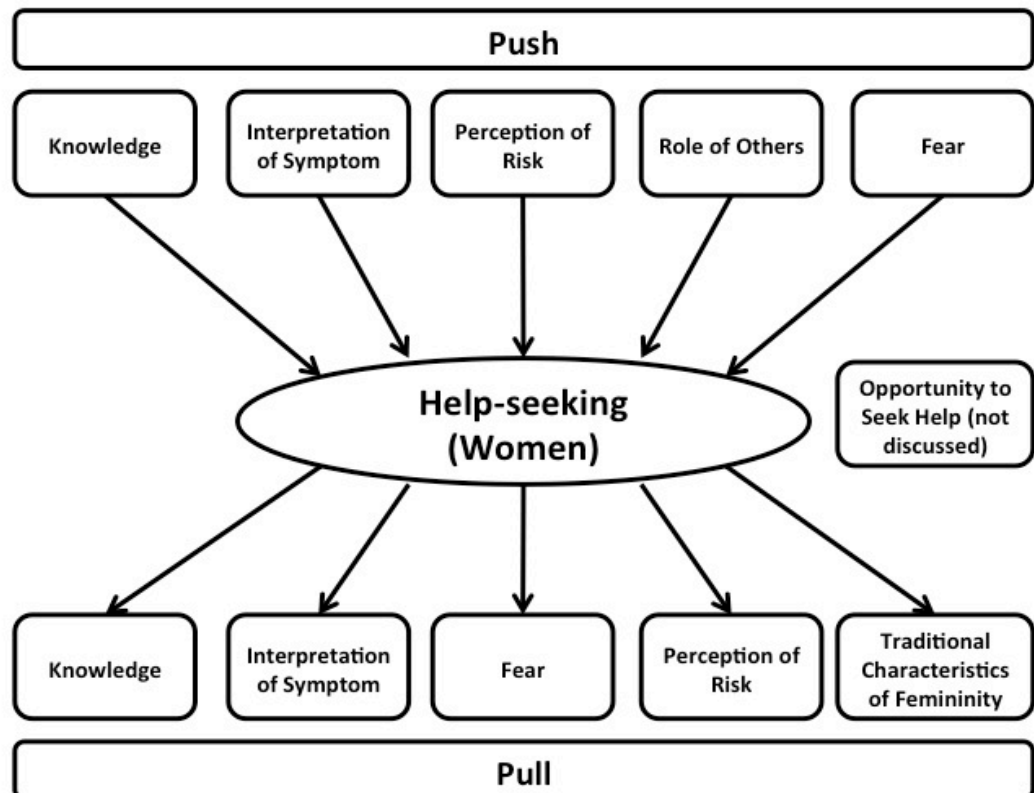


Figure 3: Women's Push/Pull Factors in Help-seeking

First, knowledge of breast cancer had both positive and negative effects on the help-seeking behaviour of the men and women in this study. The findings that both men and women had poor knowledge and concurs with other studies (France L et al., 2000, Pituskin E et al., 2007, Moser et al., 2007, Grunfeld et al., 2002b, Ramirez et al., 1999), although many more men were completely unaware that men could even get breast cancer. In both groups, having some knowledge of breast cancer did not always lead to prompt help-seeking. Six men said they knew men could get breast cancer, yet only one man was suspicious that his own symptom could be indicative of breast cancer and sought help promptly. One explanation for this may be the rarity of breast cancer in men. None of the men in this study said they had a family history of breast cancer (in men or women) and this was not a disease that any of the men felt at risk of developing. A further contrast with women is that none knew of another man who had the disease.

By contrast, women knew about breast cancer before their diagnosis and some feared the disease. However, few knew any details of breast cancer risk factors or what symptoms to look out for. The knowledge that they did have was often incomplete and so symptoms could easily be misinterpreted. For example, one woman dismissed a soft lump because she thought a cancerous lump would be hard or pea-sized; another woman ignored an itchy, bleeding nipple until she found a lump. Misinterpreting symptoms has been found elsewhere to be a significant factor in delayed help-seeking (Mitchell et al., 2008), in particular when symptoms are vague or do not cause pain (MacLeod et al., 2009, de Nooijer et al., 2001b). The experience of losing a loved one (a sister or friend) appeared to have a greater impact on the women's help-seeking than reported knowledge. These women said they made choices to see their doctor because they knew something had changed in their breast, although they were unsure what was wrong.

A lack of knowledge did not always lead men to delay in help-seeking. Most men questioned what their symptom was and attempted to rationalise it. The men who were unable to explain their symptom often went on to seek help promptly (Pituskin E et al., 2007, Iredale R et al., 2006). However, some men initially had found plausible explanations for their symptom. Two men recalled an injury to their chest, and another two attributed their breast tenderness to recent gym

activity. Three of these men eventually asked their wives for advice, and a fourth man's wife noticed his nipple was inverting. 'Normalizing' a symptom will lead to a delay in help-seeking while an individual waits for it to resolve. In this study, a lack of breast cancer knowledge delayed help-seeking in some of the men because so few knew that men could even get breast cancer, so few of them attributed their symptom to cancer. Furthermore, beyond the specific of their symptoms, some studies have suggested that men who have never experienced significant ill-health or considered their bodies fallible will not consider themselves 'sick' when something goes wrong (White and Johnson, 2000, Mason and Strauss, 2004). Annandale and Clark (1996) suggest this may be as a consequence of "women's health constructed as 'poor' against an implicit assumption that male health is 'good'" (p 32) therefore making it harder for men to see themselves as ill.

In this study, most of the men said their partners encouraged them to seek help. Fewer of the women had partners but there was evidence of husbands and occasionally children influencing their help-seeking. Current evidence suggests there are a variety of ways that someone can facilitate the help-seeking behaviour of another (de Nooijer et al., 2001b, Howell et al., 2008, Scott et al., 2006). In this study men and women used their partners to feel for changes in the breast, to confirm suspicions, and to discuss and agree what action should be taken. Both the men and women said that following discussion of their symptom with others, they sought help promptly. Mason & Strauss (2004) suggest that it is the emotional support offered by partners that is significant in the help-seeking process and those who share concerns have usually decided to seek help. Robertson (2003) suggests that men are faced with a dilemma of 'don't care, should care' (p.112) when considering their health. He undertook four focus groups and individual interviews with twenty men (including homosexual, heterosexual and disabled men) to investigate their use of health services for preventative medicine. He found that his participants reported that men did not care about their health yet felt that each individual was responsible for themselves and therefore should care about their health. This was apparent in the men's narratives when they compared their past help-seeking behaviour to their present behaviour. Some men said they had not seen their doctor for years, whereas now they felt comfortable seeking help. O'Brien et al

(2005) demonstrate how some men reconstruct their masculine identity to incorporate health and help-seeking as a positive following illness.

In many ways the accounts presented by men resembled those recounted in other studies. The men said that their wives arranged appointments or encouraged them to seek help. They justified their reluctance to seek help as not wanting to be seen as time wasters or hypochondriacs for minor ailments (Gascoigne et al., 1999a, Chapple and Ziebland, 2004, O'Brien et al., 2005). They considered GPs to be busy and thought their services should be reserved for 'sick' people, a group which they did not identify with. Denying they had a symptom requiring medical assessment is one process that White & Johnson (2000) found in their study investigating men's reaction to chest pain. They suggest that men denied the significance of a symptom to avoid the vulnerability of illness. By doing so, the men could preserve their masculine identity as a strong, resilient man. Further assertions by White and Johnson (2000) and others (Chapple and Ziebland, 2002, Gascoigne and Whitear, 1999b) that men deny the seriousness of symptoms for fear of being thought of as weak and vulnerable are not supported within this study.

There was one man who refrained for a long time before seeking help despite his wife and daughter 'nagging' him to see his GP. Andy waited approximately six months before he eventually took an opportunity to take time off work. Addis & Mahalik (2003) suggest that a man is least likely to seek help for problems perceived to be unusual, particularly if they are usually self-reliant. They argue that men like Andy would be sacrificing their control of the situation if they were to seek help and that could threaten their autonomy and self-control. Addis & Mahalik (2003) suggest that maintaining control protects a man's masculine identity and social standing within his social group.

However the women's findings in this study do not support the assertion that is often made implicitly or explicitly by men and health professionals that women are regular attendees at their doctor's surgery (Chapple and Ziebland, 2002, George and Fleming, 2004). The analysis of these women's accounts showed that women often shared similar concerns with the men about not bothering their doctor with trivial matters or delayed seeking help while they 'wait and see' if symptoms resolve without treatment. Some women said they monitored

symptoms for weeks, while others waited months. In some cases, the health of others was prioritised over their own health needs (something which was not mentioned by any of the men) and again delays of months were reported. These findings support the work of Pill and Stott (1982) that a stereotypically nurturing feminine role does not encourage help-seeking for oneself, but rather inhibits women focusing and prioritising their own health.

As noted above, not all the men or women in this study had a partner or someone close to them they could discuss their symptom with. However, the single men and women appear to have had different help-seeking narratives in this study. The single men did not talk about sharing their symptom concerns with anyone. All four single men delayed seeking help in line with other findings (Smith et al., 2009). In contrast, the single women in this study said they talked to their children or close friends about their symptom and the absence of a partner did not stop these women seeking the advice of others. This reflects findings reported by Facione (1993) who found there was no difference in help-seeking between married or single women in her meta-analysis of help-seeking in women with breast cancer.

In this study there was no evidence of fear and perception of own risk affecting the help-seeking behaviour of the men and women (de Nooijer et al., 2001b, Macdonald et al., 2006, Mitchell et al., 2008, O'Mahoney and Hegarty, 2009). Fear was not discussed by any of the men (Howell et al., 2008, Scott et al., 2006). One explanation for this could be that you cannot be fearful of something that you perceive yourself to have no chance of getting. For those who were aware that men could get breast cancer, they knew it was a rare disease in men and considered breast cancer to be highly unlikely to happen to them. The women in this study were more aware of breast cancer, and more aware that they could conceivably get breast cancer even if they did not feel personally to be at high risk. Some women talked about being 'scared' of receiving a breast cancer diagnosis. However, it was perhaps surprising that not more of the women talked about being at risk or being fearful of breast cancer. One possible explanation could be their lack of knowledge of breast cancer, although it is impossible to be certain when using secondary data and not knowing the extent of questioning during the primary interview. Some women suggested that because they had no family history and were older that they were not at risk of

breast cancer, when in fact only 10% of breast cancer is genetic (Mc Pherson et al., 2000) and older age significantly increases a woman's risk of developing breast cancer (Grunfeld et al., 2003, Moser et al., 2007). Furthermore, one woman reported delaying seeking help for lumps she found in their breast because she had a history of 'lumpy breasts' during her menstrual cycle. This normalisation of symptoms was evident in other cancer studies (Smith et al., 2009) and indeed the men who reported having had a lump in their breast for many years also said they delayed seeking help when they noticed changes in their breast because they had previously been told it was nothing to worry about or it did not cause them any pain.

To conclude, in this study there are many similarities between the accounts of the help-seeking behaviour of men and women with breast cancer. Knowledge of breast cancer risk factors and symptoms was poor. Men did not consider breast cancer a disease that would ever affect them and women misinterpreted symptoms based on incomplete knowledge. Both men and women used partners and children to discuss concerns, and support their decision to seek help. Both men and women monitored symptoms and both attempted to 'normalise' them through reference to everyday explanations such as injury or having 'lumpy breasts'. In contrast, some men said their wives insisted they seek help which was only evident in one woman's narrative. This study suggests help-seeking is a complex process including personal and social dimensions, including knowledge of breast cancer, the role of others and previous help-seeking behaviour. It has been shown that stereotypically 'idealised' masculine and feminine characteristics such as men perceived as being self-reliant and women as caretakers of their families created barriers to help-seeking. The gender specific stereotypes of men as reluctant users of healthcare and women as frequent users of healthcare have not been supported.

5 To Tell or Not to Tell? Disclosing a Breast Cancer Diagnosis

5.1 Introduction

This chapter presents the findings relating to who the men and women did or did not tell about their breast cancer and the reactions of others. First, the disclosure literature will be discussed. Then the findings will be presented focusing on how and when disclosure occurred, the reactions from others and the role their sick bodies played in their disclosure behaviour.

5.2 Strategies for disclosing illness

In the context of cancer care, disclosure has been defined as “the degree to which the patient openly discusses his or her thoughts and feelings” (Porter et al., 2005). It is perceived as a positive adjustment behaviour that enables someone to make sense of their diagnosis and help them to re-organise their thoughts (Mallinger et al., 2005, Hilton et al., 2009). Disclosure is also necessary to seek and gain support from others (Gray et al., 2000, Yoo et al., 2010).

However, disclosure is not simply a decision about whether to share information or not. Charmaz (1991) contends there are emotional consequences attached to disclosing personal information. Relationships may be affected and the individual may experience a loss of control and autonomy. The dilemma is “to tell or not to tell? How much to tell? Risk disclosure but face rejection?” (p108). Charmaz (1991) outlines two types of disclosure. First, disclosure may be spontaneous, enabling the individual to freely express oneself. Spontaneous disclosure often occurs soon after receiving life-changing news or when people are overwhelmed by illness. This can either leave individuals vulnerable to emotional distress or open to new sources of support (Yoo et al., 2010). Second, disclosure may be protective and self-limiting. Providing essential information avoids vulnerability to emotional distress and separates the recipient from the realities of illness. This enables the ill person to be objective about their illness, limits the emotional risks and controls the disclosure. Charmaz (1991) calls this type of disclosure “strategic announcing” (p 121). It has three main advantages: it

preserves the ill person's autonomy and independence; gives them control to reduce the potential of harm and maintains relationships.

For some however, disclosure of a cancer diagnosis may have too many risks attached, such as fear of losing status, losing control of their emotions or being unable to cope with the emotions of others. Non-disclosure can be a natural response to illness (Charmaz, 1991). This is different to concealing an illness. Concealment of an illness takes a lot of effort and shrouds the illness in secrecy. Both non-disclosure and concealment create distance between the person and the illness and avoid any associated stigma. Goffman (1963) describes stigma as an “attribute that is deeply discrediting” that reduces the individual “from a whole and usual person to a tainted, discounted one” (p 3). Building on Goffman’s work, Link and Phelan (2001) suggest that “stigma involves a label and a stereotype, with the label linking a person to a set of undesirable characteristics that form the stereotype” (p 369). Goffman (1963) suggests there are three types of stigma: physical deformities, a character flaw and ethnic and cultural stigmas that may be passed through the generations. A stigma may be hidden, allowing the individual to participate fully in society. However revealing the stigma may lead to invasions of privacy, the withdrawal of support and being ostracised from society.

Yoo et al (2010) contend that breast cancer and its treatment are stigmatising. It can result in physical deformities, is associated with death and in some cases has a genetic risk factor. There is growing evidence that suggests that men feel stigmatised when diagnosed with cancer. A study interviewing men on their experiences of having testicular cancer (n=20) found that some participants were aware of the scars on their abdomen and worried about people asking them what had happened and having to give an explanation which may reveal their cancer diagnosis (Gordon, 1995). Similarly, Gray et al (2000) found that the men who were reluctant to disclose their prostate cancer to others perceived prostate cancer to be a stigmatising disease, associated with death and that may change people’s perceptions of them. The men reported this made them feel vulnerable and under threat of being pitied.

5.3 Are there gender differences in disclosure strategies?

Harrison et al (1995) identified a lack of research on gender differences in confiding amongst cancer patients. They interviewed 520 men and women with cancer of the colon, lymphoma, female reproductive tract and testes to explore whether women would be more likely to confide than men, and if women would use a wider network of confidantes. They found that although there was no significant difference in the amount of confiding amongst men and women, men were more likely to utilise only one person to confide in, whereas the women in the sample were more likely to use a number of confidantes. They also reported approximately one third of both men and women did not disclose concerns to others, contradicting the common assumption that men disclose less than women. Similar findings were reported by Ullrich et al (2008) who matched men with prostate cancer (n=88) to women with breast cancer (n=88) by age, cancer stage, education and income. They found that the frequency of disclosures amongst men and women were similar, although women discussed a wider range of concerns than men.

These findings have been supported by qualitative studies of men's and women's disclosure habits. Emslie et al (2007a) explored how men (n=16) and women (n=22) with depression discussed their emotional distress. They found that although both men and women struggled to articulate their feelings initially, they were both willing to talk and share their experiences of depression. Another qualitative study used secondary analysis comparing young men's and women's (n=37) experience of disclosing their cancer diagnosis to family and friends (Hilton et al., 2009). They found that both men and women found disclosure the hardest thing to do, but were open about their diagnosis to dispel any rumours circulating about them (Hilton et al., 2009). Within this study there were men and women who concealed their diagnosis or delayed telling some people to protect loved ones. However, one difference between the sexes was the men linked their diagnosis to a gendered identity more than women. They used stereotypes of women being better communicators and attributed their lack of disclosure to the male stereotype of men as reluctant to talk about their health. Furthermore, they used humour in interactions with others to maintain their status as 'one of the boys'. Both men and some women did not want to be thought of as the 'cancer victim' and wanted to be treated the same as they

were before their cancer diagnosis. Two women with cervical cancer concealed their diagnosis because of its association with sexual promiscuity. Both these studies however, used data from DIPEX and there may have been a greater willingness amongst these participants to disclose.

5.4 How Men Disclose Illness to Others

The assumption that men do not disclose has previously been explained with reference to traditional male characteristics. Jourard (1971) suggested:

The male role requires men to appear tough, objective, striving, achieving, unsentimental and emotionally unexpressive... The male role, and the male's self-structure will not allow man to acknowledge or to disclose the entire breadth and depth of his inner experience to himself or others. Man seems obliged, rather, to hide much of his real self... from himself and from others.

Jourard (1971, p.35)

While these attributes may be observed in some men, Jourard's fixed notion of masculinity has been contested and rejected by recent evidence (Gray et al., 2000, Emslie et al., 2007a, Oliffe, 2006, Hilton et al., 2009). These studies support a dynamic set of socially constructed relationships which are created and recreated in life where gender is not fixed and masculinity and femininity are not opposing (Connell, 1995, West and Zimmerman, 1987). For example, Jackson et al's (2010) exploration of disclosure in men with prostate cancer contradicts the expressionless male stereotype. Telephone interviews were conducted with thirty five men who had an average age of 65 years. Half were African American and half Caucasian. The men reported disclosing their diagnosis to family and friends because they felt they had the right to know. In addition, the men also reported sharing their diagnosis in order to help and inform other men who may be at risk of the disease or struggling to cope. The men realised they gained emotional and practical support by sharing this information and perceived an improvement in their quality of life as a result.

Despite another study finding similar results in respect of men's disclosure amongst close family, they reported more problematic disclosure to wider associates (Gray et al., 2000). Gray et al interviewed men and their partners (n=34 couples) about their decisions to share information about their prostate cancer diagnosis at three different time points over the first year of treatment.

They found most of the men wanted to avoid discussing their diagnosis, only telling people who they felt really needed to know. This was mainly family members considered to have a right to know, or employers to arrange time off work. Some men needed time to come to terms with their diagnosis before telling others, and told people in such a way that allowed them to ask for more information if they wanted it, but did not disclose too much information at once. They often used humour to convey information around sensitive issues such as impotence. Some men who were having treatment for prostate cancer found they had no choice but to tell people due to their ill appearance. Otherwise, the men said they did not tell other people to ensure they maintained a sense of normality without having to deal with the concerns of others.

In this group of men, prostate cancer was often associated with impotence and death which the men perceived as stigmatising, a belief reported in other studies (Papadopoulos and Lees, 2004). They felt vulnerable to insensitive comments and pity from others that ultimately led to less disclosure about their diagnosis. Gray et al (2000) suggest whether someone tells others about their diagnosis or not, it is not indicative of how successful they have been at adapting and accepting their illness. A survey that compared cancer discussions and adjustment among female breast and male prostate cancer survivors (n=88 pairs) also found that among men, cancer discussion was not associated with depression or quality of life. In contrast, for the women in the survey cancer discussion was associated with increased depression and poorer quality of life (Ullrich et al., 2008).

Boehmer and Clark (2001) carried out retrospective focus groups with men with metastatic prostate cancer (n=20), and another group with their wives (n=7). The aim of the study was to explore the perceptions of the men and their wives about their views regarding changes that were caused by prostate cancer and its treatment. They found that despite both groups reporting strong and happy relationships, there was a lack of communication by both sides for fear of causing upset to their partner. The men felt their wives would not cope with too much information and interpreted the lack of communication about sexual loss as not upsetting. These men also felt uncomfortable sharing their diagnosis with family and friends and relied on their wives to do it for them. If they did

disclose, they were more likely to disclose to another man. The wives in turn reported limited disclosure because they too did not want to upset their husbands and draw attention to issues such as changes in physical appearance or impotence in case the men were unconcerned.

5.5 How Women Disclose Illness to Others

Pistrang and Barker (1992) suggest that disclosure can be an effective coping strategy for women dealing with breast cancer. It helps the woman find meaning and significance in their experiences of a life threatening illness (Henderson et al., 2002). Women have been identified as emotion workers and appear to do the majority of the disclosing within families (Gray et al., 2000, Yoo et al., 2010). One study of 299 women attending a private clinic in the United States found the majority of women (approximately 80%) discussed their diagnosis with at least one person. Those more likely to disclose their diagnosis were younger women, women with more advanced disease and women who had a more optimistic outlook (Henderson et al., 2002).

However a cancer diagnosis creates difficulties for women who are managing the feelings of others at a time when they are in need of support. Figueiredo et al (2004b) surveyed 66 women with breast cancer and found that women's main concerns were fear of disease recurrence and the effect their diagnosis had on others. In addition, they found a quarter of their participants said they did not disclose disease concerns to others. They found an association between non-disclosure and poorer levels of emotional well-being. Furthermore, non-disclosure was negatively related to social support and positively related to unsupportive responses. Similar findings were reported by Yoo et al (2010). They interviewed 176 women from different ethnic groups in the United States. They explored the emotion work involved in disclosing a breast cancer diagnosis. They found that sharing a breast cancer diagnosis was an extremely difficult process for the women. Different strategies were adopted to share information, protect others and gain support. Some women decided against disclosure until they had successfully completed treatment to protect people they perceived as vulnerable such as elderly parents. Other women offered encouragement and minimised their diagnosis to convey a positive outlook. Finally, some women used their diagnosis to educate and encourage other women to be vigilant. Yoo

et al (2000) also found some women reported being fearful of people's reactions and decided not to disclose while other women who did disclose reported negative experiences including a lack of support and the withdrawal of friendships. Within this study the sample included different ethnic groups (African American, Asian and Latino) who reported higher levels of non-disclosure than white women. Yoo et al (2000) suggest this may be due to cultural differences linking cancer and death and fear that cancer is contagious more frequently in ethnic groups than western cultures.

In addition An Australian study investigated how women with gynaecological cancers developed an identity in relation to their illness(Wray et al., 2007). Fifty two women were interviewed, aged between 27-80 years and diagnosed with ovarian, endometrial, cervical or vaginal cancer. The study found that there was a reluctance to discuss their cancer site because there was a lack of acceptable lay language to describe the area of the body affected. Euphemisms were used such as "under the knickers" rather than explicitly naming their cancer site. Women were also reluctant to disclose their diagnosis because of the perceived link to sexual promiscuity. This resulted in difficulties receiving support and information about their illness. Of the 52 women interviewed, only six (all with ovarian cancer) attended a support group. Two women with vulval cancer attempted to join a support group but were advised they would not 'fit in' to the group and thus felt isolated and stigmatised. They eventually found support from the internet where they could talk freely and receive support.

5.6 Disclosure Amongst Men with Breast Cancer

Current evidence suggests that men with breast cancer disclose their diagnosis in similar ways to men with other cancer types. Williams et al's (2003) small study (n=9) reported all participants said they were open about their diagnosis. Similar findings were presented by Pituskin et al (2007). They found that the men in their study (n=20) disclosed their diagnosis to their immediate family, but took longer to tell extended family and friends. In a survey (n=161) by Iredale et al (2006) 80% of the men disclosed their breast cancer diagnosis to their partners and close family, however 37% (n=60) chose not to tell extended family and work colleagues. These men said they feared being stigmatised because there was a perceived lack of awareness that men could get breast cancer, and some did not

want sympathy. Feelings of embarrassment were discussed in one small study (n=6) by one man who reported being reluctant to tell people (France et al., 2000). The other men said they were not embarrassed about telling people their diagnosis, but were reluctant to disclose their diagnosis because others responded with shock that men could get breast cancer and often said it was a women's disease.

5.7 Disclosure of Men with Breast Cancer

All the men interviewed were asked specifically about who they told their diagnosis to and how they did this. They were also asked about anyone they did not tell and the reasons for this. In this study all but two men said they were open about their diagnosis and told everyone. While there were few explicit examples of men struggling or choosing not to disclose their diagnosis, the men did use strategies to minimise the effects that their disclosure would have on themselves and others. The findings relating to disclosure to their immediate family are presented first, followed by those in respect of disclosure to wider family, friends and work colleagues. Most of the men interviewed had wives, but four were single and three had no children.

5.7.1 Disclosure to Family

Most of the men had their wives present when they were told they had breast cancer (11/19) but four men had to go home and tell their wives and children. Both Andy (MBC73) and Eric (MBC71) had expected to return to work after their hospital appointments but instead sat in their cars for some time trying to decide how they were going to tell their wives that they had cancer. Andy's wife and children were all at work so he phoned them and they all met at home later that day to "decide the future." Eric knew his wife was at home and was worried that if he just showed up panic would set in so he phoned his wife first to tell her his diagnosis. By the time he had arrived home she had phoned their children to tell them.

It is not clear whether Eric asked his wife to tell their children or if she had made that decision herself. However, Eric's wife was not the only partner who told their children. Four other wives were reported as doing so because the men said they felt unable to tell them. Mani (MBC76) felt that it was not good to keep

secrets and his wife told their son (who was twelve years old at the time) as he said he felt unable to tell him. Mani later however, said he started to hide his emotions to protect his family and other patients at the clinic. He wanted to appear positive for them and wore a smile to mask his anxiety from the outside world. He also felt unable to drink alcohol because he feared losing control of his emotions. He did not talk to anyone about his fears. Tony struggled with his emotions when telling his young children and relied on a friend to tell them while he walked on ahead, allowing him time to compose himself. Tony was divorced from the children's mother and relations between them were poor but he felt he had to tell them in person. His children lived in another part of the country and he visited soon after being told his diagnosis to tell them. However, when it came to telling them he could not find the words:

I wouldn't tell them on the phone. I had to, I had to, in myself I had to go and tell them, but I couldn't actually get it out to tell them. It was a friend who had to tell them. When they, when they were told, because I had walked away, they both came and hugged me, which made matters worse for me then, I just... I'd gone (started crying), you know.

Tony (MBC70)

William waited until his children were visiting anyway a few days later before he told them his diagnosis. He did not want to upset them and felt it important to convey a positive outlook and play down the seriousness of his diagnosis, which was a view, expressed by another five men in the sample. These men reported not wanting to alarm their family or make them think they were in any mortal danger as they had been given optimistic news from the hospital and said they wanted to prevent any unnecessary upset. William (MBC83) felt he was unlikely to die from breast cancer since his consultant had been so positive. Alec (MBC91) told his children that he had "a wee touch of cancer" that had been caught early because he did not want to upset them any further after his mother-in-law had been diagnosed with cancer prior to his diagnosis. Patrick (MBC81) wanted to shield his children from the truth, particularly his daughter who was much more emotional than his sons, and did not see the point in telling them things he felt they did not need to know. Bob's (MBC89) wife was away visiting an aunt and he had to phone and tell her:

My wife was with her aunt up in [place] and so I rang her and said
“I’ve got cancer but, you know, I’m alright” so you know, don’t start,
you know, leaping about and getting back down and things like that.
Bob (MBC89)

At the time of diagnosis Bob said he felt his cancer had been caught early and he did not want anyone to change their plans to accommodate him. He felt that by being positive he made others feel positive and stopped them worrying about him. He had a once in a lifetime holiday booked and after discussion with the surgeon he delayed his surgery for three weeks so that he could go. It was only during his latest hospital check up, six years after his first diagnosis, he found out that his cancer was more serious than he had realised. On reflection he said if he had known this at the time his actions may have been different.

Despite some men reporting some restraint in what they told close family, all told their wives and children that they had breast cancer. Some men could not physically tell their children and relied on their wives to do this. Most of the men did not reveal why it was their wives that did this apart from Tony, whose female friend told his children, as he was emotionally upset and could not speak. In fact, there was an assumption within the narratives that their wives and children would be told regardless of how the men felt, but this was not reported when discussing disclosure to their wider families, friends and colleagues.

5.7.2 Reactions of Family

Compared to the women’s interviews, the men did not discuss the reactions of their families to their breast cancer diagnosis in much detail. Most of the men (11/19) make reference to their wives and children being shocked at the news and tell how they pulled together as a family to support each other. Four men described themselves behaving in a stoical manner, putting on a brave face while their daughters in particular are described as being devastated. William (MBC83) talked about how emotionally upset his daughters were. He said he played down the seriousness of his breast cancer to try and instil some confidence in them. Andy (MBC73) said, “Obviously there were tears from the girls [his wife and daughter] and my son just, pff...” Patrick also described his daughter as being “a bit more emotional than the two lads” and limited what detail he gave to his children so that he could “shield them” from what was

going on. He also said he tried to “be upbeat about it” as he had been given positive information from the hospital on his prognosis. There were “tears” from Henry’s (MBC93) daughters when he told them he had breast cancer but he said he told them they would get through it.

5.7.3 Disclosure to Extended Family, Friends & Colleagues

Most of the men (17/19) said they told ‘everyone’ about their diagnosis. There was little discussion during the interviews about how they did this. Andy (MBC73) said he was not frightened to tell people he had had breast cancer and felt he should so that they knew to check their own breasts. He had not known men could get breast cancer before his own diagnosis and saw no reason why he should “keep it quiet.” Clive (MBC67) also said he tried to “spread the gospel” and would tell men about his experience of breast cancer whether they asked him about it or not. He said he felt “passionately men should know that [breast cancer] was a possibility.” He said he told anyone who would listen to him and hoped they would check their breasts and would seek help if they found something wrong.

Six men talked in some depth about how they felt about disclosing their diagnosis to others. Embarrassment (MBC52 & MBC83), humour (MBC89 & MBC59) and feelings of no option but to tell (MBC71 & MBC91) emerged from these narratives. Despite George (MBC52) having a supportive wife and granddaughter he said he felt embarrassed by his diagnosis and was not keen on others knowing. George had had a mental breakdown some years earlier and likened the stigma he felt then to the stigma he felt as a man with breast cancer. He knew people were wondering why he was attending the hospital and his wife thought they should know:

So who was it that you told about the breast cancer?

Well, my wife did it mostly

And were you happy for her to do that?

Oh yeah, yeah. Well let’s put it this way - yes and no. Yes and no. Because I thought it were a stigma, you know? As long as the...more people didn’t know much about it, it would be better for me. I mean, I were going backwards and forwards to hospital.

Why did you think it would be better for you?

Because I thought I like to keep things to meself, but I have to tell them why, because the point is she [his wife] looks after me.

George (MBC52)

William (MBC83) was also embarrassed to tell people, particularly men, he had breast cancer. Unlike George, he would tell people himself but said he felt embarrassed doing so. William also stopped telling people once his treatment had finished. He did not want to dwell on it and although it was never a secret he did not like to talk about it:

So how did you feel as a man with breast cancer?

Embarrassed. A bit embarrassed, uh huh. As I say, I didn't think that, you know, I was going to die with it - probably part of the reason for that was the hospital were so positive about - they were very positive. So I wasn't worried about that - but probably a bit embarrassed about it, especially talking to men you know? Women, they sort of, "oh" they were a bit surprised as well, you know? But they were probably more sympathetic, you know? But there's no doubt that, at times, I did feel a bit embarrassed about it.

William (MBC83)

Embarrassment was not the most prominent emotion to emerge from Bob's narrative, instead it was humour. Bob (MBC89) was one of two men that talked about using humour when telling others he had breast cancer. When asked if he told people about his breast cancer diagnosis he said he told everyone "cos it gets me a free cup of coffee." He said he made jokes to raise the subject and talk about breast cancer and that men can get it too. Jack (MBC59) also used humour in his narrative when he talked about his breast cancer and his wife's inoperable lung cancer. In fact, despite Jack being open about his diagnosis and being very willing to talk about his experiences, it was his wife's illness that dominated the interview, and this was the case when asked about who he told he had breast cancer. His wife's cancer had been diagnosed before his, and she was still having treatment (chemotherapy) at the time of the interview, which had made her very sick and weak. Jack's breast cancer had been diagnosed and most of his treatment had happened during his wife's ongoing treatment. He admitted to finding it very difficult to find someone to talk to when his wife was so poorly. Indeed, there was a lot of sadness in his interview. He explained that his wife was very resentful of him having his cancer cut out and he described

himself as “cured” after having his cancer surgically removed. He recalled that after her getting her diagnosis he made light of it in the pub:

Whereas, when [my wife] was first diagnosed, that was two questions she asked the specialist. The first one was “will I lose my hair?” And he said “no, but it’ll go very thin” and the second question was “can I still go to the bingo?” So, I told my mates about that in the pub like, “nowt much wrong with her still wants to go to bingo.”

Jack (MBC59)

Jack used a number of strategies for disclosing his and his wife’s illnesses, with humour being one example, but he also felt he did not have any choice about telling people. He lived in a small community where news travelled fast. This was also true for Alec (MBC91) and Eric (MBC71). They too lived in small villages where they felt they couldn’t hide their illness otherwise the truth may come out by accident and they did not want that:

Well yeah, when sometimes, when people react differently you feel a bit of a fool and perhaps you shouldn’t have said anything. But then afterwards you think well no, it’s better off out, because it’s- because if you don’t, it’s always difficult to carry on like successfully. Not many people can do it. If you don’t, if you only see them once every ten years you’d probably get away with it, but if you seeing them week in, week out going to let something slip so you might as well tell them straight away.

Eric (MBC71)

At first reading it is easy to assume that the men disclosed their diagnosis with relative ease. However, on further analysis it became clear that the men adopted various strategies to convey their diagnosis to both their loved ones and wider associates. Some men felt they had no option but to tell to keep gossip to a minimum, while others found telling people too distressing and needed help from wives or friends to tell people. However, telling people is only part of the process. The reactions of others may encourage or deter further disclosure and may lead to offers of support and information.

5.7.4 Reactions of Extended Family, Friends and Colleagues

The first reaction from others when they were told about the men’s breast cancer diagnosis was interpreted as shock and surprise yet half of the men said they found friends to be supportive after the initial shock (9/19). Five men reported some people’s disbelief at their diagnosis. They felt they had to

challenge this disbelief. When discussing breast cancer with his work colleagues, Alec (MBC91) said he told them “he knew all about it” and went on to tell them about his experience. They did not believe him when he said he had had breast cancer, but he told them it was not something he would make up. He then went on to describe the community’s support for him:

And how did you find people’s reactions to that [telling them about his diagnosis]?

Well, I can answer you - that, that and the likes of - I would say we’re a religious family, right? We go to mass every Sunday. Right? And sometimes we go to [village]. I was brought up in [village], it’s about eight or nine mile away from here. And I mind one Sunday we went down to [village] and it was about a year after it [his diagnosis], you know, and the people that had prayed for me down there, people that I hadn’t seen for years and years and that was the kind of reaction I got with it you know.

Right

But everybody - everybody round about, weren’t they, they were fine. But a lot of people brought me back the likes of medals from Lourdes, and you know, rosary beads and all that you know. I could start selling them in fact (laughs).

Alec (MBC91)

Alec said he felt supported by his community, and was reminded of this when someone new would tell him they had prayed for him. However, four men said they found that the response they got from men and women was different. They complained that men were quiet and did not ask any questions whereas women took more of an interest and asked questions. Clive (MBC67) said he felt that it was important to “spread the word that men can get it” and also felt that “women listened with interest. Men just didn’t want to know.” This made him feel very lonely:

When you tell people they say “oh” and that was the end of it. Whether they thought about it when they got home, I don’t know.

How did that make you feel?

Very alone. Very alone

Who... was there anyone you didn’t tell?

No, I don't think there was. Everybody I come into contact with. Just to spread the word that men can get breast cancer.

Clive (MBC67)

Donald (MBC87) had had his breast cancer ten years previously and could not recall any negative comments but did remember friends being quieter than usual and not asking many questions. Nick (MBC55) felt annoyed at the attitude of his male friends and thought that their refusal to discuss men having breast cancer could be potentially dangerous to their health. However he hoped they would now know enough that if they did ever find a change to their breast they would seek help:

I have found that males just say "oh yes" and change the conversation. They're either not interested or they don't want to know. I think they're not interested. Females are entirely different - as soon as they hear about it, they're almost invariably horrified and interested as well too, and supportive

Did they ask more questions than the men?

Oh yes - the men didn't want to, most of them didn't want to know

Right - how did that make you feel?

Em... a bit annoyed. As I say, I'm trying to get over to the males to be careful of these things - but they've got it in their minds now, so I would imagine that if they do have a problem there, they'll think back on the conversation and do something about it.

Nick (MBC55)

When met with disbelief from others, three men felt they needed to validate their story by showing off their mastectomy scar. Tam (MBC77) talked about his breast cancer in the pub and at work. He showed anyone who doubted him his scar:

Do you tell people you've had breast cancer?

Oh yeah. I've showed many men, many men, cos they didn't believe me.

Really?

And I showed them it [mastectomy scar]. And when they saw it they are, they said "must be right". You know what I mean? Showed many, many men it, cos they're embarrassed about it.

They're embarrassed?

They was embarrassed cos they didn't believe me at the time - "oh no, no, men can't get it", you know what men are, but men can get it, yeah.

Was there anyone that you didn't tell?

No. I've told everybody, told everybody. Even when I was working for a weekend, all the lassies knew. Some of them didn't believe me. I showed them.

Tam (MBC77)

There were two men who described extremely negative encounters with other men when they disclosed their diagnosis. Eric (MBC71), described a man he knew as "funny" at the local rugby club where he was a keen player when he was younger and a linesman in retirement. He said he felt he should have known better and expected as much from people at the rugby club:

...And then this chap said to me "what's up with you are you queer?" I said "what do you mean" He said "are you queer?" I said, "no, why?" He said, "only women get breast cancer". I said "hold it", I said "they don't, cause I've got it", I said "and I aint a queer." So, but you know, weird comments like that you see. And it - people don't understand so it's - I mean afterwards he accepted it like.

Eric (MBC71)

Eric's narrative suggests that he had his masculinity and sexuality explicitly questioned because he had been diagnosed with breast cancer. This was an issue that was also evident in Andy's narrative, although other men did not explicitly challenge him. Andy talked about one man he knew who described his wife as having "women's problems". It soon emerged that his wife had actually been diagnosed with breast cancer and Andy became very upset and "aggressive" that his friend had described breast cancer in such a way. He retorted, "it's not a women's problem, breast cancer, it can happen to anybody."

5.7.5 Non-Disclosure

Within the sample it was not a pressing concern for most of the men to keep their breast cancer diagnosis secret (17/19) and this could be attributed to the characteristics of the men that took part in the study. None of the participants reported keeping their diagnosis entirely secret. However, for two of the men

hiding their breast cancer diagnosis from some people was an issue. Nick (MBC55) was concerned that there were some people within his community who may laugh at him and make jokes at his expense. He felt people were frightened of the word 'cancer' and people with cancer used to be stigmatised, although he thought society was now more open about cancer. However, society's openness did not extend to "nasty" people that he said he had to keep at bay:

Do you ever not tell people?

No, well there's one or two people I know perfectly well, if I told them that, they'd probably laugh, you know. There's some nasty people in the world, as you may know? I don't tell them. Obviously I keep them at bay.

Do you think they would make jokes because you're a man with breast cancer?

Yeah. They would, but that's life. There's some nasty people, as I say.

Is that men and women like that?

No, no - just men, I would imagine.

And why do you think they're like that?

Because they're unpleasant people and they're always trying to be nasty, and that's one good way of being nasty. But I haven't had anybody being nasty to me so far.

Ok - so there are some people, then, that you've chosen not to tell?

Em... Yes. I would say yes, uh huh.

Nick (MBC55)

Although Patrick (MBC81) was open about his diagnosis to family and close friends he was determined to keep his diagnosis hidden from wider associates and his local community. He saw no reason to tell people as he felt it had nothing to do with them and he wanted to keep his illness separate from his everyday life. During chemotherapy sessions he avoided speaking to anyone else in the chemotherapy suite, as he did not think it was appropriate. He declined any offers of support from the Breast Care Nurse and also appeared to find the interview quite difficult as he felt he was recalling things he wanted to forget:

You said that you chose carefully who you did tell but is there anyone specifically that you just didn't want to know your diagnosis?

Well ex-colleagues. I used to be a teacher, so I didn't particularly tell anybody. Well that's not true, I told one. But then I had to, because, she was quite observant and you know (laughs), you can't really hide it, you know. Well I couldn't from her. So ex-colleagues, I suppose just people that just you meet in the ordinary course of- I mean I sort of felt, well you know it's nothing to do with them, it's my business and you know, just have normal relationships, I didn't tell anybody, cause I'm an artist, and I have studio and a studio complex and I you know, didn't tell anybody there, you know because I sort of figured that, that's a different life you know. And that's what you know- I'll get on with my life.

Patrick (MBC81)

While accounts of non-disclosure are not present in most of the narratives both Patrick and Nick discussed times when they felt disclosure was not appropriate or in their best interests. While earlier findings highlighted men using humour themselves to disclose sensitive issues Nick did not feel able to do so and would rather avoid people he felt would make fun of him. Patrick said he wanted to keep his illness private and return to his 'normal' life when treatment was finished. For this to happen, no one was told anything about his illness.

5.7.6 The Projection of a Sick Body

Four men felt that disclosure was inevitable because their physical bodies showed signs of illness and alerted others to their ill health. Despite Jonathan and Adam being open about their cancer diagnosis, both felt self-conscious of their bodies. Adam had a "square of what it [radiotherapy] does to you" on his chest where half his chest was hairless over his mastectomy site. He maintained he was not bothered about it but described it as being something "lost" that needed to be covered up so that he did not offend or embarrass anyone as well as having to keep it out of the sun:

I've still got the square that must be there for life, the square of what it does to you. But I'm not ashamed, I'm not... I was told always to wear a hat and always to cover up in the sunshine which I've never... not done. I've done it all the time, I always put a hat on and I always have a jumper on or a t-shirt, where you see all the men and all everybody bearing their chests, all that, I think well, but I don't.

Adam (MBC79)

Jonathan (who was still having radiotherapy at the time of interview) felt very self-conscious about his scar and described it as “quite prominent still” and “sore at the moment to touch”. However, he likened his self-conscious attitude to people recognising that he has had chemotherapy just by looking at the shape of his face:

It [the scar] is a little bit unsightly. It's not, you know, it's quite red. In fact it's a bit more redder now because of the radiotherapy treatment. And I suppose it makes me just self-conscious a little bit. But... actually sort of... I think it's also the same thing if you go out, you go out in the street and somebody sees... sees you, there are certain people that you know, oh, I know that fellow's got cancer, by just looking at the face. I do this, and sometimes when I'm sitting waiting to see my oncologist and he's got patients prior to me, and all the same thing, bald, you know, I mean, fortunately I didn't lose my eyebrows. But they all have a... as I said before, a typical look, and you sort of, some people say to you, you know... yeah, sometimes I think... they're talking about me. That's how I think somebody would perceive, you know, if they saw me lying out on a deckchair doing the same thing, it's... I'll probably get over it. And I mean, I'm not that self-conscious of it. I mean, I'm self-conscious when I see myself in the bathroom sometimes because I think it's [the scar] ... it isn't a particularly nice thing... And I suppose that's how I perceive it at the moment. Yes, a little bit self-conscious of it, yeah, but I think in time, I'm not self-conscious that I'm vastly depressed about it... had you not brought up the subject I wouldn't have thought about it, but no, I suppose going away, going away on holiday obviously I can't expose myself to the sun anyway.

Jonathan (MBC75)

Jonathan felt his hairless head and “look” gave him away and despite saying he “wouldn't have thought about it” had I not brought it up, his narrative suggests otherwise. This is in contrast to Patrick who openly discussed the anxiety he felt about his hair loss and being visible as a sick person, and the steps he took to conceal his illness. Instead of walking he took the car and he had various hats to disguise his hair loss. He was very concerned about other people knowing he was ill and talking about him when he felt it was none of their business:

Well I told my immediate family, my children. You know I'm a fairly private person and I certainly didn't want to- and I told some... one or two very close friends. But I certainly didn't- you know and I- I was really concerned because there was a- not a triage nurse, what do they- you know a nurse who, you know swabs you for MRSA and I can't remember what you call them, and she lives up there you see. So I was a little bit concerned that things would get around and, you know. I sort of, I quite like my privacy, as opposed to everybody knowing everything about you, you know. And so, it was a fairly limited number of people that we told, because again, I mean until it actually becomes really obvious you know, that you're losing your hair for instance, then- and, and with that I just, I did withdraw a little bit I think with that. I did feel it was so obvious you see. So I just kept, kept- went in the car and such like, you know.

Patrick (MBC81)

For Patrick, there was immense relief when his treatment finished and his hair started to grow back. He just wanted to get back to normal and "just do what I'd normally do."

Finally, Angus did not express any concern about his own appearance but described how his friends could not handle seeing him so thin and did not come round as often. When his hair started falling out he asked a friend to shave his head, and knowing that Angus was a hippy his friend refused at first. Angus said that he was not worried about losing his hair, as he knew it would grow back, but it took him three weeks before he managed to persuade his friend to shave his hair off. However, it was the behaviour of his family at his mother's funeral that upset him the most. Angus did not describe his family as close, nevertheless his family all knew that he had recently completed treatment for breast cancer, had no hair or eyelashes and was very thin:

You were still going through your treatment?

I was just aff it, just aff it.

Just off it.

And I went aw I cannae handle this. Aye. And I didnae think my nephew handled it well either cos he never even turned to face me, didnae want to see us. Couldn't handle it.

To see you?

I had my bandanna on...I wis a pure baldy, I'd nae hair yet I mean, just finished, ken, the radiotherapy and all that tamoxifen.

Mhm.

Aye.

And how old was he?

A grown man.

A grown man.

Ken what I mean, cannae handle anything like that, couldnae dae nothing ... got your back turned to me. Aye, I just left.

Angus (MBC86)

Within these narratives are a variety of responses that the men had to their “sick bodies” in relation to disclosure. For Adam and Jonathan, there was a resigned acceptance that they had the physical appearance of someone who had cancer that they felt they could not conceal from others. Patrick changed his daily habits and withdrew from society to avoid disclosure of his illness and maintain his own privacy until his hair grew back and he could return to his normal life, and Angus said he felt ambivalence towards his ill appearance despite his friends and family expressing shock and some people ignoring him.

5.8 Disclosure of Women with Breast Cancer

All but one woman describe why they chose to disclose or not, and some accounts are richer than others. However, there are rich data on disclosure to close family and to extended family and friends, and the reactions the women received.

5.8.1 Disclosure to Family

Within the narratives the women talk of a tension between wanting to tell family that they have been diagnosed with breast cancer and a desire to protect their loved ones from the anxiety and fear they may feel when they are told. Most of the women (15/23) told family and friends immediately that they had breast cancer. Some families understood that a recall notice to attend the screening service for further tests might indicate there was a problem. Rashida’s (FBC98) family, for example, had “already realised” and were prepared for bad news. Abina’s (FBC96) daughter also realised there may something serious wrong and

accompanied her mother to her recall appointment following breast screening. Her daughter then helped her tell her other children and explain what was happening:

Well when we came from the hospital my daughter and I, after they told us what happened and I told them I wanted it done, when we reached here she called my two sons and tell them to come down after work. It was important you know, and then we put a call down to my daughter, tell her to sit down and [her daughter] explained it to her you know, tell her what was happening you know. And then when the two came, my two sons came over after work they sat down, I cooked them dinner and everything...

Abina (FBC96)

Hannah's (FBC62) husband had been confident there would be nothing seriously wrong and did not go to the hospital with her. Hannah had insisted on attending on her own but when she arrived a close family friend was there waiting for her which she appreciated. After being told that she had breast cancer and what was going to happen next, she went home to tell her husband:

And when my husband came home he asked me whether I was okay and he was convinced that there wouldn't be a problem and of course there I had to tell him there was.

Hannah (FBC62)

Despite most of the women telling family immediately, there were five women who changed their disclosure pattern as time went on when circumstances changed or when they felt family were reacting negatively to the news. Mary (FBC66) did tell her husband immediately but was very careful what she told him as his first wife had died from cancer and she did not want to worry him. She was also open with her friends and found it comforting to receive get well cards and to know that her church group were praying for her. However, Mary said she did not like the reactions and comments from others when she told them she had breast cancer. She wanted people to react positively (as she had done) and not with sympathy as though she was going to die:

...I would like somebody to say "Oh I'm so glad you're well" not "Oh you poor thing, you've got breast cancer" you know (laughs). Other people may be comforted like that but you know I just, it's not for me you know...

Mary (FBC66)

Marion (FBC64) said she felt people withdrew from her when she disclosed that she had breast cancer to them. She talked about discovering who her real friends were and how she stopped telling people as it made her uncomfortable:

You find out who your friends are, and I found out who my friends were, definitely. And became closer to some people because of it, particularly my friend who was here most of the time. She was the right personality, she did not panic, and she did not encourage me to get maudlin but on the other hand she didn't push me either. And we did things, we went out and she went through most of it with me, practically all of it. To start with I used to tell people, and then I realised no, people back off from you. I like going away on courses, it probably was June and I told somebody who I happened to be talking to and I noticed, maybe I'm ultra-sensitive about it, but I noticed that some people back off. So now I don't mention it. My friends all know.

Marion (FBC64)

The other women who said they changed their disclosure pattern were more concerned about the effect their disclosure had on their loved ones and did not want to give them any more reason to be worried. Fara (FBC90) found it very difficult to tell her husband and children when she initially received her diagnosis. When she did, she found them to be very supportive. Despite this she did not want to worry them about the disabling hot flushes she was experiencing because "they would be upset." Catherine (FBC52) had breast cancer twice and one of her sisters had died of breast cancer at a young age. Her family was extremely worried about her. Her relatives were devastated when she was diagnosed the first time. They would phone her and cry, saying that they thought she was going to die and this upset her. When she was diagnosed for the second time she decided not to tell selected family because of their reaction to the news the first time. Eventually she felt she had to tell them all as her husband and her sister that knew felt under enormous pressure keeping her secret and she decided it was not fair on them. Susan (FBC76) also said she felt under pressure about what to tell her family. She initially said she felt she had "a duty" to tell everyone. However, at the time of the interview she was being monitored for pre-cancerous changes in her uterus and had not told anyone she was having regular hospital appointments to assess what should be done. Susan said she felt it would be a "great burden" on them to know and they would only worry:

Oh no I went round telling absolutely everybody...I felt almost a duty and I can't really understand the psychology behind that because I actually now have, I don't have a malignancy in my uterus but I do have pre-cancerous changes which is going to require us to do something, having a hysterectomy or something, and I feel quite differently about that, as though I do want to do it by myself, I don't want to go around telling all my friends. For a start you realise after a while that it does make them anxious and it's not really a help to talk about it. I mean I think if it gets further and gets worse, then I would, but at the moment I just want to kind of work it out in my own head.

Susan (FBC76)

These women said that despite their own willingness to disclose, after experiencing the reactions of their loved ones, they became more aware of what they told them and limited information to protect them from the ongoing surveillance they were undergoing for their breast cancer.

In contrast there were five women who chose to limit who they told they had breast cancer initially and then became more open over time. Two of the women, Jess and Emma, decided not to tell their elderly mothers that they had been diagnosed with breast cancer initially. Jess told her mother when there was an important family occasion coming up and she felt she had to tell her. Emma told her mother after she had surgery and could give her good news that it had been dealt with which reassured her:

Was there anybody you didn't want to talk to about it [the diagnosis] in particular?

I think I didn't tell my very elderly mother until I'd been done [had surgery].

Yes

Yes, and the day I came out of hospital I went and fetched her and brought her up here and sat down and told her I'd been in hospital. And all she says "well are you alright dear?" So I said "I'm fine." "Good," that was fine yes. But I didn't want to worry her. I mean she really was, five years ago, late 80s, I didn't want to tell her till it had been done and I could reassure her, because I don't think I could've coped with it either with her, you know. So that worked well.

Emma (FBC86)

Another woman, Andrea (FBC80), also said she did not tell her father immediately, but this was to ensure he did not tell her sons by accident as they were sitting important exams and she decided not to tell them until they had finished. Andrea felt fortunate as she did not require surgery immediately and the tumour was initially treated with tamoxifen to reduce its size thus allowing her time to keep her diagnosis from her children. However, she said she struggled keeping this from them, as she did not “like them being in the dark”. Helen (FBC72) struggled to keep her diagnosis from her husband but for different reasons. Helen said she wanted to cope with her cancer diagnosis as he had done with his, which she felt was in a responsible and independent manner. While waiting for the test results she felt that this had been wrong and she needed her husband with her:

Well I decided at first that I was going on my own because my husband when he was ill, he's very independent, not initially, when they first diagnosed him with cancer, but he likes to do things on his own, and I felt too this time I was going to do that, I was going to make the decision, I wanted to feel that, you know, I was responsible. But once they had done the biopsy and told me the position and said, you know, go off and have a cup of tea, come back in half an hour, I went and sat and thought well that isn't right, I must, I think I'll phone him and tell him, which I did and of course he came straight up, so that was right.

Helen (FBC72)

Helen had still not told her oldest son that she had had breast cancer at the time of the interview and had asked her daughter-in-law to tell her youngest son for her. She wanted the timing to be right, and reflected on her own experience of being told a loved one had cancer. She said she felt it was more difficult for the carer than for the person with cancer, but had not actually talked to her children about her diagnosis or how they felt. Helen said she did not see the point in telling her family unless there was no hope of survival, then they would need to know:

Have you told your children, grown up now, about what's happened?

I told my daughter-in-law and asked her at the right moment to tell my youngest son, I don't know what their feelings are really.... The oldest son we don't have much contact with, this is something that I shall think about. As I explained I don't really want to feel that it's, I feel when the children should be all told when it's a no go situation, where it's only right and proper, so I mean they've all got families and things going on, so I will think about, you know, have to think about that. I'm sure when the time comes I shall know when it's right.

Helen (FBC72)

Whether these women told their families immediately or delayed, all were aware of the importance of telling them at what they felt was the right time and considered their situations and the effect their diagnosis would have on them. The women did not appear to prioritise their personal needs but instead seemed to consider the feelings of those who are important to them before their own.

5.8.2 Reactions of Family

Most of the women (15/23) said that after the initial shock their family and close friends were all very supportive. Abina (FBC96) found that "family and friends just rally round" and Rashida (FBC98) never knew how much her family were upset or worried because they did not share worries with her. Rashida said her family reassured her she would be all right and did so with confidence so she believed them.

There were two women, Camilla (FBC84) and Catherine (FBC52), who talked of their family's initial shock and distress when they had told them they had been diagnosed with breast cancer. Both women said their families had been hysterical and thought they were going to die very soon. Camilla had been slow to disclose her diagnosis to her family and her daughter was hurt that she did not know sooner and had told her mother off. When Camilla told her sisters they reacted so badly that Camilla had to hang up on them, as she could not cope with their grief:

...And I had two sisters that went absolutely hysterical on me because they thought I was going to drop down dead the next day, you know. And I just had to put the phone down on them because I, you don't need that when you've got something wrong. You need somebody that's a bit sane to talk to you.

Camilla (FBC84)

Catherine's sister had died quickly from breast cancer before Catherine's diagnosis and so she had personal experience of breast cancer and loss. Catherine's family immediately reacted as though she too would die:

And see when I came back, told my husband about this, "it's cancer, I've got breast cancer," oh I just couldn't accept it. And of course then I phoned my mother and my sisters, oh they had me dead you know and I just wanted to run away with everybody and forget about it.

Catherine (FBC52)

While Camilla and Catherine talked of the reactions of their siblings and mothers there were six women who talked of their children's reactions. This included one woman (FBC78) whose children reacted angrily and the others who talked about their sons questioning whether they were going to die. Amelia (FBC78) had recently been diagnosed with a second primary breast cancer in her other breast and although she felt she was coping much better, her children were not coping and were devastated that it had returned (although this tumour was not related to the first). Amelia's son and daughter were "really upset and worried" and "angry, simply because they couldn't believe it and they wanted me terribly to be well." The women who talked about their son's reactions did not say that they found their sons unsupportive, but their initial reaction was to question their mother's mortality. Emma (FBC86) was open about her breast cancer diagnosis, and used the word 'cancer'. Emma did not "like to pretend it doesn't exist" and talked about the shock her children experienced and their sudden realisation that their mother was not immortal. She also reflected that at this time she had to come to terms with her own mortality too:

"Oh God mother's not going to live forever", (laughs). It was the first time the children, grown up though they are, had thought I wasn't going to live forever, it was the first time they'd had to confront my mortality as well as I'd had to confront it, and I think that's difficult. Once I'd spoken to them on the phone and reassured them I wasn't going to die tomorrow because by then I realised I wasn't going to die tomorrow, it was fine.

Emma (FBC86)

Jennifer's (FBC50) son had recently moved out into his own flat, and she was unable to tell him about her diagnosis herself for fear of breaking down so her husband told him about her breast cancer over the phone. She asked him to

come and see her which he did and she told him what was going to happen without crying. She found it very difficult to talk to him:

I couldn't speak to him [her son] because I knew that if I spoke to him on the telephone I'd burst into tears so I said "come and see me," because I knew that if he came to the house I would be able to control myself, that I wouldn't allow myself to cry. So I sat and explained it to him and really the only thing he said to me was "But you're not going to die are you?" (laughs). So that was very difficult you know, I think telling my son was very much the hardest part.

Jennifer (FBC50)

Ada's (FBC74) husband also told their two sons, as she felt unable to do so. Ada's youngest son also asked his father if she was going to die:

My husband told them, because that was at a stage when I wasn't going to, I didn't feel I could sort of tell anybody, so he told them, and one of them, the younger one, wanted to know whether I was going to die apparently and so my husband said, he said no.

Ada (FBC74)

Ada did not talk about her older son's reactions but she does say that he was very supportive and would work from home when he could to allow her husband to go to work and would help her during her chemotherapy. Jane (FBC68) told her twelve year old son herself which left him distraught and fearful that she would die soon:

My son who was 12 at the time just cried and cried and cried, and said "You're going to die aren't you, I know you're going to die," and er I said "No, I'm not, not yet anyway."

Jane (FBC68)

Unfortunately Jane's sister had died from breast cancer before she had been diagnosed which her son would have been aware of. Jane said although she was not offered counselling for herself she knew where to get it, but there was no counselling available for her son. While their children raised these women's mortality, Andrea (FBC80) was the only woman who reflected on her father's reaction. She had delayed seeing her GP after finding a thickening in her breast because her dad had had a stroke and required looking after until he had improved and returned home. Andrea also did not tell her dad immediately in

case he accidentally told her sons who were in the middle of sitting exams, but when she did tell him, she found him to be the hardest to tell:

And probably the most difficult person was my father. I found that, I think partly because he's of the generation that don't talk much about personal issues, and I just think, and he was really shocked. I think you know when you're a parent; you don't expect your children to get life threatening diseases while you're still alive you know. So that was quite difficult. And it actually took him quite a few months before he'd really start talking about it.

Andrea (FBC80)

5.8.3 Disclosure to Extended Family, Friends and Colleagues

As discussed previously, the women's narratives do not always distinguish between when they disclosed to close family (husband and/or children) and extended family and friends. However, the findings suggest that while the men and women discuss the same issues affecting their disclosure (such as having no alternative but to tell, the practicalities of their work and the inability to hide their diagnosis because of their physical appearance), the women's perspective on these areas is different. There were also four women who felt it was important to raise awareness of breast cancer despite some negative reactions that they experienced. For example, Hannah (FBC62) told all her friends to check their breasts and go for screening when they are invited. She continued to do this despite experiencing friends avoiding her in the supermarket. Another woman Margaret (FBC54), was a public figure and decided to "go public" with her diagnosis. She told her story to newspapers and magazines to raise awareness.

Most of the women (20/23) indicated they had no issue with others knowing that they had breast cancer. Fourteen of these women talked in depth about their disclosure to others during their interview.

Similar to the men's narratives, there were some women (6/19) who felt they had no choice but to tell. Lesley (FBC70) lived in a small village and felt that if she did not tell people then rumours would start. By being honest, she said she felt everyone supported her and she took comfort from this:

And there's no point in not telling people. I made sure, because I live in a small village, and before I went into hospital I made sure that key people knew why I was going into hospital, what was being done, so that silly rumours didn't start circulating. And I said you know "Do tell anybody you want to, there's no point in keeping it quiet." And you know, as a consequence of that you get enormous support. Cards, I mean my room is, you know, covered in cards and that is very uplifting to know there are other people out there both with experience of cancer and those without. But it's so common now that, you know, everybody has had somebody who has been affected by cancer.

Lesley (FBC70)

Four women said they told their employers immediately that they had breast cancer. These women said they thought it important to let their employers know so that their time off could be planned. Hannah (FBC62) returned to work after her consultation with the surgeon where she was given a date for her surgery. She immediately told her work colleagues "that I had to go off sick and the reasons why and then I went, got myself ready and went into hospital to have surgery." Jess (FBC60), Andrea (FBC80) and Jennifer (FBC50) told their boss at an earlier stage, before their diagnosis had been confirmed although they decided not to tell their colleagues until there was a definitive result. Jess said her boss was "very supportive" and even phoned her from abroad on holiday to see how she was. Jennifer also said her boss was supportive and helped her decide when and what to tell her colleagues:

Did you tell your colleagues at that time as well?

Er yes I did, when I went for the initial appointment and I phoned my immediate boss and I told her that it was cancer. And she said, "what do you want me to tell everybody?" I said "well tell them I've got a chest infection and to wait until I'd been to the doctors the second time." So I went, I went back the next night er and I phoned [my boss] to confirm it and she said, "well what do you want me to do?" I said, "well just tell them." I said, "there's no point in keeping it a secret because it's going to come out, I can't hide it."

Jennifer (FBC50)

These four women talked about how they told people about their cancer diagnosis. Only one woman said that she did not mind others knowing but felt unable to tell people herself and relied on her husband to do it for her. Ada (FBC74) was worried about how people would react when she told them and did not think she would be able to cope with the expected sympathetic reaction.

Her husband phoned her boss to tell him then when she saw him they decided he would tell the other staff when she was away:

And of course I was supposed to be at work, so I had to do something about telling people at work what had happened, and I decided actually I couldn't do that, I decided that I don't mind people knowing but I didn't want to actually have to tell them, which might seem a bit odd but anyway I couldn't. So anyway, my husband phoned up my boss, who was very nice about it, and the following day I went into work and he, again he was very nice about it and sort of asked me how I wanted to play it. So I said "well wait until I've actually gone away, send everybody an email to tell them, and then that's fine, because I'm quite happy to talk to people about it er once they know about it," but I didn't want to have to tell them. I think I was sort of scared what their reaction would be to be honest. So that was that, so I continued to kind of work normally because there was nothing wrong with me.

Ada (FBC74)

Whether these women told people themselves or not, they all said they felt their colleagues needed to know why they were absent from work and to allow other arrangements to be made. Being open about their diagnosis also allowed the women to carry on with their daily routine without having to hide what was happening to them.

Unlike the men, five women who discussed the effects that their breast cancer and subsequent treatment had on their disclosure did not talk about it negatively. Jennifer (FBC50) who had not hidden her diagnosis said that she did not wear a scarf or wig when she lost her hair during chemotherapy and "took the attitude that it doesn't upset me so why should it upset you." Catherine (FBC52) used a prosthesis to balance out her body and Layla (FBC82) used a wig. When people commented how lovely her hair was looking she never told them it was a wig, she said she and God knew it was a wig but noone else needed to. It was only Jess (FBC60) who talked about her physical body revealing she was sick and yet she described other people's actions and comments in a positive manner and did not talk about it upsetting her. Jess had secondary bone cancer in her lower spine and hip and her mobility had been affected:

Even now I've been limping down the garden with crutches or a zimmer frame and I have got about seven gardens that all back onto mine as you go down, and they've come very tentatively and said "what's happened, have you had an accident?" because I'm normally at work and they haven't seen me so, and so that's wonderful, the people around here have been marvellous. My neighbours put the dustbins out without asking me and they come and do things. If they don't see the car in the drive they come and check on me, see I'm okay, often phone and say, "we're going to so and so, do you want anything?" So they've been kind, so I think it's better, I don't find any difficulty in telling people and I think it's better to be as open as you can about it.

Jess (FBC60)

Jess did not say she found the queries from others an intrusion into her private life that she wished to avoid, rather she said it had a positive impact on her life gaining the support and help from her neighbours and friends. The women who talked about their physical bodies revealing they were ill either talked about it in a positive manner or had aids available to them to hide the side effects of treatment, such as using a wig or prosthesis. None of the women said they changed their daily routines or avoided places because of their appearance.

5.8.4 Non-Disclosure

Throughout the women's narratives, there was only one Marion, (FBC64) who talked explicitly about non-disclosure of her breast cancer. Marion did not tell her son who was autistic. After discussing it with his doctor they both agreed it would be detrimental to his mental health. If her cancer was to become incurable then she said she would tell him, but in the meantime she saw no reason to upset him. There were, however, two women who indicated that they only told close family and friends (FBC82 & FBC92) and a further two (FBC74 & FBC98) who did not mind who knew they had had breast cancer, but by the time of the interview felt it was something they had and did not need to tell people anymore. Ada (FBC74) said she had a positive attitude and "wasn't trying to hide anything" but felt her cancer was behind her although she knew there was a chance it may recur. Rashida's (FBC98) reason for not telling anyone other than close family and friends was that her breast cancer was found and treated within four weeks:

When you told your children and you had breast cancer, did you tell any other people as well?

The whole family knew, but noone else. In four weeks it was all done anyway. In four weeks (laughs), so quickly, noone even knew about it.

Rashida (FBC98)

5.9 Discussion

The data presented highlight the dilemmas that exist for men and women over whether or not to disclose their breast cancer diagnosis. The findings concur with Charmaz's (1991) description of tension between wanting to tell and a desire to protect loved ones from emotional distress. The men and women in this study agreed that their immediate family had a right to know about their illness, concurring with other findings (Gray et al., 2000, Jackson et al., 2010). This does not suggest, however, that the men and women told their families in similar ways or at similar times (see box 2). Furthermore, similar to other studies, the men with partners identified them as their main confidante (Gray et al, 2000; Jackson et al, 2010). Most of the women with partners identified a wider group of confidantes including partners, daughters and close female friends (see also Pistrang and Barker, 1992; Yoo et al, 2010). The discussion will now follow the descriptions of disclosure behaviour outlined by Charmaz (1991), beginning with those who spontaneously disclosed before discussing limited disclosure, strategic announcing, non-disclosure and concealment of the cancer diagnosis.

Similarities Between Men and Women

- Most of the men and women wanted to tell their families and friends about their breast cancer diagnosis.
- Most men and women experienced a shocked reaction from other people when they told them they had breast cancer.

Differences Between Men and Women

- Some men had to challenge people's disbelief that men could develop breast cancer.
- Most men felt it was their duty to educate others that men can, and do, develop breast cancer.
- Some women changed their disclosure strategy over time. Some women became more open about their breast cancer and others stopped telling people to protect themselves from negative reactions or to protect loved ones.
- Some men said they felt they looked like a "cancer victim" and could not disguise the effects the cancer and its treatment had on their appearance.
- Some women said they used prostheses and wigs to hide the effects of their cancer and its treatment.

Box 2. Summary of Similarities and Differences in Disclosure of Men and Women

Charmaz (1991) cites Schneider and Conrad's (1983) description of spontaneous disclosure as the "full expression of raw feelings, open exposure of self, and minimal or no control over how, when, where, what, and to whom to tell" (p 119). Spontaneous disclosure is the most expressive form of disclosure. In this study, there were four women whose disclosure was interpreted as spontaneous. They were in need of emotional support at a time of crisis and openly disclosed their diagnosis to receive support. However, this approach was not unproblematic for these women. The emotional distress to the families of these women was considerable. One woman described the anger her children felt towards her diagnosis, another woman's family was hysterical and another talked about friends who distanced themselves from her. Only one woman appeared to benefit from spontaneous disclosure. Her family lived abroad and her open disclosure led to her receiving support from friends and work colleagues. Some women replaced spontaneous disclosure with non-disclosure when they realised it was causing them harm having to deal with the loss of friendships and emotional distress it caused to close family.

Spontaneous disclosure was not confined to the women. Five men's disclosure was interpreted as spontaneous, thus challenging the traditional male characteristic of stoicism (Seem and Clark, 2006). These men's disclosure appeared to be driven by a lack of knowledge and not finding meaning in their diagnosis. Three of these men continued to spontaneously disclose, unlike the women who said they found it emotionally draining. In particular, Andy (MBC73) said he did not feel frightened telling people about his breast cancer diagnosis and said he had no reason to keep it quiet. He said it was important to educate other men. One man however did change his spontaneous disclosure. After telling everyone about his diagnosis, he concealed feelings of anxiety and distress to protect his family and instil confidence in fellow patients at the hospital clinic.

The majority of men and women who were interpreted as spontaneous disclosers did not gain the support or affirmation that they were seeking. Instead it produced negative emotional encounters and in one man and woman led them to conceal their true emotions to protect loved ones. Spontaneous disclosure was a hazardous and emotionally exhausting method to use.

Approximately half the men and women in this study used what Charmaz (1991) termed 'protective or self-limiting disclosure'. This type of disclosure protects the individual from emotional distress and maintains control of the information shared. Using self-limiting disclosure, the men in this study were able to construct a masculine identity that protected loved ones, distanced themselves from their emotions and preserved their status within the family. One strategy that enabled this was to convey a positive attitude while disclosing. Telling others their cancer had been caught at an early stage or relaying the positive messages received from medical staff were examples of this. Another strategy was using wives to tell others about their diagnosis. This distanced the men from the emotional distress experienced by others, which concurs with other findings (Gray et al, 2000; Yoo et al, 2010). Two men to disclose their diagnosis to others used humour. This enabled them to diffuse potentially embarrassing encounters for themselves and others. Chapple and Ziebland (2004) suggest that making jokes about themselves conveys to other men that it is acceptable to joke about their illness and reduces the stigma surrounding their illness. It enables men to talk about their illness in ways that do not exclude them from their social network, similar to findings by Hilton et al (2009).

Self-limiting disclosure however did not eliminate all negative encounters or feelings of embarrassment and loneliness for either men or women. Men sharing their breast cancer diagnosis sometimes led to shock and disbelief from the people they told and having their masculinity questioned for having a 'female' disease. Some of the men reported feeling embarrassed sharing their diagnosis with men and one man stopped disclosing when his initial treatment was complete, similar to findings by France et al (2000). The men reported receiving different reactions from men and women. After the initial shock, women would often ask questions and appeared interested and sympathetic. Men however, usually said nothing more about it leaving the participants feeling angry, isolated and lonely. Furthermore, some men felt compelled to use their mastectomy scars to validate their diagnosis and confirm that men can, and do, develop breast cancer. In some cases, this was not enough to stop exchanges where their masculine identity was explicitly challenged. Associations between men with breast cancer and homosexuality were present in some narratives. These men were stigmatised and marginalised as men because of their diagnosis (Goffman, 1963, Connell, 1995).

The women in this study said they wanted to protect their loved ones from emotional distress and drew on traditional feminine characteristics such as caring and nurturing for their families (Pistrang and Barker, 1992). While dealing with the emotional well-being of their families, women used similar strategies to the men to control disclosure. Some women relied on their husbands to tell their children and work colleagues to protect them from the emotional distress that would follow. For example, one woman feared people's reactions to her diagnosis, but felt able to cope seeing them once she knew that they had been told she had breast cancer. Another strategy was not to tell anyone until initial treatment was complete, usually to protect frail parents. Delaying disclosure enabled women the opportunity to convey that treatment had gone well and there was nothing for others to worry about. Another strategy used by some women was to limit disclosure to their initial diagnosis and treatment plan, and not disclose any further information. These women reported wanting to protect loved ones from the unavoidable side effects of treatments, similar to findings reported elsewhere (Gray et al., 2000, Jackson et al., 2010). Once initial treatment was complete for some women, they felt there was no benefit to themselves or to others to keep talking about it.

Some men and women however appeared to develop their disclosure rather than stop talking about it. Charmaz (1991) uses the term 'strategic announcing' to describe self-limiting disclosure. I propose that strategic announcing is a development of self-limiting disclosure that enables the individual to present their diagnosis in an informative and educational way that removes any perceived stigma and facilitates the discussion of their illness in a neutral manner. Raising awareness and offering support has been found in other studies of men and women (Jackson et al, 2010; Yoo et al, 2010). The men talked about breast cancer with men in the pub or at work, and the women told friends and told their stories in the newspapers.

In this study, there were no participants who did not tell anyone about their diagnosis, which is not surprising given the sample recruited. There were only two women who delayed disclosing their diagnosis, until circumstances changed and they felt it was appropriate to tell others. Other studies have found greater numbers of people with cancer prefer to not disclose their illness (Harrison et al, 1995; Henderson et al, 2002). The aim of producing an open website 'module'

may have affected the likelihood of recruiting people who wished to stay anonymous and may have been discouraged from participating in this study.

There were, however, detailed narratives from the men regarding the expression of illness through the body that exposed their diagnosis. Boehmer and Clark(2001) found similar results with men with prostate cancer who struggled to come to terms with the physical changes caused by treatment. In this study, the shape of their body, the missing hair and the steroid-induced bloating to their face was described by one man as looking like he had cancer. This was similarly defined by women in Hilton et al's (2009) study as looking like a "cancer victim". The men felt this drew unwanted attention to them and they *had* to tell people they had cancer. One man changed his habits to avoid people he knew, wore a hat and scarf and drove instead of walking he was so concerned his appearance would give him away. They perceived cancer as stigmatising and did not want to be labelled as a 'victim'. Wray et al (2007) illustrated the invasion in privacy that can occur to people with visible stigmas when a woman in a wheelchair was subjected to intrusive questioning why she was in a wheelchair at her daughter's wedding. In this study, one man who was undergoing chemotherapy reflected on the stigmatising behaviour his nephew displayed when he would not even look at him at a funeral. In contrast to the men's accounts, the women talked about the different ways they concealed the physical effects treatment had on their bodies. They had wigs and prostheses to hide the hair loss and give their bodies symmetry under their clothes. This, according to Goffman (1963) hides stigma, so allowing them to fully participate in society without fear of being ostracised. The men in this study did not discuss using prostheses or wigs to conceal their illness and some men felt compelled to remove themselves from their normal lives to protect themselves from the stigmatising effects of their illness.

Men and women with breast cancer were faced with similar dilemmas whether they should share their diagnosis or not. The men however, were faced with additional reactions of disbelief and challenges to their masculine identity. Despite this, most of the men said they continued to disclose their breast cancer diagnosis to raise awareness and educate other men that they are also at risk. Although the men said they felt supported by their wives, one possible explanation for their 'evangelising' may be that they had not received enough

support or information from other sources. This will now be explored within the next chapter.

6 Experiences of and Needs during Active Treatment

6.1 Introduction

This chapter explores the experiences which men and women with breast cancer had during the diagnostic and active treatment phase of their illness. This includes the healthcare environment, treatment decision-making, information and support needs. There are studies that have compared the needs of men and women and this literature will be presented first before focusing on the gender-specific needs of men and women. The findings will then be presented and discussed.

6.2 Are There Gender Differences in Healthcare Experiences?

This section will focus on comparisons between men and women's needs during their experiences of healthcare. There are few qualitative studies available comparing men's and women's experiences of the healthcare environment. In contrast there are a large number of studies comparing the information and support needs of men and women with a cancer diagnosis. Information and support can help individuals manage their disease, improve compliance to treatment and increases their healthcare satisfaction (Gaston and Mitchell, 2005, Van Der Molen, 2000). The gender comparison literature will now be presented.

6.2.1 Experiences of the Healthcare Environment

Patient satisfaction surveys were the preferred method to collate information on hospital service provision until recent evidence found they did not capture the complex feelings patients had towards their healthcare provision (Staniszewska and Henderson, 2005, Collins and O'Cathain, 2003). An example of this is highlighted in the study undertaken by Rogers et al (2000). They carried out a post-bereavement survey on a random sample of people who registered cancer deaths in an inner London health authority to examine the causes of dissatisfaction with hospital-based care in the last year of the life. Of the 229 people who responded to the study, 138 included written comments about the

care received in hospital. Eighty two (59%) made a negative comment about hospital care. Of these, 48 respondents made at least one negative comment about the healthcare team. Negative comments related to the respondents feeling their relative's wishes were disregarded by the hospital staff and perceptions of their loved ones being devalued by poor service provision and inadequate communication with hospital staff.

A recent qualitative synthesis (Bridges et al., 2010) found that older people and their relatives valued reciprocal relationships with hospital staff which enhanced the patient's sense of significance, maintained their personal identity while in hospital and included them in the treatment decision-making process. Arman et al (2004) suggest healthcare professionals are required to have an understanding of the 'whole patient' to ensure their physical, psychological and spiritual needs are met during their illness experiences. Their study interviewed sixteen Swedish women with breast cancer to explore patient experiences of suffering related to healthcare from ethical, existential and ontological standpoints. They found that most of their participants reported their healthcare experiences increased their suffering. Patients who perceived their healthcare to focus on their physical needs struggled to maintain their dignity and sense of 'wholeness' as an individual. However, they also found their participants had not complained about the care they received. Another Swedish study (Jakobsson et al., 1997), interviewed eleven men with prostate cancer, exploring their met and unmet needs from healthcare professionals. They found the men's reported unmet needs were largely related to existential and emotional issues rather than physical needs. They suggest this may be due to their physical needs already being met by the hospital staff but that the finding raises the importance of caring beyond the physical body to include psychological and spiritual dimensions, which in this study were found to be lacking.

One area of healthcare that is pertinent to the current study is the use of mixed-sex wards in hospitals, a practice that has received political attention and various pledges to abolish the it in the UK over recent years (Doult, 2009, Department of Health, 1991). One small study explored the meaning of dignity and factors that compromised and promoted patients' dignity on mixed-sex wards in one hospital (Baillie, 2008). Twelve patients were interviewed following discharge from hospital and a further twelve were observed over a four hour

period in hospital. Following the observation, thirteen ward nurses involved in the care of the patients were interviewed. Baillie (2008) found that both patients and staff regularly cited mixed-sex wards as a factor that impinged upon the dignity of patients. Inadvertently exposing parts of their body, embarrassment and lack of privacy were key issues that undermined the dignity of patients. Similar findings were reported by Bryant and Adams (2009).

6.2.2 Information Needs

The provision of information for men and women diagnosed with cancer is to ensure treatment consent is truly informed and that the individual has the knowledge to participate in decisions surrounding treatment in a meaningful way (Gaston and Mitchell, 2005). The healthcare team are the main providers of information to patients about their illness (Husain et al., 2008), but other sources of information may be other patients, family and friends, support groups and the internet (Clarke et al., 2006, Seale et al., 2006).

To meet the information requirements of men and women, it is necessary to understand if there are differences between men's and women's information needs. Boudioni et al (2001) analysed data collated on men and women's information requests from a cancer charity. Their aim was to examine men's health behaviour in relation to information and support seeking patterns. Data on information requests from 5,874 men and women between April 1996 and March 1998 were analysed. Women sought more information than men during this time to a ratio of 3:1. Boudioni et al (2001) found that men with different types of cancer requested different types of information. Men with colorectal cancer were more likely to want information regarding clinical trials and diet compared to men with prostate cancer. Employed men with colorectal cancer were also more likely to request emotional support and less likely to ask for cancer-specific information than other men and women with cancer. Although none of these findings were statistically significant, gender differences were found in respect of information seeking.

Another source of information is the internet. Information is readily available and health websites are among the most commonly used resources (Eaton, 2002). Ziebland et al (2004) used secondary analysis of existing qualitative interviews carried out with men and women who had been diagnosed with

prostate, testicular, breast¹, cervical or bowel cancer to explore their use of the internet. One hundred and seventy five interviews with men and women aged between 19 and 83 years who had been diagnosed since 1992 were identified (before 1992 use of the internet was relatively uncommon). They found the internet offered individuals flexibility in accessing information at any time of day and at any point in their illness. It removed any feelings of embarrassment and facilitated privacy when searching for sensitive information. Ziebland et al (2004) found that women with breast cancer were among the highest users of the internet and they concluded this was probably due to the amount of information and online support networks available for women with breast cancer. They also found that in general, older patients (particularly those with prostate and bowel cancer) were least likely to use the internet for information. Not all participants however used the internet. Some were unsure of the quality of information available and were fearful of being misled. These participants said they trusted their doctors and nurses to give them all the information they required.

6.2.3 Availability and Use of Social Support

Support from family is considered particularly important when dealing with a cancer diagnosis (Baider et al., 2003). Using secondary analysis of interviews with 17 men and 16 women who were married or cohabiting and diagnosed with colorectal cancer, Emslie et al (2009) found that most participants spoke positively about the support they received from their partners. Support was mutual and a two-way process between the patient and their partner. However men and women highlighted different aspects of the emotional support they received. The men suggested that their partners were dependable and towers of strength. The women said their partners expressed optimism and cheerfulness. This positive attitude prevented some women freely expressing their fear and worries. Emslie et al (2009) suggest that both types of emotional support maintain normality and promote control when dealing with serious illness. Controlled expression of negative emotions is often used to protect loved ones, although elsewhere it has been associated with poor adjustment to a cancer diagnosis (Porter et al., 2005).

¹The breast cancer data used in Ziebland et al (2004) and Seale et al (2006) is the same data used for secondary analysis in this thesis.

Within the healthcare setting, support is often offered from the multidisciplinary team. Clarke et al's (2006) qualitative study interviewed 11 melanoma patients (six men and five women) and five women with breast cancer. Their aim was to explore how patients perceived the support they had been offered. They found the women were more likely to accept offers of emotional support and used a number of different sources for support, such as family, friends and healthcare staff. The men however, were less likely to look for emotional support and said this type of support was not as important as receiving information. Most of the men interviewed said they did not need emotional support and did not require support from healthcare staff. However this study only examined the support offered by healthcare staff and it is unclear whether the men felt they did not need support from anyone, including partners and family or whether their responses were solely regarding support offered by the hospital.

Online support groups are another source of support to men and women. Seale et al (2006) compared men and women's use of online cancer support groups. They used secondary analysis of ninety seven people with cancer (forty five women with breast cancer² and fifty two men with prostate cancer) and analysed current and archived postings from two of the most popular breast and prostate cancer websites. They found that men were more likely to use the internet to gather information while the women were more likely to be looking for social support. The analysis of the online support forums found that the men were looking for information about their treatment, procedures and medical personnel. In contrast, the women wanted emotional support as well as information and discussed concerns about a wider range of issues including concern for others. Similar findings were reported by Dubois and Loiselle (2009).

6.3 Men's Experiences during Active Cancer Treatment

6.3.1 Treatment Decision-Making

Studies specific to men's decision-making have focused on men with prostate cancer and as previously discussed, the treatment decision-making process for men with prostate cancer is complex. In one focus group study with fourteen men at different stages of treatment for prostate cancer, one theme that

²The breast cancer data used in Ziebland et al (2004) and Seale et al (2006) is the same as the data in this thesis

emerged was the confusion about treatment options and the struggle to decide what treatment was appropriate to them (Harden et al., 2002). Henrikson et al (2009) found similar results when undertaking secondary analysis of 31 interviews and five focus groups with men with localised prostate cancer. They also found that decision-timing was important to the men in this study. Delaying decisions allowed some men to gather more information and maintain some control over their disease. In contrast, there were other men who wanted to make a decision quickly to 'get it over with' and be decisive.

6.3.2 Information Needs

A qualitative study by McCaughan and McKenna (2007) explored the information-seeking behaviour of 13 men newly diagnosed with cancer, five healthcare professionals and four lay sources who regularly came into contact with men and women diagnosed with cancer. They found that some men did not ask for the information they required. They described feeling 'out of place' and 'uneasy' within the hospital setting. Furthermore, few men reported actively seeking out information from other sources such as cancer support services or charities. However the men said their wives sourced information for them. McCaughan and McKenna (2007) suggest men with cancer are under the 'gaze' of health professionals, family, friends and colleagues while undergoing treatment for cancer and their natural reaction is to construct a traditional masculine identity with stoical and controlled characteristics as a coping strategy

6.3.3 Availability and Use of Support

Men with prostate cancer receive the majority of their support from partners (Clarke et al., 2006, Bottorff et al., 2008). Wives influence their husbands' experiences of prostate cancer and it has been described as a 'couple's illness' (Bottorff et al., 2008 p1217). One small study however reported findings that suggest this is not always the case. Navon and Morag (2003) interviewed 15 Israeli men receiving hormonal treatment. Their average age was 70 years and all were married or living with a woman. They found that while seven participants described their relationships as supportive and loving, eight men described deterioration in their marital relationship, and reported feelings of isolation and emasculation. These feelings were heightened by the feminisation of their bodies as a side effect to their treatment that led to self-loathing and disgust.

Another source of support is formal support groups, although it has been suggested that few men attend support groups (Gray et al., 2000). Gray et al (2000) undertook qualitative interviews with men pre and post prostate cancer surgery and found that the few men that did go rejected the notion it was for support, but said it was to gain information about their illness. Support groups are also found online. Broom (2005) interviewed 33 men with prostate cancer about their use of online support groups. He found that those who did use online forums said the anonymity enabled them to ask embarrassing questions they could not ask anyone in person, reduced inhibitions and gave them a resource where they could openly share experiences. Some men said they did not share on the forums but 'lurked'. These men felt too embarrassed to ask questions themselves but the forums enabled them to read other men's questions and answers. However some men refused to use an online support group and were suspicious about those who did. They rejected the notion of 'hiding' behind the anonymity of the internet and were suspicious of the sources of information and worried about being misinformed. They viewed internet forums as a potential source for infidelity and being deceived because they would not know who they were 'talking' to. For these men, the internet was highly problematic and they would only ask trusted sources (such as healthcare professionals) for information.

6.4 Women's Experiences during Active Breast Cancer Treatment

6.4.1 Treatment Decision-Making

In recent years women with breast cancer have become increasingly involved in the clinical decision-making process (Fallowfield, 1997). It has been suggested that a greater involvement in decisions about treatment will lead to better psychological outcomes for the patient and reduce anxiety and distress following treatment (Deadman et al., 2001). In general, being actively involved in the treatment decision-making process is favoured by most women with breast cancer (Sabo et al., 2007, Keating et al., 2002). Treatment choice however, is not always possible depending on the biological type of tumour and where the tumour is located in the breast (Deadman et al., 2001). Furthermore, some women do not want to have a choice in their cancer treatment (Fallowfield, 1997). In Norway, where patient treatment choice is mandated in law, one study found approximately one quarter of their participants (n=194) did not want any

involvement in their treatment choice (Schou et al., 2002). One possible explanation given for women not wanting to participate in the decision-making was that some women may find it hard to accept there is no difference in outcome between breast sparing or breast removal surgery and are fearful of choosing the wrong option (Schou et al., 2002).

There is some evidence that suggests younger women, women who spent longer in education and women with higher annual incomes are more likely to want to participate in the treatment decision-making process (Sabo et al., 2007). This has not been found in other studies however (Schou et al., 2002, Bleicher et al., 2007). In addition, all the studies discussed have sampled from women with early stage breast cancer. The decision-making process of women diagnosed with advanced or terminal breast cancer has received little attention. Fallowfield (2008) suggests that it is more important to match the patient's preferred role in treatment decision-making (be it either an active or passive role) with the actual level of participation. This will result in improved psychological outcomes for patients.

6.4.2 Information Needs

A comprehensive literature review carried out by Rees and Bath (2000) examined the information needs and preferences of women with breast cancer. They found that women's information needs changed over the course of their illness. At diagnosis the information required centred on the disease, treatment options and chances of a cure. When treatment was commenced, information needs shifted to treatment, side effects and chances of recurrence. Once patients completed active treatment, they looked for information on recurrence but also wanted information on risk to other members of their family and improving their lifestyles. This literature review helps our understanding of women's information needs, but does not explore men's information needs.

6.4.3 Availability and Use of Support

Women with breast cancer regularly identify their families and friends as their main sources of support (Van Der Molen, 2000, Landmark et al., 2002, Browall et al., 2006, Thewes et al., 2004). Crooks' (2001) qualitative study interviewing 20 women aged over 60 years found that different people offered different support. For example, daughters provided psychosocial support whereas husbands offered

more practical help such as accompanying the women to hospital appointments. These women also felt supported by other women with breast cancer and disregarded unsupportive friendships. Similar findings were reported by Landmark et al (2002). Their small study interviewing 10 Norwegian women found social support included emotional and practical aspects, sharing information and advice. Positive interactions reinforced the support the women felt they had and encouraged them throughout their treatment. However, the women also experienced negative encounters where some people withdrew from them resulting in feelings of isolation, confusion and depression.

Formal support groups are another source of support to women with breast cancer. A small qualitative study (n=8) by Power and Hegarty (2010) used focus groups to explore women's experiences of attending a six week facilitated face to face support programme. They found that women wanted to attend the support group to meet other women with breast cancer and to share experiences after feeling isolated when treatment had completed. The support group enabled the women to consolidate the information they already had with new information shared within the group, and they reported feelings of hope after meeting a 'cancer survivor'. Support groups however are not always appealing to women. Emslie et al (2007b) undertook seven focus groups with thirty six women diagnosed with breast cancer. The women had participated in a randomised controlled trial (n=203) exploring the effect of participating in an exercise programme twice weekly for twelve weeks during their treatment. All the participants had been allocated to the exercise programme and had an average age of 53 years. Emslie et al (2007b) found that the women valued exercising with other women with breast cancer and the expert instruction they received. Similar to those in Power and Hegarty's (2010) study, these women reported feeling isolated before participating in the exercise programme. This was resolved when friendships developed and experiences were shared during the programme. These women however, said they did not want to attend a formal support group and denied that the exercise programme was similar to a support group. The women in Emslie et al's (2007b) study perceived traditional support groups negatively and thought a formal support group would involve sitting around, participating in deep and meaningful discussions. These women constructed their identities in opposition to this, as getting on with their lives, being active and not dwelling on their illness.

6.5 Experiences of Treatment, Information and Support in Men with Breast Cancer

The existing studies of men with breast cancer say little about their experiences during the active phase of treatment (Naymark, 2006, Pituskin et al., 2007, Iredale et al., 2006, Williams et al., 2003, France et al., 2000, Donovan and Flynn, 2007). Donovan and Flynn's (2007) was the only study to report findings on the men's interaction with healthcare services. Their sample was comprised of five men from the UK and ten men from overseas. The men they interviewed reported occasions when they were asked to sit in different clinic areas to women and use different entrances and exits. This led to feelings of marginalisation and perpetuation of the perceived stigma attached to men with breast cancer.

All of the studies however, highlighted the lack of male-specific information available to men with breast cancer (Naymark, 2006, Pituskin et al., 2007, Iredale et al., 2006, Williams et al., 2003, Donovan and Flynn, 2007, France et al., 2000). The participants said they did not receive enough information regarding their disease and its treatment (Pituskin et al., 2007, Naymark, 2006) and some felt the information they did receive was not relevant (Donovan and Flynn, 2007).

The main source of support for men with breast cancer was reported to be from their wives (Pituskin et al., 2007, Williams et al., 2003, France et al., 2000). Support was sometimes offered by breast care nurses, however few had ever supported a man with breast cancer before (France et al., 2000). The married men in Pituskin et al's study (2007) said they did not want to attend a support group, but Williams et al (2003) found that the men in their study reported a desire to meet other men with breast cancer to share experiences and information. Similar findings were reported by Iredale et al (2006). The men they interviewed reported a lack of interest in talking to men with other forms of cancer or to women who had breast cancer.

6.6 Experiences of and Needs of Men with Breast cancer

6.6.1 Experiences of Healthcare

Despite some (10/19) of the men reporting embarrassing or negative interactions with the healthcare providers most (13/19) described their overall experience of the health service positively. When questioned about their treatment, most of the men immediately talked about how good their care had been. Regardless of whether the men thought they had received excellent care or not, they were not prohibited from talking about issues within their treatment that they were either dissatisfied with or from reflecting on embarrassing and insensitive interactions with others.

Six men explicitly said they thought the NHS was an amazing institution that provided treatment and care of the highest standard. For example, William (MBC83) thought his treatment was “superb” and Jack (MBC59) felt he had been “extremely lucky” and “been to the best cancer hospital in England.”

Some men (6/19) compared the care and treatment they received with what they perceived women would get, of whom some (4/6) downplayed the care they required and said breast cancer for women was a more significant disease. For example, Bob (MBC89) suggested that he thought the service he received was a “little bit better” than what a woman would get. He thought that this might be because he was a “lone soldier” amidst the women. He said he regularly attended the hospital for other health issues and would pop in to see the staff in the chemotherapy ward for a coffee. He said they all knew who he was as he was the only man they had seen with breast cancer at the unit and he appeared to revel in the celebrity status he felt he had there.

Bob’s account contrasts with that of Patrick’s (MBC81) who felt his treatment was probably inferior to what a woman with breast cancer could expect. He reflected that maybe it was his fault for not asking the right questions, but that the time the physiotherapist spent with him following his surgery was too short:

I had this young lad came to me, and it was a very brief sort of visit. And he just said 'oh do this' and he gave me a sheet and- I just sort of feel that, you know that that side of things, were for me, didn't seem to be properly gone into. You know I just feel as though I could have done with a little bit more support there. You know just somebody, give me a little bit more time. I know people are rushed and all the rest of it. And it as I say, it's probably my fault for not asking the right questions you know.

Do you think that was because you were a man with breast cancer, or do you just think it was the way the system is and they're busy?

Well it was possibly that. But I think there is an element of it being a man with breast cancer's a bit different than a woman, you know. I just sort of feel that women, because of the nature of the thing, get looked after slightly differently, than men do.

Slightly better?

Possibly, yes. But then you see, I mean I- didn't avail myself of the things, because- and maybe if I had I'd have felt oh...(laughs). So I can't really complain, it's probably my fault. (Laughs.)

Patrick (MBC81)

Another two men talked about being told by their healthcare team that they had to be treated as though they were women because they did not know any other way. For example, Tam (MBC77) said he thought the care he received was very good despite being told that they did not know how to treat him as a man with breast cancer. He said at his diagnosis the doctor had told him "they didn't know what to treat me at the time, so they treat me like a woman." He said the staff told him how shocked they were throughout his treatment:

I think they was more shocked...I think because I was a man, I think they was more shocked than anything, even the nurses when we were getting chemo [said] "we've heard about it but we've never had one here."

Tam (MBC77)

Jonathan (MBC75) also said his doctor told him he could "only treat you as I treat a woman" and accepted this because he knew there was little evidence for treating men with breast cancer.

Another comparison discussed by one man Henry (MBC93), was that he felt women should get better treatment than men since the prevalence of breast

cancer in women is much higher. He reflected that there were forty five thousand women and only two hundred men a year³ diagnosed with breast cancer. He did not think that meant he had inferior treatment to women but said the impact of his breast cancer was less for him than it would be for a woman:

Do you think men and women are treated differently?

(pause) Sigh. I mean I suppose, at the bottom yes because we are different. But if you mean do men get pushed on one side, not in the experience I've had. Anything that's happened with me I've felt I've been looked after just as well as anybody else.

Henry (MBC93)

6.6.2 The Healthcare Environment

One prominent theme to emerge from the data were the difference in the men's experiences of attending hospital in comparison to the women's, particularly the breast clinic and being an in-patient in the breast unit. Eight men described scenarios that occurred in hospital. These men discussed being scrutinised by the other women in the waiting areas, and insensitive and embarrassing interactions with healthcare staff.

Six men recalled events, which drew attention to their status as male breast cancer patients within the clinic setting. Bob's (MBC89) narrative is a typical example of the insensitivities he experienced from healthcare staff. He recalled when he attended the clinic he was the only man surrounded by two hundred women and it was his wife that was getting called in to see the doctor instead of him. Similarly, Mani's (MBC76) narrative included several different accounts of occasions when staff made errors calling him in or mistook his wife as the patient. Mani's wife usually waited for him outside the clinic and was regularly encouraged to move in to the clinic assuming she was the patient, and he recalled how the staff regularly called "Mrs" at him:

³Henry slightly underestimated the number of new cases of breast cancer in men per annum in the UK. Figures show approximately 300 men are diagnosed each year in the UK (Cancer Research UK 2010).

I've got one other problem at hospital. They keep calling me Mrs - when they call Mrs [surname] I say, "Not Mrs, Mr [surname]," you see? Everybody, they think that it will be a she. I said, "No, it's a he."... They're all about Mrs. Yeah, all about the ladies, so I can't blame them.

Mani (MBC76)

Mani was not a man that wanted to complain about his treatment. He felt the clinic was focused on women, which he felt was correct and he did not want to make a fuss about the insensitive treatment that he received. He said when he went to the clinic staff would comment that "the smiling man is coming." Despite never intending to put on a "brave face" he realised it made them happy to see him smiling while inside he wanted to cry:

Yes - I kept on smiling. I always, yeah, I kept on smiling. I never said I had a brave face there, yes.

Did you feel that helped you?

Yes, it did help me and it did help them as well, that I was facing people looking after me. They saw me smiling all the time.

Did you ever just want to scream and shout that you weren't smiling inside?

Yes... No - sometimes I wanted to cry, but it wouldn't help.

Why not?

I don't think the environment, the surrounding of, yes, you have to look after everybody there - so you keep on smiling, people will say, well [inaudible] even in the hospital, when I was there, I was chatting with everybody. I was talking with everybody, so somebody, people sometimes, there were ... we're in the same boat.

Mani (MBC76)

Tam's (MBC77) narrative around the clinic setting did not focus on the actions of the healthcare staff but on the reactions from the women he was sitting next to. He said he felt embarrassed sitting as the only man surrounded by women. He thought they wondered why he was there and when his name was called out "fucking hell! They wondered why I was coming." Tam thought it was because not many women would have seen a man with breast cancer and he had to endure the same experience every time he went for a check up. Eric (MBC71), another example, did not find the clinic experience as embarrassing since some husbands would be present with their wives but he found having his biopsy (an

out-patient procedure) very embarrassing, sitting in a dressing gown with women wondering why he was there:

That [having the biopsy] were very embarrassing. Well you can imagine that you're sat there in a dressing gown, in the waiting room, full of women and they're all looking at you and thinking, what's he doing here? (Laughs.) So that, that, you know, I mean that's one drawback I've got when you go for the thing, you're sat with women. I've... Obviously when you go for check-ups, there's husbands with them and what not, so they don't know really. But when they call you they know that it's you. But that's a little bit embarrassing, but apart from that, you know, I've had some comments as well, some weirdo comments.

Eric (MBC71)

One man's experience of attending clinic was particularly difficult because the new unit that he attended had breast care and gynaecology in one building and was promoted as a centre for women. To overcome the embarrassment that he felt, Nick (MBC55) decided to pretend he was a doctor and was then legitimately entering when he had an appointment there. By doing so he did not feel out of place:

They had a new place, a new suite for female - I think I was the first one, at least one of the first people in it, and that was a little bit of a problem, going into a gynaecological unit, walking in there to get my seroma syringed, but I just pretended I was a doctor walking in and it didn't bother me at all.

Nick (MBC55)

Nick also felt uncomfortable with a doctor telling him he was "special" as a man with breast cancer. This was not a label that he wanted and could not understand why someone as healthy as himself would have got cancer, particularly a rare type of cancer for men:

I've been told I've been special by a doctor - but I don't want to be special in that particular type of way.

Nick (MBC55)

The only time most of the men were segregated from female breast cancer patients was when they were in-patients, undergoing surgery. Most of the men reported being on all male surgical wards, although a few men were in side rooms within the breast unit. This did not appear to cause problems for most, but Angus (MBC86) and Adam (MBC79) talked of their experiences in the ward.

Adam said he felt discriminated against because the women all received a nice bag to carry their surgical drains around in immediately post-op whereas he was given a carrier bag. He said this made him feel different. His wife brought him in a bum bag, which held the drains well and was a much better solution for him. Angus was the only man in the ward and as a smoker went to the ward's designated area where the women openly challenged him as to why he was there. He had to show them his drains to prove that he had had surgery:

So they put you in the breast cancer ward?

Me and women. I was the only man, and the women like that, I went for a smoke, like, ken? They were all in the smoking room, that's where you were allowed away to smoke. They were like that, "what are you daein' here?" I said "the same as you." I'd to carry my bag, same as them, ken what I mean? This bag, two tubes in it.

Angus (MBC86)

6.6.3 Choice of Treatment

A relatively recent development within healthcare practice is the role the patient now plays in choices about their treatment. However, the findings suggest that most of the men with breast cancer were not given a choice in their treatment and there was a scarcity of information (in any form) for them to access.

Two men (William, MBC83 and Tam, MBC77) said they felt included in the decision-making process and were given a choice in their treatment. Tam said the doctors told him everything that was going to happen and would ask him for his thoughts beforehand which he appreciated. However, William found the decision-making process overwhelming and did not like making the final decision. He felt the doctor, as the specialist and extensive knowledge should make the decision:

Were you given any choice in what treatment you had?

Well, the way they do things nowadays, in the health service, you know? They don't tell you. They suggest, you know? And you've got to make the decision, you know, which I find a bit strange - but that's the way things are done nowadays, you know? They said, "well you know we recommend that you have radiotherapy, but you know, do you want it?" In fact, the chap, it was quite a young oncologist - he said, "if you take no treatment at all, you have a sixty four percent chance of living for ten years," you know? "But if you have radiotherapy, then that's increased greatly, you know?" So he told me that. But you know, I had to make the choice, you know? Yes or no, in other words.

Yeah - and how did you feel about that?

I felt as if he should be telling me, not just asking me, he should be telling me, you know? That's just the way it is now, and I find that a wee bit of getting used to. That and the other, the way that they tell you, give you so much information now. That can be quite overwhelming, like when I went for my consultation to the [hospital], you know, they were hitting me with all sorts of information you know and trying to take it all in - that's why they say that you should take someone with you, so that if you don't pick it up, they will, you know?

William (MBC83)

In contrast, most of the men (14/19) said they were given no choice in what surgery or adjuvant therapies they should have. For example, George (MBC52) and Tony (MBC70) said they were told what they were getting and because they did not know anything about treatment they just accepted it. Michael (MBC85) said he "was just told what they were going to do" and Angus (MBC86) said he was raised to accept whatever the doctor said and to never question their expertise. Most of these men did not suggest this caused them any concerns. Nick (MBC55) said his treatment was "routine" and Clive (MBC67) reflected there was nothing else the clinician's could have done.

Mani (MBC76) said he felt coerced into treatment he did not want. He did not want chemotherapy but was told that if he did not have it then he would not get herceptin, at that time a new and expensive drug that was only given to people who had had chemotherapy. He said he felt pressurised into having the chemotherapy which made him very sick but felt he had no choice if he wanted Herceptin which could improve his chance of survival:

What did you think at the time?

I was just thinking I shouldn't have chemo, yes

Did you feel pressured?

A little pressured, but I think they did the best thing for me.

Mani (MBC76)

In contrast to Mani, Andy (MBC73) said he was not offered any treatment choice or the chance of new therapies that were being trialled at his local hospital. When he was having his chemotherapy he would be sitting in a room with women having their treatment discussing what trials they were on and their different treatment regimes. He said he was not given any choice, and when he asked about taking part in clinical trials he was told he could not because he was a man and he did not meet the study criteria:

I'm sat in the chemotherapy room, going back to the chemo days now, but we're in a room where there were maybe, you know, eight to twelve people and obviously all women cos they were all breast treatment on the same day, and you listen to them talking. "Oh, what kind of trial are you on?" "Oh, I'm on this trial" and "oh, I'm on this trial." "Oh, I'm not having radiotherapy, I'm just trying this chemo." "I ain't had an operation." I'm going "hold on a minute, what's going on here?" I were just told that I would be having a full operation, full mastectomy, I would be on chemotherapy and I would be on radiation treatment. There were no mentions of trials or what you want for this and what you want for that. I said, "what's all these trials?" "Oh, well, we were given the choice". I thought oh, weren't a choice for me. I were just told. Why not a choice for a man? I've no idea. When I started asking, "oh, well, there's no trials for men because there ain't enough men get it", simple as, and it's down to cost, like everything's down to cost, so... you can apply for these trials if you want, so obviously you're recovering, they say you can't do anything, so you're trawling the internet looking for info and you're finding all these trials, and I put my name down for trials. Trial here, trial there, only to get replies... oh, we're only looking for pre-menopausal women or we're only looking... I said, "well, I'll never had a menopause in my life so I'm ideal obviously." "Oh, but you're a man, we don't want men". Simple as, you know? So nobody wanted a man to be anything, so...

Andy (MBC73)

6.6.4 Information

Information can come in many forms such as leaflets, speaking to someone or via the internet. The men interviewed discussed whether they were given leaflets

and their content; using the internet; speaking to other men with breast cancer and whether they used their breast care nurse as a resource.

Ten men said they did not get enough written information. Some men felt there was simply a lack of written information available for men with breast cancer. For example, when asked why he did not get any written information Henry (MBC93) replied, "Because there's nothing" and George (MBC52) said he did not think there was any written information because he was never given any from the hospital. Angus (MBC86) said he thought the literature was generally written for women as "everything for breast cancer was for women."

There were eight men who said they had received enough written information, and three of these men, Donald (MBC87), Eric (MBC71) and Alex (MBC91), suggested they also read this information. However, five of these men said they did not read *any* of the leaflets they were given, but had other people read them and find information for them. For example, Tam (MBC77) was not given any leaflets and despite not knowing anything about breast cancer had decided if he wanted to know anything he would ask his wife who would go onto the internet to find out what he wanted. Another man, Mani (MBC76), despite being given written information also chose not to read it and put it on the table for his wife to read. She would tell him what he wanted to know. He later revealed that he did this so that he did not have to read about having cancer, something that caused him upset:

They gave me information to read while I was in hospital, but in hospital, you see, you don't read all this information. It is only when you go home, then. I put it back - I put it on the table. My wife, she was the one that read for me.

Right.

Was reading for me and telling me this, this, this - and I don't want to see all these booklets, all these books, you see? I don't want to go on that feeling again that I got cancer.

Mani (MBC76)

Another reason for not accessing information given by one man was that it was enough for him to know that he was going for surgery and having his cancer cut out. He did not feel he needed to know any more. He said the leaflets he was

given were written specifically for women but even if they had been written for men, he would not have read them anyway:

He [the surgeon] told me what he was going to do. He says “we’ll get this away from you and you’ll be fine.” And I can ayeways remember him going like that and “you’ll be fine mate.” I went “well that’ll do me.”

Alec (MBC91)

Jack’s (MBC59) narrative was slightly different because although he said he got enough information, he generally admitted he wanted more information about his radiotherapy. He did not ask for anymore information because he felt the staff were “busy enough without [him] asking ... daft questions.” He also compared his experience with his wife’s. She had not been given any written information about her cancer or treatment, and although what he received was inadequate, it was still more than she had.

Regardless of whether they felt they received enough information, there were nine men who discussed the inappropriate content of some leaflets they were given as they were all written female breast cancer patients, with no mention or advice for men. For example, Bob (MBC89) said the information pack he was given from the hospital included information about wearing a soft bra after surgery, and Andy (MBC73) was given similar information in a leaflet on aftercare following his mastectomy. He described the content of the leaflet as exclusively for women and did not feel he could relate to anything being said:

I was given a leaflet on aftercare, after your mastectomy, what do you do? Well, put on a bit of make up, cause it makes you feel better. Put your favourite perfume on, cause it lifts you. Thought, pff, I’ve not got any make up or I don’t do make up - only at weekends
(Laughs.)

Andy (MBC73)

Similarly, Michael (MBC85) talked about the leaflet he received about his hormonal therapy and read how the drug was normally given to “post-menopausal ladies and [he] should have problems with bits and pieces he hasn’t got!” Clive (MBC67) also found the information and advice sheets he received from the hospital to be focusing on women and he had to complete forms relating to his treatment that asked him questions about “when was your last

period or are you pregnant?” He had to put a line through these questions then found there was very little left for him to complete.

Two men (Andy, MBC73 and Angus MBC86) who were in their early fifties when diagnosed said that in addition to feeling excluded because most of the literature was for women, when men were mentioned in the literature, the average age of diagnosis was much older than they were and they could not relate to these men:

Cos there’s nothing there for a man, it’s all women. Everything for breast cancer was for women. I’ve no read anything about a man until now. Well, ken what I mean?

Uhuh. And how did that make you feel?

Angry, because you’ve kentabout that for a long time, I got telt word o’ mouth, ken, fae a nurse, that men 70 to 80 get breast cancer. That’s how it’s never reported. I thought it was very stupid on the medical staff’s part, men are getting breast cancer at 70 and 80, eventually would get it younger, cos?? ken what I mean?

Angus (MBC86)

Some men (8/19) used the internet as an information resource, although most continued to find the amount of information available was limited for men. For example, Michael (MBC85) eventually found some information but it took him some time to find any information specific to men as most breast cancer sites focus on women:

Yes, I think the- especially the NHS [web] site, it doesn’t talk about- there is a dearth of information about male, and it sort of infers that it is solely a female problem, yes I mean. I suppose if you go back ten years probably yeah that was true, but now it isn’t true and I think... it eh, em, (pause) I suppose, again having access to the internet, and I always... I have a theory, it’s out there somewhere, it may take you a few minutes to find it, or a few hours to find it, but you can find websites about it. But it’s not- when you put in, you type in breast cancer and the first website that comes up won’t necessarily refer to- it can happen in men.

Michael (MBC85)

Three of the men who spoke about the internet said it was not them that used it as a resource, but their wife or daughter. All three felt that they had enough information but would ask for it when they wanted it. Patrick (MBC81) said his wife was a “dab hand” at the internet, and while he did not want to know any

more about his breast cancer, his wife got “chapter and verse on it.” Alec (MBC91) did not have to ask his daughter, she would spontaneously tell him what she had read. Similarly, Tam’s (MBC77) wife went straight onto the internet for information when they got home from his hospital appointment when he was told he had breast cancer. He said he never used the internet and if he wanted to know anything his wife would search for him:

I don’t go on the internet, I don’t use the computer so I wouldn’t know. When they first talked about it at the hospital, you know, if I would do it, my wife came out, got the internet and she saw it on the internet and she saw the man talking - and he didn’t seem one bit of embarrassment. And I think it did good, but not many men go on the internet.

Tam (MBC77)

There were a few men (3/19) that became frustrated when they could not find appropriate information and wanted to meet another man to discuss and share their experiences. For example, Andy had searched the internet and had found websites based in the US and Australia but he wanted to relate his experiences to someone else living in the UK. Eventually, through a breast cancer charity he found another man to talk to and was so relieved:

We got on with Breast Cancer Care and I heard about this peer support thing which is you can, you know, contact Breast Cancer [Care]... and they will put you in [touch with] somebody, cos you’re wanting to know, I couldn’t find any answers to my questions. I wanted to know another man who had gone through this, but men are few and far between in this country. Only places where I could get information was America’s got a good site, Australia’s got a dedicated site for men with breast cancer, and... too far away. Can’t talk to men in Australia and America, I don’t know anybody, and eventually I went through this peer support with Breast Cancer Care and got in touch with a guy in [place] in Scotland, believe it... a guy called [man’s name]. And what a relief it were, talking to a guy who’d gone through -exactly the same things that I’d gone through, who had had a mastectomy and who’d had chemotherapy and who’d had, he could answer all my questions, you know? And it was really good.

Andy (MBC73)

Andy however went on to talk about problems he had on the forum from women asking him why he was speaking to them about breast cancer. He said few knew that men could also have breast cancer and his forum use was met with suspicion from some women. He felt his experience was similar to younger

women with breast cancer; both were rare and both groups had to persuade people they were telling the truth about their diagnosis.

Another man, Clive (MBC67), managed to make contact with a man with breast cancer who lived in the same region as him. He enjoyed meeting him to share experiences and ask him questions about his treatment and how he felt:

I knew they say this man in [city], and this was quite a long time after. But... it was, it was very worthwhile, going to [town] and having a couple of pints and having a word with him. It was very, very worthwhile.

What sort of things did you want to know? Did you just want to share your experience or...?

Share me experience and how you felt and how long it'd be before you felt reasonable again. He'd been... I think he said it was three or four years since he'd had his mastectomy, and he said "oh, I'm just about getting over it now". I thought three years to go. But I still go to the hospital.

Clive (MBC67)

6.6.5 Availability and Use of Support

The level of support that someone may need during treatment for a life threatening disease will vary and it is difficult to predict who may need more support. Eleven men said they had families that offered support. Yet despite this, some of the men (11/19) said talking to someone who had shared similar experiences was an important issue although not all of them were offered the chance to either attend a support group or meet another man who had breast cancer.

Only one man, Tony (MBC70), who had a strained relationship with his mother, was invited to join a support group. He attended every month. He felt very comfortable in the women's company and although he thought of breast cancer as being "their disease", he said he both gave and received support. Tony said he felt more comfortable talking to women within the group than if a man was present because he felt he could cry with them:

They laugh and joke with me because they like my sense of humour, so they always... they come round and say that I'm one of the girls. They treat me as one of the girls, which is nice. I know... it's nice where women can give you that banter and if... obviously you need a man that can take it. That doesn't bother me. I like all the banter off the ladies. Actually, I have a better conversation with them than I do with the general Joe Public...Where the women are concerned, I always look at it as their disease but... and I like it, it's like supporting them as well even though I know I'm getting that support off of them, I don't look at it that way.... you meet a lot of ladies that are going through it [breast cancer], and as I say, that brings me back to where (pause) I feel as though I can discuss things easier, more comfortably with the ladies than I can with like a gentleman sat there. If it's a gentleman going through breast cancer, that's a different issue, then I'd like to talk to him, but no, ...but I never, ever feel uncomfortable when I'm in their presence. I can sit, I can cry with them.

Tony (MBC70)

There were another five men that said they were offered the chance to go to a support group but did not go. They all gave different reasons for this. For example, Michael (MBC85) said he "cringes" when counselling is mentioned. He said he did not believe in it and did not get any when as a child he witnessed other children dying during the war, he "just got on with it" and believed this was how he should approach his breast cancer diagnosis. Bob (MBC89) at first said he did not have time to attend the group because it was held on an evening when he did something else. However, he went on to say he thought it would be mostly women there and he did not feel he could relate to their experiences, he wanted to "relate to men":

I had been looking for some time as to (pause) I'd looked at the [support] group and asked the breast nurses how many people went and they said "oh about twenty" and I said "is there any men" and they said "no, no men." And I said, "Ok, I don't want to go and talk with women because..."

Was that the support group?

Yes, yeah. And if it's all women, they want to be talking theirs and, you know (pause) the male is gonna feel different in some way, so I'll try and support men, but I couldn't find any other men.

Bob (MBC89)

While Bob said he felt he would not be able to relate to women, Adam (MBC79) said he felt that he would not be able to relate to other people's stories as each person's experience is unique and he did not think anyone else would understand what he had gone through.

Some men (7/19) were not given the opportunity to attend a support group but said they would have liked to have gone along. This group included Donald (MBC87), who despite being deaf would have gone along to a group if he had known where to go and if he could communicate effectively. Michael (MBC75) said he felt it was difficult to say whether he would have attended, but if he had been offered. He thought he would have gone if he felt his experience would help anyone else. Clive (MBC67) was never offered the chance of going to a support group and felt very alone as he had no one to share his experience with. He reflected on the support women had:

...the thing that did annoy me was feeling alone. I mean, forty odd thousand women, they've all got support groups. Who do I go to? Nobody. You sit and ponder yourself.

Clive (MBC67)

As described earlier, despite not having a support group to attend, Clive did get in touch with another man who lived within a few hours drive away who he met to discuss their experiences. There were five other men that wanted to meet another man who had had breast cancer but were not given the opportunity (there were also another two men who reflected during the interview that meeting another man may have been beneficial at the time of treatment but at that point they had not considered it). For example, Angus (MBC86) did not know any other men who had breast cancer, but thought another man may be "more willing to talk about it" and he would have liked to share his experiences to see how his compared to those of another man. Similarly, Mani (MBC76) was hoping his participation in this study might enable him to meet another man with breast cancer so that they could compare experiences.

Three men said that even if they had been invited to a support group they would not have gone. William (MBC83) and George (MBC52) had both at times referred to feeling embarrassed about their breast cancer diagnosis and said they felt their families were all the support they needed. William also had a strong Christian faith that he derived great comfort from. He also had a close friend who was a retired breast surgeon who, despite being retired, would "wander in as if he still owned the place" when he was in hospital and talked him through his treatment. Nick (MBC55), a single man with no living close family, said he was strong enough to get through his experience himself (despite earlier talking about how good his breast care nurse was at supporting him) and said having

breast cancer for him, a man, did not bother him compared to a woman who he thought had a far more emotional and traumatic experience:

When you went to the hospital, did the nurse ever offer you a chance to go to any support groups?

No, I don't think so. I wouldn't have went to a support group anyway - I don't think I need support.

Why not?

Because I'm strong enough to do it on my own.

You don't think sharing ideas or symptoms...

Yes, but I have to share ideas and symptoms with any males, and there's very few of them around.

What do you think the differences would be between a women's group and a men's group?

Women, it's much more intense - it's a tremendous problem for a female, having breast problems. For a male, it doesn't bother me at all, not in the slightest - not interested.

Nick (MBC55)

6.7 Experiences of and Needs of Women with Breast Cancer

Breast clinics have been developed to facilitate a multidisciplinary team approach to the provision of healthcare for *women* with breast cancer. This is reflected within most of the women's narratives with many examples of good experiences described, although not all experiences were positive.

6.7.1 Experiences of Healthcare

Most of the women interviewed described their diagnosis and treatment being carried out by a multidisciplinary team at one-stop clinics that included a surgeon, radiologist and breast care nurse. Most of the interviews implied they were happy with the care they received and seven women said explicitly that they had been given a high standard of care.

Similar to the men, a few of the women discussed problems with their healthcare provision, including Marion (FBC64) who received her breast cancer

diagnosis over the phone and Abina (FBC96) who had to wait some time for surgery. Two women discussed problems at their clinic appointments that led to frustration and lack of continuity of care. Ada (FBC74) questioned the need to attend the clinic regularly as “nobody ever finds anything” and she was “slightly disappointed” that she did not see her consultant but more junior doctors at the clinic. Jane (FBC68) complained of similar problems at her clinic appointments. She found the lack of continuity frustrating and demoralising and felt the team looking after her should be fully briefed on her progress.

Another area of concern for three women that was not discussed by the men was a frustration that their consultants did not use lay language when discussing their diagnosis and treatment leading to considerable distress and confusion. For example, Jess (FBC60) said her doctor used “some terminology which was confusing” and did not understand that ‘metastatic’ meant her cancer had spread to another site (her bones) and thought it was a different, new cancer. Another example was Charlotte (FBC94) who had attended breast screening as part of an insurance medical. Her diagnosis was “the most terrible shock” and she was unprepared for having further invasive tests to determine her type of breast cancer. She felt the speed of her diagnosis was difficult to cope with and that she needed more information to help her decide what treatment to have. She felt the terminology the doctor used was inappropriate and confusing:

And this surgeon who had been performing lumpectomies and breast removal and treatment for other cancers too er was talking to me about having a full axillary clearance. I guess my criticism of the medical profession is that the lack of sensitivity in communicating it, certainly in my case, and then using words that normal lay people don't understand.

Charlotte (FBC94)

Charlotte's confusion centred round her treatment options. Her doctor was advising her to have a procedure that she did not understand. Her own research suggested an alternative that had fewer side effects for which she was eligible.

6.7.2 The Healthcare Environment

The women talked of their healthcare experiences in a holistic fashion that included the physical environment and the support and information they received from staff and other patients to make them feel supported as an

individual. For example, Emma (FBC86) said she felt she was “treated as a person at the hospital, which was excellent.” Jess (FBC60) described the clinics as “unhurried” and “quiet” and despite sometimes waiting longer to see the doctor, she knew that if she needed more time with them they would not rush her and would answer any questions she had. Jess also described the hospital ward as “just wonderful” with the facilities available and the support given by staff encouraging the inpatients to talk to and support each other, all of which she found “extremely helpful.” She kept in touch with the women she met on the ward, and described them as her “own support group.”

The chemotherapy suite was another area of the hospital that some of the women (5/23) discussed as being a comfortable and supportive environment. Hannah (FBC62) described her experience of the chemotherapy suite as ‘comfortable’ and the nurses as supportive to her and her husband. She knew at that time her husband was struggling to cope with her diagnosis although he would not admit it to her. They later separated and divorced but she was very pleased that during her treatment he was offered the opportunity to talk:

At chemotherapy they were wonderful, it’s a very comfortable, it was a very well built unit, very comfortable chairs to sit in. We went into a small sitting room to be seen by the, by the nurse that was going to be giving me the drugs and as much time was given to my husband as it was, as to me... But she [the nurse] explained everything, she asked him if he had any problems, if he wanted to ask anything. She made me feel so at ease, I still know her and she is, she’s an amazing lady as they all were on there, I’m very impressed by their standards and how I was cared for there.

Hannah (FBC62)

6.7.3 Choice of Treatment

Choice of treatment is tumour dependant. For some women interviewed there was no choice because they had rare forms of breast cancer. For example, Margo (FBC88) was diagnosed with Paget’s disease and Jennifer (FBC50) had inflammatory breast cancer. Both cancers are difficult to treat successfully and both women required mastectomies. There were seven women who said they were given a choice in their treatment but not all liked having to choose, and felt ill-informed to do so. For example, Lesley (FBC70) was given a choice of either having a wide local excision of her breast tumour or a mastectomy, and was advised that both had similar survival rates. She was given time to consider

which option to have and looked for information to help her make her decision. She also contacted friends for advice and discussed it with her family. She chose to have a mastectomy as she previously had had some calcification (pre-cancerous cells) in her breast and decided it was not a “worry to lose it [her breast].” Hannah (FBC62) was also given a choice, in how to have her radiotherapy. Although she said the doctor talked her through the options and what effect each one would have, she still felt she needed more information and phoned her local cancer information centre that was very helpful:

Nowadays you're given choices and although at the time when they're giving you the choices they explain the choices, it actually leaves you with a dilemma because you want to find out which is the best direction to go. And that happened with, I was offered, I could either have three days radiotherapy a week or five days. Now I knew that most people I'd talked to had been offered three days so I did a lot of phoning around and findings things out which worried me about the people that wouldn't know where to go and how to get the information. There was a cancer information centre... I phoned them and in fact, I had a very, very, very interesting conversation and she, the lady that ran it, found out all the information I needed and sent me a very, very well constructed letter about it.

Hannah (FBC62)

6.7.4 Information

The information needs of the women changed over the course of their breast cancer experience. Some women (11/23) said they had not wanted information from diagnosis, but would instead look for information as they needed it. For example, Camilla (FBC84) “ignored the fact” that she had breast cancer and knew that she could get more information if she wanted. Others, once they had come to terms with their diagnosis, wanted to know all that they could and would speak to friends, search the internet, talk to their doctor and go to the library, although some remained cautious and did not want to hear anything that may upset them. For example, Marion (FBC64) did not read anything about breast cancer for the first year after her diagnosis. She knew the cancer could return and although her consultant was confident it would not, he told her that it may come back with different symptoms which upset her. She said that the staff “must be able to smell the fear in that waiting room” and she stopped reading anything. Eventually she realised she needed to know more and went to the library:

Well to start with in the early days I didn't want to know too much because I felt I couldn't cope with it, but as the months went by I did want to find out much more. I shied away from reading any articles about it for a long time and then I started to read things. I went to the library, I'm a great library fan and have been ever since I was a child, and I went to the library and I found one excellent book on breast cancer, I'm damned if I can remember what it was called, it wasn't a very big book but it was very good and very helpful. I used to flick through, there's quite a lot in the libraries, but I flicked through them and if they look particularly frightening I thought, no, no I can't read that, I can't read that. I'm still a bit wary of what people say to me, a bit yes, but I really had to find out.

Marion (FBC64)

Although most of the women said they were either given enough information or would know where to find it when they wanted it, there were six women who said at times they found information to be lacking, and in particular with regards to lymphodema, a swelling that can occur in the arm of the affected side, caused by the removal of the lymph nodes under the arm. For example, despite Susan (FBC76) describing her care as "very good" she was not warned that lymphodema may occur and when it did, her arm was extremely painful and she found coping with that "more difficult than cancer" because it was so unexpected. Another example was Mary (FBC66) who felt most of the information she was given was not relevant to her. She had had a lumpectomy and was given information about pads and prostheses that she did not require, but was not given anything about lymphodema. She struggled with the swelling in her arm for some time before her hospital doctor referred her to a specialist clinic:

All this time I never had any advice at all about possible lymphodema. I had somebody come to see me in the hospital before I left to give me advice on little things, pads that you could put on your breast...If people have a full mastectomy presumably they do have problems and need to have little fittings and special bras. They should teach each person differently. I didn't need her, I needed somebody to tell me that my left breast would be larger than the other one, and there was no problem there. But the exercises for lymphodema which they could do, you know the only thing really in years to come that you will have a problem with is your arm because you've had your lymph glands out. Not a word, not a word of that, but just to take exercise. And I've looked back at the leaflet about exercise and there's nothing about lymphodema at all.

Mary (FBC66)

6.7.5 Availability and Use of Support

Any assumption that the women would attend a formal support group was not supported within their narratives. About half (13/23) said they did not attend a support group, although a few (3/23) met other women during their treatment and developed close friendships with them that may be considered an informal support group. For example, Jess's (FBC60) experience of the ward setting, discussed earlier, in which she was encouraged by the ward staff to support fellow in-patients. She made long-term friendships during that time and they met regularly thereafter. Ada (FBC74) also knew some women who had had breast cancer and would occasionally meet up to chat about their experiences. In contrast, Susan (FBC76) was supported by her family and despite being told about the local support groups she could attend, chose not to as she felt she was coping:

I did know about support groups and people did phone me and say you know "We do have a support group and you know you'd be very welcome to come if you wanted to." And I just felt, I don't know it it's blasé to say so, I think it is because actually looking back on it I thought I was doing, all of us in the family and myself were coping extremely well but actually breaking my ankle made me realise that I wasn't coping as well as I thought I was going to. Whether that would've been a help to have a support group I rather think not. I think some things you just have to do on your own and er talking to other people, may be one other person if they'd been the right person would help, but I think joining a group, I'm not sure that would help me.

Susan (FBC76)

Susan was not the only woman who was unsure about the benefits of attending a support group. Jane (FBC68) used to run a support group when her sister was undergoing breast cancer treatment. Despite making some good friends she said there were "some awful people in it" who talked "about nothing else but the operation, the effect it's had on them, the treatment, the awful things that happened to them, this, that and the other." She knew that talking about their experience was good for them, but felt it had a negative effect on the rest of the group and left other women feeling very upset. Once she realised the harm being done to some of the women she closed the group.

Five women said they had attended a support group and described feeling supported, learning from the other women and said it was a positive experience.

For example, Rashida's (FBC98) group was for Punjabi women and she could communicate in her first language and Layla (FBC82) found it helpful talking to other women who had "the same experience as you" and understood what she was going through. Similarly Fara (FBC90), who struggled to accept her diagnosis initially and was fearful of treatment, thought the group she attended was very helpful and informative and helped her cope with her hair loss while having chemotherapy:

How did you find out about the support groups, like this group?

Oh very beneficial, very beneficial, because yes from this group I learnt, I was very much worried about the hair loss and all those things. When I came here I saw that all the hair grew. Instead when I lost my hair my hair grew very, very thick and beautiful.

Fara (FBC90)

6.8 Discussion

The findings presented in this chapter focus on men's and women's experiences of their treatment. Within the men's narratives there are striking accounts of being the odd one out in the hospital environment, of experiencing suspicion from other patients and the consequences of having treatment that has not been researched in men. There is a lack of choices for men with breast cancer in treatment, perceived service availability, information and support. This contrasts with the women's narratives (see box 3). The women discuss choice in their treatment, having easily available resources to obtain information quickly and describe their healthcare experience positively.

Needs of men and women with breast cancer are complex and change through the course of their treatment. There are similarities in the decision-making and information and needs of the men and women, yet unlike women, the needs of men are often left unmet. In contrast to the women, some men recalled negative healthcare experiences in the clinic and ward setting. This did not prevent most men's initially responding that their healthcare was positive which concurs with recent evidence suggesting that patient satisfaction surveys are inadequate to describe healthcare experiences (Collins and O'Cathain, 2003, Staniszewska and Henderson, 2005).

Similarities Between Men and Women

- Most men and women initially described their healthcare experiences and treatment as good.

Differences Between Men and Women

- Some men experienced insensitive and embarrassing interactions with healthcare staff.
- Some men said they felt embarrassed being surrounded by women in the treatment settings.
- Few men were offered any choice in their treatment.
- Some men said they did not receive enough information and had to read information specifically written for women.
- Some men wanted to talk to another man about their experiences but few were offered the opportunity to do so.
- Some men would have liked to attend a support group but were not offered the opportunity to attend.
- Some women said they found the medical terminology used by doctors confusing, and at times, distressing.
- Most women said their treatment was delivered in a holistic fashion that met their support and information needs.
- Some women's information needs changed over time but they knew where to access information from and had a variety of sources available to them.

Box 3. Similarities and Differences in Healthcare Experiences of Men and Women

Most men and women expressed a desire to be part of their treatment decision-making process, concurring with recent research (Keating et al., 2002, Sabo et al., 2007, Henrikson et al., 2009). However, not all men or women wanted choice and some said their treatment should be a decision made by the experts (Schou et al., 2002). Importantly, most women said they were given a choice but most of the men said they were not, and for some this caused distress. Deadman et al (2001) found a lack of involvement in treatment choice led to an increase in anxiety and distress during treatment. Brain et al (2006) reported in their survey of men with breast cancer (n=161) 23% reported high levels of cancer-specific distress. They suggest threats to their masculinity, fear of stigma and isolation may be possible causes, and findings in this study suggest a lack of involvement in the decision-making process may also be a contributing factor. There is however, a lack of clinical evidence for breast cancer treatment in men, and treatment choice is therefore limited (Ottini et al., 2010). It is widely recognised that men with breast cancer are an under-researched group and

there have been recent calls for collaborative studies to improve the existing knowledge and treatment choices for men (Korde et al., 2010).

In this study, the clinic, ward and treatment areas were also problematic for men when they were in areas used predominantly by women. In the clinic setting some men said they were uncomfortable in an all female environment, and recalled insensitive interactions with staff, concurring with findings by Donovan and Flynn (2007). Compared to the men and women admitted to gender-specific wards, the ward setting was problematic for men admitted to the specialist breast ward despite having single, private rooms. The advantages of a specialist ward for medical and nursing expertise, and for (in this case) women to meet others in similar situations are evident within the women's narratives. In contrast the men on male-specific wards and not specialist wards, found their hospital experience more acceptable and less problematic. These findings highlight poor incidents of healthcare provision that did not meet the men's needs for supportive care that undoubtedly caused distress (Jakobsson et al., 1997, Arman et al., 2004) and challenged the men's dignity (Bryant and Adams, 2009, Baillie, 2008).

Different strategies used by the men to cope with negative healthcare experiences and treatment was found. Some played down the effect their breast cancer diagnosis had on them stating it was worse for women, while some constructed different traditional male identities to cope with their clinic visits. Masculine images of lone soldiers in a female environment and strong, stoic identities that hid true emotions of fear and upset were present within the men's narratives. The use of metaphors when talking about cancer has been widely acknowledged, in particular the use of military metaphors to describe the cancer experience (Sontag, 1991, Langellier and Sullivan, 1998, France et al., 2000, Seale, 2001a). Reisfield and Wilson (2004) suggest the military metaphor is the most frequently used because it is easily understood and intimates the gravity of the disease. Another, uncommon metaphor present within the men's narratives is the use of biblical references to 'evangelise' and 'spread the word' that men can, and do, develop breast cancer. Within the women's narratives there were also religious metaphors such as 'being in God's hands' and their survival being 'the will of God'. Metaphors are chosen based on what individuals know and have value to them. Religious metaphors help people understand their

illness and survival as “outcomes of divine will” when other explanations for their illness are inadequate (Seale, 2001b p427).

The information needs of the men and women were found to be similar. Both wanted disease-specific treatment information. The women reported similar patterns of accessing information to those presented by Rees and Bath (2000). Some women felt overwhelmed with information at diagnosis and did not want it then, but slowly accessed information, as they required it as their treatment progressed. In contrast, the men were given very little information at diagnosis and attributed this to the lack of any male-specific information being available. This did not change throughout their treatment and was problematic for most of the men. The lack of male-specific information has been widely recognised as problematic within other studies (Donovan and Flynn, 2007, France et al., 2000, Iredale et al., 2006, Naymark, 2006, Pituskin et al., 2007, Williams et al., 2003). Furthermore, findings in this study suggest when male-specific information was available, some men could not relate to it because they did not match the description of the men in the leaflets. In particular the younger men felt excluded because breast cancer in men was typically described as a disease of older men.

The women reported using a wide variety of information sources including the hospital, internet, library and friends, similar to other findings (Ziebland et al., 2004, Dubois and Loisel, 2009, Luker et al., 1996b). In contrast, most men identified the internet as the only resource used to gain information similar to other findings (Seale et al., 2006, Ziebland et al., 2004). However, some men did not search for information themselves, they said they relied on their wives to find, read and impart any information they had. Findings concurred with McCaughan and McKenna (2007) who suggest that men under the ‘gaze’ of healthcare staff, family and friends, construct a traditional, stoic masculine identity as a coping strategy. Asking and searching for information may be at odds to the masculine identity constructed. Another consideration may be that the constant reference to women within the literature, which may reinforce the rarity of breast cancer in men and increase the isolation that some men discussed. This may heighten their need to meet another man with breast cancer to share experiences from a male perspective. Similar findings were reported by Williams et al (2003).

The wife's role during their husband's breast cancer experience was not only to provide information, but in addition they were identified as main sources of support, similar to research that described prostate cancer as "a couple's illness" (Bottorff et al., 2008). Whether the men wanted to attend a support group or not, few were offered the opportunity. Most men rejected attending a support group because they said they had enough support from their wives and families, similar to other findings (Clarke et al., 2006, Pituskin et al., 2007). Some men dismissed the idea of needing support or counselling and suggested women would not want them there. Existing studies suggest men attend support groups to gain information (Gray et al., 2000, Bottorff et al., 2008). It is likely the men did not think they would get male-specific information from groups attended by women only. Broom's (2005) study exploring men with prostate cancer's use of online groups, found men either enjoyed the anonymity of the web forum or were suspicious and rejected using the online forum. In this study however, unlike prostate cancer online forums, breast cancer forums are predominantly female environments. Some men chose to access these forums however their participation was rejected by other (female) users who were suspicious of their motives for being there. Thus, any advantages of using an online forum were not available to the men in this study.

One man attended a support group. He was single and had a strained relationship with his mother. Despite attending the group to meet his unmet support needs he suggested breast cancer was a woman's disease and was more comfortable speaking to women instead of men. He constructed his masculine identity within the group using traditionally feminine qualities such as empathy and the ability to express his emotions. He did this whilst maintaining his role as supporter of the other women within the group, setting him apart, helping them through 'their' disease. Oliffe (2005) found similar findings in a study exploring men's experiences (n=15) of impotence following prostatectomy. He suggests this demonstrates how masculinity can be constructed in relation to femininity and other masculinities.

In line with findings in respect of the men and with other current evidence, support group attendance was not required by most of the women because they felt supported by their friends and family (Van Der Molen, 2000, Landmark et al., 2002, Browall et al., 2006). Some of these women, however, had met

women whilst in hospital and continued to meet for mutual support. However a small number attended a support group to share experiences and support from other women and found it to be a positive experience as described in other studies (Power and Hegarty, 2010).

It would be wrong to suggest that women with breast cancer have an unproblematic experience of healthcare during their breast cancer diagnosis and treatment. However compared to men, whose narratives of healthcare throughout their diagnosis and treatment are littered with negative and challenging accounts, they do appear to have particularly good care. This may be the result of the development in recent years of national clinical guidelines for the treatment of breast cancer *in women* that promote a holistic, multidisciplinary team approach (SIGN, 2005, NICE, 2002). Outwith the NHS, men with breast cancer discussed limited sources of information and support. Even online sources of information and support, considered private and flexible for embarrassing illnesses (Ziebland et al., 2004), challenged men's legitimacy to have a breast cancer diagnosis. Living beyond this active treatment phase is the focus of the next chapter.

7 Breast Cancer Survivorship: The Embodiment of Cancer, Treatment Effects & Romantic Relationships

7.1 Introduction

In the UK, it is estimated that there are approximately two million people living with or beyond cancer, and this number will increase by approximately 3% per annum if trends in recent years continue (Maddams et al., 2009). There is no one accepted term for describing people living beyond a cancer diagnosis (Brearley et al., 2011). The term ‘cancer survivor’ is often used, particularly in the United States, and is becoming more frequently used in the UK. Cancer survivors are defined as “those people living with a diagnosis of cancer from some point in their past” (Maddams et al., 2009). Doyle (2008) further develops this definition into a concept that is “dynamic” and may be defined as “a process beginning at diagnosis and involving uncertainty. It is a life-changing experience, with a duality of positive and negative aspects unique to the individual experience but with universality” (p.502). Doyle proposes that cancer survivorship may have positive and negative attributes that incorporate the physical, psychological, social and spiritual health of an individual who has had a cancer diagnosis. A survey of ‘cancer survivors’ carried out by MacMillan found that almost 42% of those asked preferred using the term ‘living with and beyond cancer’, 36% preferred ‘survivorship’ and almost 13% preferred ‘life after cancer’ (MacMillan Cancer Support, 2008). Within this chapter I endeavour to discuss the men and women as living beyond their cancer diagnosis in line with the preferred terminology of those sampled by MacMillan.

This chapter presents the findings relating to men’s and women’s experiences of the lasting effects cancer treatment has on their bodies and relationships. Existing literature exploring sexuality, body image and intimacy of men and women is first presented before a brief overview of what is already known about the embodied effects of treatment and the impact breast cancer in men has on their relationships.

7.2 Are There Gender Differences in Cancer Survivorship?

Different aspects of survivorship have been explored, including living in fear of cancer recurrence and uncertainty (Hodges and Mumphris, 2009, Taylor et al., 2011) and health-related quality of life (Kahana et al., 2010, Ostroff et al., 2011). A recent systematic review investigated what is known about the physical and practical problems faced by people living beyond their cancer diagnosis (Brearley et al., 2011). Of the nine papers that met the quality inclusion criteria for the review, six focused on physical well-being (for example pain, fatigue, gastrointestinal problems, sleep disturbance) and three on employment and finances. Brearley et al (2011) concluded that while these are key areas affecting the ongoing well being of men and women living beyond their cancer diagnosis, there are gaps in knowledge around sexual function and the effects of hormonal treatment. Men and women with hormone sensitive breast cancer are expected to complete a five year course of hormone ablation therapy to reduce their chance of cancer recurrence and increase their chances of long term cancer survival. The most common side effects of this treatment include loss of libido, hot flushes and night sweats (Hunter et al., 2004). However none of these studies compare men's and women's experiences or explore these issues from a gender perspective.

7.3 Men, and the Embodied Cancer Experience

There is limited evidence on the effects hormonal therapy may have on men with breast cancer but more evidence on the use of hormonal therapy in men with prostate cancer. Erectile dysfunction is the most common side effect of any active treatment for prostate cancer and for many men this can be more distressing than urinary incontinence (Bokhour et al., 2001). It is only in recent times however, that researchers in this area have begun to explore men's sexuality beyond the ability to obtain and maintain an erection that is adequate for penetration (Kiss and Meryn, 2001). There is also an assumption that it is the cancer diagnosis that causes erectile dysfunction, when in fact sexual problems are relatively common in the general population (Foster et al., 2009). For example, Boehmer and Babayan (2004) interviewed twenty one men recently diagnosed with early stage prostate cancer waiting to start treatment. Only nine said they had full sexual functioning prior to their diagnosis, and five had been

treated for erectile dysfunction in the past. Boehmer and Babayan (2004) found the men who had already experienced erectile dysfunction were more accepting of this new potential threat than those who had never experienced any previous problems. These men talked of the loss in relation to being part of the ageing process, and as a natural decline to their sexual lives.

Despite having medical treatment options available to improve their sexual functioning, most men declined the opportunity to try them or found them too regimented and painful to use (Fergus et al., 2002). The loss of desire and spontaneous, natural and firm erections could not be replaced by artificial and pre-planned sex (Oliffe, 2005). Some couples redefine their sexual habits and find alternative ways to pleasure each other without having penetrative sex. However, the men who continued sexual activity had to rely on other coping mechanisms such as humour to divert themselves away from detrimental thoughts such as self pity (Fergus et al., 2002).

7.3.1 Sexuality and Cancer

A man's sexuality is not a straightforward and easily explained concept. Each individual is reconstructing their identity within their own environment, culture and beliefs (Oliffe, 2005). Furthermore, older age may lead to a social construction of masculinity where power from sexual potency is diverted and invested in other aspects of a man's life such as in their status within their family and work (Oliffe, 2005, Oliffe, 2006). However, sexual function in older men may still be an important part of their life, this can decline with age, and can remain an important part of their lives well into old age (Bokhour et al., 2001). Furthermore, the loss of physical performance also had a wider impact on men's relationships with women in general. Chapple and Ziebland (2002) found the men in their study were aware that their sexuality had changed for the worse when meeting and interacting with women. The sexual frisson that may be experienced in every day interactions had gone and they mourned the loss of this aspect of their lives.

7.3.2 Body Image

Body Image is more than just the perception of the physical body. It is "the perception of one's own bodily appearance, function and sensations as well as feelings associated with this perception" (Dropkin, 1999 p310). Burbie and

Polinsky (1992) contend that all cancers affect body image and can have a significant impact on sexual intimacy between patients and their partners. It can be reasoned then that men who have had prostate cancer treatment may have an altered body image because of the change in their physical functions despite some not having any visible scarring. A survey of perceptions of body image among men with prostate cancer (n=132) found that those who had hormonal treatment had a significantly greater degree of body image dissatisfaction than those who did not (Harrington et al., 2009). In addition, there was an association between higher Body Mass Index (BMI) and poorer body image. Hormonal treatment may cause weight gain, or the participants may have been overweight to start with causing dissatisfaction with their body image. However, while this study has some weaknesses it gives an indication that body image disruption may play a role in a man's decline in sexuality.

7.3.3 Intimacy

Intimacy is an important dimension of spousal relationships (Walker and Robinson, 2010). Tolstedt and Stokes (1983) propose intimacy is a combination of three categories: verbal (self-disclosure), affective (closeness and bonding) and physical (including sexual bonding). All three categories are distinct, equal and strongly related to marital satisfaction. It has been argued that partners are equally affected by the side effects of hormonal treatments such as loss of sexual intimacy, partner's mood swings and anger (Harden et al., 2002, Clark et al., 1997). They also have to contend with the fear that their partner has a potentially life limiting disease and try to live with this fear alone on a daily basis to protect their partner from any upset (Harden et al., 2006).

A study by Bokhour et al (2001) carried out focus groups with men who had been receiving prostate cancer treatment for one to two years. They found that the loss of physical intimacy had led to deterioration in their relationship with their partners. The men reported withdrawing emotional intimacy to protect themselves and their partners from the disappointment of not being able to perform physical intercourse. Boehmer and Clark (2001) reported similar findings. They explored the views of twenty men with metastatic prostate cancer and seven wives on the effects of their disease and treatment. Both the men and their wives admitted to withholding emotions and fears to protect their partners. However, both denied that this had a negative affect on their

relationship. Despite this, some men and partners shared accounts of changes within their relationship. One man said his wife found him difficult to get along with and some wives said their husbands had shrinking social networks and increasingly relied on them.

7.4 Women and the Embodied Cancer Experience

Women with breast cancer face a number of psychological and physical challenges presented by the disease and its treatment. Cancer of the breast may cause distortion of the body leaving scarring, a constant reminder of what has happened and the possibility of recurrence (Thomas-MacLean, 2004). Physical side effects of treatment can include fatigue, hot flushes, sleep disturbance and pain (Janz et al., 2007), painful intercourse (Speer et al., 2005), vaginal dryness (Ganz et al., 1999), reduced libido and lack of sexual pleasure (Avis et al., 2004, Foster et al., 2009). These symptoms have been found to be predictors of poorer sexual health among women with breast cancer (Ganz et al., 1999). They are also more prevalent in women who have chemotherapy treatment (Emilee et al., 2010). In addition, chemotherapy can cause short-term hair loss, which can be devastating to some women. In one small (n=18) study some women described feeling “faceless” without eyebrows or eyelashes (Wilmoth, 2001).

Women who had mastectomy were more likely to feel differently towards their body than women who had lumpectomy. One study however by Figueiredo et al (2004a) explored older women’s body image concerns. They carried out telephone interviews with 563 women with early stage breast cancer aged 67 years and older over a two year period. They found that women who had had a mastectomy were more likely to have body image concerns than those who had breast conserving treatment and concluded that their findings showed that body image concerns following mastectomy were not confined to younger women, but present across the life course.

7.4.1 Sexuality and Cancer

Unlike men, there is no sexual function measure available for women (Kiss and Meryn, 2001). A lack of sexual desire may be attributed to an altered body image, attractiveness to a partner or treatment side effects such as weight gain (Wilmoth et al., 2004). One small qualitative American study interviewed

eighteen white women aged between 35 years and 68 years (mean age 50 years) to explore what aspects of sexuality were important to women after breast cancer treatment (Wilmoth, 2001). Each woman was asked to describe what the word 'sexuality' meant to her and explain how her breast cancer diagnosis had affected her sexuality. Wilmoth (2001) found that the women "said that sexuality was more than the act of sex, that it included companionship, touching, and affection, and that their sexuality was the gestalt of feelings toward another and their partner's feeling toward them" (p.284). The women hinted that when they were diagnosed with breast cancer they re-evaluated their sexuality. Some women described how they rebuilt their confidence with the help of their partners or participated in new experiences. This group however, included pre and post-menopausal women whose sexuality may differ across ages and pre-existing sexual problems or age-related changes were not explored within this study.

One systematic review found that significantly more women living beyond a cancer diagnosis reported a lack of sexual interest, lack of enjoyment and lack of arousal when compared with healthy women (Foster et al., 2009). Panjari et al (2011) undertook analysis on a representative sample of all women newly diagnosed with breast cancer in Victoria, Australia. Over one thousand women were recruited within twelve months of their breast cancer diagnosis and followed up twelve months later between June 2004 and December 2006. Women aged 70 years and older were excluded from this analysis due to the researchers' anecdotal experience of older women reporting little interest in sexual function. The mean age of the sample was 59 years and the youngest was 28 years. Prior to diagnosis, 82% of the sample reported their sexual function was good and satisfying. At follow up 70% of women were reporting sexual function problems. Women who reported sexual function problems were more likely to feel differently towards their bodies, or thought their partner felt differently about their body.

7.4.2 Body Image

Langellier and Sullivan (1998) suggest breasts are the most visible and obvious manifestation of what it is to be a woman and there is an assumed connection between breast cancer and an altered feminine identity. A study by Reaby (1998) interviewed 95 women who had a mastectomy. Sixty four women did not

have reconstructive surgery and used an external prosthesis and 31 had breast reconstruction following mastectomy. There was a significant age difference between these groups. The breast reconstruction group were significantly younger (mean age 49 years) than those in the prosthesis group (mean age 63 years). Reaby (1998) found the women who had reconstruction wanted it to replace a lost body part. They did not undergo surgery for vanity or to improve their marital and sexual relationships. Partners of the women were generally described as supportive and did not pressurise the women to have surgery. The main reasons given by women who did not have reconstruction were: it was not essential for their physical well-being (88%); it was not essential for their emotional well-being (86%); they did not have enough information to make a decision (85%) and they did not want anything unnatural in their body (80%). Some women also said they felt they were too old for reconstruction (22%).

However, some researchers contend that the challenges to a woman's sexuality and body image have been over-estimated and their coping strategies underestimated (Meyerowitz et al., 1988). Langellier and Sullivan (1998) interviewed 17 women aged between 32 years and 64 years. They explored how the women talked about their breast cancer diagnosis and the meanings they constructed when talking about their body image, femininity and sexuality. They found that some talked about their breast as a medicalised body part, detached from any emotional or sexual meaning. Their overriding aim was to survive and regain their health. Having a breast (and cancer) removed was a step closer to achieving this. Some women said their breast had served its purpose having breast-fed their children, and the need to keep it had diminished.

Some studies suggest it is not the mastectomy that alters a woman's body image, but the adjuvant treatment required, in particular chemotherapy and the resultant hair loss experienced (Richer and Ezer, 2002, Browall et al., 2006). Browall et al (2006) interviewed 20 women aged over 55 years who had finished a course of chemotherapy within the last year. They reported that the women discussed their chemotherapy and resultant hair loss as being more traumatic than their mastectomy. Most of the women said they felt physically well before treatment and worried about what the treatment would do to their looks. Once treatment had begun the women reported physical changes to their appearance and felt they began to look sick as their hair fell out. They also began to feel

physically unwell as they experienced side effects of treatment. This reinforced the reality of their life threatening diagnosis. These findings are similar to those reported by Richer & Ezer (2002) who interviewed ten women after every chemotherapy session. They found that the women were ambivalent towards their bodies, as they felt let down by them. They wondered if they could have detected the cancer earlier if they had paid greater attention to their bodies. Six of the women said they felt it was the hair loss that made their illness a reality for them. Seeing their reflection would immediately remind them they had cancer.

7.4.3 Intimacy

Sexual dysfunction in women is complex, and emotional and relational aspects appear to be more important in women than in men (Kiss and Meryn, 2001). A recent literature review concluded that in general, there are few studies exploring sexuality and the effects on intimate relationships (Emilee et al., 2010). Relationships however are an important aspect that add or detract from a woman's quality of life following a breast cancer diagnosis (Wilmoth, 2001).

One study by Gray and Fergus (2009) investigated the impact of a breast cancer diagnosis on heterosexual relationships, with a view to identifying factors that facilitated greater intimacy or conversely created distance between couples. Nineteen women at various stages of their illness were recruited and 11 partners (two of whom were widowers). First, a scoping focus group was carried out to help inform the study, prior to the couple interviews. Lone interviews were then conducted to allow individuals to talk freely and to explore specific areas of interest. Gray and Fergus (2009) found that a breast cancer diagnosis caused relationship strain and the dynamic of the partnership often changed as each individual came to terms with the diagnosis. Within this sample, non-disclosure of concerns and a desire to protect loved ones from the disease led to emotional and physical strains within the relationships which concur with other study findings (Lauver et al., 2007, Manne et al., 2004). Conflict also arose when spouses held different views of the disease timeline. Partners often felt the completion of treatment coincided with the end of the disease, whereas the patient often recalled renewed uncertainty and increased anxiety at the completion of treatment. It was a time when they felt abandoned by the hospital. Gray and Fergus (2009) highlighted the partners feeling ill-equipped to

deal with the needs of their wives. They felt able to offer practical help, but they did not feel able to offer emotional support. This often became a barrier to the couple adjusting to the diagnosis.

7.5 Men with Breast Cancer: Embodiment and Romantic Relationships

The majority (90%) of breast cancer in men, like that in women, is hormone-sensitive (Fentiman et al., 2006, Ottini et al., 2010). Tamoxifen, a hormone ablation therapy is regularly used as adjuvant therapy for five years following diagnosis. Iredale et al (2006) reported in their survey (n=161) that 126 men (78%) were prescribed tamoxifen as part of their treatment. Retrospective studies have shown tamoxifen use by men improves disease free and overall survival rates (Lanitis et al., 2008), however there have been no randomised studies investigating its use in men with breast cancer (Giordano et al., 2002). Its main side effects are reduction in libido, impotence, hot flushes, mood changes and deep venous thrombosis (Ottini et al., 2010).

There is little on men's sexuality and the effects that breast cancer has on a man's intimate relationships. Donovan & Flynn (2007) found some men reported the resultant erectile dysfunction challenged their masculinity. However, any effect this had on their relationships was not reported. Pituskin et al (2007) is the only paper identified which reports findings on the effect breast cancer and chemotherapy has on younger men's relationships. These men said they were fearful about their ability to provide for their families and of their reliance on others when they were usually independent. This was not a finding reported for the older participants in this study, and it is unclear whether this continued beyond the completion of treatment.

Body image however, was a theme presented in most of the qualitative papers (France et al., 2000, Iredale et al., 2006, Williams et al., 2003). Men discussed coping strategies that included keeping their chests covered, stopping activities such as public swimming, hiding their chests in changing rooms or keeping their tops on when visiting the beach (Pituskin et al., 2007, Naymark, 2006, Donovan and Flynn, 2007). There were some men however, who did not mind showing off their scar and described it as a 'war wound' (France et al., 2000, Pituskin et al.,

2007) or downplayed the effect on them of their mastectomy compared to women (Naymark, 2006).

7.6 Men with Breast Cancer: The Embodiment of Cancer, Treatment Effects and Effect on Romantic Relationships

7.6.1 The embodied effects of treatment

The men's treatment varied, however all had a mastectomy and all were prescribed hormonal therapy following active treatment. The narratives of surgery and the effects on their bodies are presented later when discussing body image. Sixteen men however had radiotherapy treatment and three discussed the scarring that radiotherapy had caused to their chest. In all three cases, the scarring was described as similar to sun burn. Clive (MBC67) said he "still bears the scars" from radiotherapy and Henry (MBC93) said he was "quite burnt" at the time. Both Clive and Henry had been treated for breast cancer eight and four years respectively prior to interview and their scarring had reduced. Jack (MBC59) however, had been treated within the last year and his chest was "still a bit warm". He was concerned the ongoing heat in his chest was an indication that his wound was not healing properly and asked a doctor to have a look at it. Jack said he misunderstood how and when he was to apply an emollient cream to the area to ease the burning and was chastised by the hospital staff for not using enough. When interviewed he was using the cream twice a day and leaving his top off whenever possible to allow the cream to absorb. In the past however, he would normally have been topless at his allotment but he now keeps his top on when gardening to save any embarrassment his scarring may cause:

I said, the only time I'm stripped to the waist is usually I sit in here at nights with nothing on because I put the cream on and all that, and I'd rather it soak into me than into me clothing, and of course, weather like this, down on the allotment, I strip to the waist... [the scarring] it curtails it [removing his shirt] a bit because I don't want to embarrass them [other gardeners] or myself for that matter.

Jack (MBC59)

All the men who participated in this study were prescribed hormonal therapy, most commonly tamoxifen, an anti-oestrogen drug that stops oestrogen-sensitive tumours recurring. There is no research to date that has explored the effects

which taking this treatment has on a man's body and this caused concern for some men (4/19). Side effects were a problem and three men had to stop treatment before the five year course was completed. The most common side effects the men complained of were hot flushes (3/19), altered emotional state (5/19) and loss of libido (7/19).

The men who reflected on tamoxifen and what it was doing to their bodies said they were experiencing severe side effects which made them wonder what else it was doing that they did not know about. For example, Tam said he felt like a "guinea pig" as they tried him on different tablets to get one that was not causing him any side effects. Andy (MBC73) said the only information he was given was relating to women's bodies and he wanted to know as a man what it was doing to him. He said he experienced severe fluid retention that worsened throughout the day and he could "blow up" a trouser size, which he had to buy new clothes to cope with:

But I was given tamoxifen, which didn't do me very well. It blew me up, it just... I got all the, you know, the menopausal symptoms. Men aren't supposed to have menopause but I had the night sweats where something... we were going through the night sweats together, so the bed were wet through [laughs]. And we had the night sweats and the hot flushes and whatever else and I were just getting bigger and carrying a lot of weight and fluid... What is tamoxifen doing?" I said, "cos I feel horrible". And... well, it's just the same as it for... but for a woman it cause, you know, problems below. Womb cancers and cervical cancer and whatever else. I said "but what is it doing to a man? I ain't got them bits." And they went "well, you know...", you do feel it affects other things as well as, you know...

Andy (MBC73)

Tony (MBC70) did not report his symptoms interfering with his daily life as Andy did, yet he still wondered what research had been done exploring the effects of tamoxifen and whether the pain in his legs were legitimate for him to have as a man. He said he felt because there was no evidence supporting his claim people doubted whether he was telling the truth or not:

Are you on Tamoxifen?

Yeah. And that's another thing, I don't think... I've not actually... as I say, I go on the internet a lot, and where Tamoxifen's concerned or any medication for the men, has there been any research on the side effects? It's okay putting all the side effects down on a piece of paper when you look at them when you get your Tamoxifen, and you read those side effects on that leaflet, but are those side effects also being checked out on men? Because there's issues like, it says on the... on one of the side effects is aching joints, muscles, and I suffer from that considerably. My legs, all the front muscles on here, my upper legs and my upper arms, really ache and I'm not sure whether people think I'm trying to put it on. I personally think they do. Some people I think do think that.

Tony (MBC70)

7.6.2 Sexuality

Seven men talked about the detrimental effect that hormonal treatment had on their libido. All lamented its loss apart from one man, Nick (MBC55) who said he felt his sex drive was always far too high and now that it was gone he could "do things without bothering about thinking about these sort of things." Later in his narrative, Nick revealed he had recently met a woman who if he had been sexually able, he would have had an intense sexual relationship with. He had not had a girlfriend for many years and dismissed his impotency as part of life:

I haven't had a girlfriend for fifty years, and then I get this [breast cancer] and I have a girlfriend. That's life, it's a bitch, isn't it?
(laughs).

Nick (MBC55)

Two men referred to their age when discussing their loss of sex drive. Alec (MBC91) said he mentioned his impotence to his GP - "I was just winding him up you know" - but when questioned further on this he retorted that he was "sixty for God's sake, you want me to go on forever!" This is in contrast to Patrick (MBC81) who was planning to see his GP about what could be done to improve his libido as he still felt he was young enough that he should be enjoying an active sex life. He was also keen to downplay the importance that sex should have in a relationship and was keen to stress how supportive his wife had been:

Has [the tamoxifen] affected [your sex drive] at all?

(Pause) Em... No I don't think it has really. It's more...(pause) well I suppose it's more my own expectations, you know. You sort of feel that being a - I still think of myself as a young man, you know, that that side of things is more difficult, and...I don't know. I'm not, I'm not sure, I've got very mixed feelings about this really. You know I sometimes think we, we pay too much attention to it anyway. It's- I mean there is, there is a difficulty there but I don't want to over-egg it, cause I do think we've become a bit obsessed with, that area of things.

Patrick (MBC81)

Two men discussed using Viagra to improve libido, although neither admitted using it. Adam (MBC79) said he had discussed Viagra with his GP but had decided against using it. He said he had "lost that [sexual] part of his life" and although he tried to show affection to his wife he wondered whether she realised he still loved her and would buy her flowers and chocolates to try and make up for some of his problems:

I blame it, I say it's [tamoxifen] tablets ... I can't get an erection. Sex doesn't bother me. I can't get, and I've had this for now a lot of years... I know I did have a talk with my doctor once, I was gone a few years and he said, he mentioned Viagra but no, I just don't even think about it... I just, it's just I'm not interested. I can't say I'm not... I'm not as... I always give my wife a kiss but that's it... That's it, you know? Maybe she says I don't say I love her like I used to. That goes with time sometimes. But it's me that... I know I love her, I do love her. I know in my heart. Yeah, I feel I missed... I don't, I'm not angry about it now. It's just part of me now, it's just... doesn't bother us. Not bothered, I don't think. I don't even think about it. Why think about it when it's not going to happen (laughs).

Adam (MBC79)

Bob (MBC89) also discussed his loss of sex drive with his GP and was given some Viagra to try although he said he never used the pills as they had been married for so long (46 years) that sex was not as important now as it once was. He said he had a loving relationship with his wife and they could still "cuddle and do other things" and did not feel the loss of his libido "too much". Bob later talked about additional health problems and at times had to sleep in his recliner for comfort.

7.6.3 Body Image

The first response from ten men about whether they felt differently about their body following surgery was that no, they did not. For example, Mani (MBC76) said it did not bother him at all and William (MBC83) said he thought it was more important to “feel ok” at his age than worry about the scars on his body.

Four men compared their breast cancer experience to a woman’s and said they felt their cancer did not have the same impact on them as men, as it would for a woman. For example, Henry (MBC93) said he did not have a breast but a “chest” and to remove his cancer was straightforward and he had no side effects from treatment. Similarly Michael (MBC75) dismissed his experience of having a mastectomy when comparing it to a woman. He had been searching for more information on one of the charity websites and did not find anything he could relate to as the breast cancer section was designed for women and he said “obviously a mastectomy in a woman is far greater than a mastectomy for a man. It’s much more traumatic.”

Reconstruction surgery was offered to five men who all declined having it and another two men who were not offered any reconstruction said they would not have wanted it anyway. For example, Michael (MBC85) referred to his scar as his “Vietnam war wound” that caused him no problem and Jack’s (MBC59) surgeon offered him the chance to have a nipple tattooed on but he felt he was too old for such treatment as no one saw his chest anyway:

I’ve no nipple because when [the surgeon] was on about rebuilding, I said, “well at my age, I’m not really bothered”.

So, you were offered reconstruction?

Yes, they said they could tattoo them if I wanted in that area. I said, “Well I ain’t really bothered”.

Jack (MBC59)

However, two of the men who said they declined reconstruction did not like looking at their scars and hid them from other people. For example, Tony (MBC70) said he was offered a nipple tattoo but thought it would be easier to take his other breast away. He did not like needles and felt he had had enough surgeries although he said seeing and touching his scar got him “down

sometimes.” Similarly Nick (MBC55) said he could do without a nipple when offered a tattoo and described his scar as “just a wound.” However, later in his narrative he admitted to finding his scar “ugly” and would not want other people to be asking questions about it:

So if you were on holiday, would you take your top off?

No I wouldn't, no.

You wouldn't do that anyway or you wouldn't do it now?

I certainly wouldn't do it now. It's still rather ugly - it's still rather an ugly wound. It's right around, underneath the armpit. It'll get better with time, of course - but I don't want to see people see me with only one nipple, they'll be wondering what's going on.

So it has affected you a wee bit?

Em... Yes, it has affected me a little bit.

Nick (MBC55)

Nick was not alone when he said he would not let other people see his scar. Five men had changed their leisure activities to ensure they always had their bodies covered. For example, George (MBC52) refused to take his top off on a warm day in case people asked him about his scar. Clive (MBC67) and Patrick (MBC81) no longer swam, a pastime they both enjoyed before their breast cancer. Clive's wife tried to persuade him to go along with her and recommended swimming as excellent exercise but he was too self-conscious about his scar:

My wife swims now, although she's a bit older than I am, she swims twice a week. She said, “Oh, come with me, good exercise.” I'm like this, “I don't know whether I want to go”. Sometimes I want to go swimming, but I don't want to walk about with nothing on... I'm self-conscious about it. I'll have to finish, I think we shall have to make a go, cos I go to the gym now once a week. My wife comes to the gym and she goes swimming twice a week, and she says “oh, come swimming with me, that's the best exercise out.” But I haven't got round to it yet. Yes, I am self-conscious about it.

Clive (MBC67)

Patrick also said he was “aware of this [mastectomy] side” and did not feel he could go to the swimming pool, strip off and “be natural about it.” He also

reflected that he thought that “women are possibly supported better than men” while coping with a mastectomy.

There were a few men who said they felt embarrassed about their altered bodies for reasons other than their mastectomy scar. For example, Tam (MBC77) said he felt embarrassed after noticing changes to his remaining breast that grew bigger after taking tamoxifen. He said it was fine as long as it was not sticking out (like a woman’s), but if that changed he would ask the surgeons to remove it:

And it’s, I think it’s hormones what they give you - that breast has got bigger, there’s no two ways about it, it’s got bigger, you know what I mean? But it’s just hormones - but it isn’t like it’s sticking out, you know what I mean? Coz if it was like that, I would just ask them to take it off, yeah. Can you imagine walking about with (laughing).

So you would rather have it taken off, rather than it be something...

It stuck out... Oh yes, yes.

Tam (MBC77)

The other two men, Tony (MBC70) and Adam (MBC79), both said their bodies were not as they once were, and ageing had made their bodies less attractive. Tony (MBC70) had been in the Army as a younger man and was often at the gym. He now could not do any weight lifting for fear of lymphodema occurring in his arm. He said there was a time when he felt “good in himself” but since his cancer he had put on weight and could not exercise to lose it. Adam’s narrative was similar. He had also put on weight and said he would show his scar to anyone who was interested, but would not like to offend anybody by having his top off because his body was not very nice to look at:

As I’ve got older your body gets a bit more obviously... and I think, well, it might put some off, and it’s not very pleasant to look at honestly. But so I’ve never taken it, I wouldn’t like to offend anybody. I was asked, as I say, “would you like to see it?” If they say yes I would say “yeah”, I’m there, I’m not bothered. I’ll show it, you know? Something that I’ve had done and it’s still in my body.

Adam (MBC79)

7.6.4 Intimacy and Romantic Relationships

Fifteen men were married when they were diagnosed with breast cancer, and were still married at the time of interview. There was a range of responses when asked about the effect their cancer diagnosis had on their relationship. Eight men said their relationships had not changed during or since their diagnosis, and they were as loving as ever. This was despite a change in their sexual function. Alec (MBC91) said that despite losing his libido, he and his wife now showed their affection in other ways. He kissed her in the morning before going to work, something he did not do before his breast cancer diagnosis and they were “more cuddly than what we were ever”. Henry (MBC93) said he thought his relationship with his wife had improved since his diagnosis. He thought they cared for each other more after dealing with a life threatening illness:

Has there been any other changes in your relationships since your diagnosis?

No I mean I think that, one should say that probably we are closer, that we somehow care for each other more. I would say it's strengthened particularly since [my wife] had breast cancer as well. That we, we both are very close and think about each other a lot and on the whole take great care of each other, and we have our little spats and, we get on each others' nerves here and there but I think on the whole we have a very, very positive relationship. And probably that has been helped in a way by, you know running these- running the gauntlet, you know. It does make you more sensitive and more caring.

Henry (MBC93)

Furthermore, three men attributed getting through their cancer treatment to the support they received from their wives. Jonathan (MBC75) said his wife gave him a lot of encouragement to “keep going”. Eric (MBC71) said his wife was always watching him and would encourage him to get up and help round the house when she saw him getting “melancholy”. He also felt they were more protective of one another and looked after each other more than before the cancer diagnosis:

She's more, protective now. Than she probably was. She worries more now. If I go anywhere and I'm not back when I say I'm going to be back now, she obviously worries. But having said that, I do the same, when she goes out.

Eric (MBC71)

Clive (MBC67) said he could not have got through the cancer experience without the support of his wife despite having problems controlling his anger, which was often directed towards her. He said he thought his anger problems were related to his chemotherapy treatment. However, the anger started months after chemotherapy while he was on hormonal therapy. His wife took the brunt of his anger and while he always apologised after (and meant it) he struggled to stop the outburst in the first instance:

Just... maybe one time my wife would say something to me, "oh, don't be silly", but now she said the same thing to me, I let fly and have a go at her for no particular reason at all, but she's accepted that it's not me. But... I don't know.

Clive (MBC67)

Clive knew his angry outbursts were irrational and was thankful that his wife knew he did not mean to upset her and remained supportive throughout:

And was your wife very supportive to you?

Yes, I couldn't have managed without her.

Yeah. How did you find her supportive? What did she do to help?

Well, if I had... had a go at her, she just put it down to oh, well, that's not you. I always apologise afterwards.

Clive (MBC67)

Clive was not the only man to describe changes to his emotional state since being diagnosed with breast cancer. Another four men reported changes to their emotional state including crying at anything - sad stories on the television, watching children play - but also reported problems controlling their temper and would get very angry at insignificant issues that before treatment, they would never have worried about. Bob (MBC89) had to change his hormonal therapy twice in an attempt to overcome the side effects he had. It also put his marriage in jeopardy, as his mood swings were so extreme. His wife had gone to her GP for help as she was struggling to cope with his anger. Bob learned to adapt his behaviour and when he felt his temper rising would remove himself and get in the car and drive until he felt he had calmed down before returning home. He

could be gone for hours while his wife remained at home not knowing where he was and worrying what he was doing:

No, the Arimidex wasn't good for me.

What was the side effects of it? Can you remember?

Oh, very aggressive and grumpy, yeah. Oh, yeah. Of course, I was getting hot and cold flushes, which women get, of course... and I was very emotional. I would cry just watching children and things like that. To not make a scene, I would just remove myself. It's a safety ploy. You remove yourself from the danger.

Bob (MBC89)

Unlike Clive, Bob said he thought he was much harder to live with since his diagnosis and had put his marriage under strain because of his emotional outbursts. Another two men talked of strains in their relationships following breast cancer. Andy (MBC73) said he did not feel as though he was the same person after his treatment. He said he verbally lashed out at loved ones and struggled to get through the treatment, which ultimately he felt had changed his personality:

The other part is the partners, you know, the people you live with, the families, and you just think well, they're going through all this as well but they're not having the drugs. You know, when you're feeling crap, and we've had some horrible sessions and it really, really takes you to as low as low as you can be, and you think is it worth it? You know, it feels crap. And we've had some shouting sessions and... but bricks aren't they, the family?... You always pick on your loved ones don't you? Nearest and dearest always catch everything. It's horrible. It's just- yeah. It's not me. It's changed me. I used to be a nice placid guy but I'm not anymore.

Andy (MBC73)

Adam (MBC79) also struggled with mood swings and anger since diagnosis. He said he thought his marriage had been good up until his breast cancer diagnosis and had "gone downhill" from there on. He said he felt the cancer had changed him. He had become "stubborn and arrogant" and recalled angry outbursts at his wife and daughter - something he had never done before his diagnosis. He said his marriage had only survived because his wife had been supportive and understanding:

Do you think it's affected your relationship?

My wife would say yes. Yeah, I think she would be right in saying that. It's changed me. It has changed me. Stubborn, very stubborn...attitude... I know I have.

Adam (MBC79)

Finally one single man, Tony (MBC70), talked about his fears of never being in a relationship again following his diagnosis. Tony had been in a long-term relationship that ended when he was diagnosed with breast cancer. While attending a support group he listened to other women talk of the support they received from their partners. He said coping with his breast cancer on his own was harder for him. Despite having made contact with women on the internet he had lost his confidence and did not feel able to meet them:

I've not got a partner, which makes my life a lot harder in a way because ...I've not got a partner to get support off of...

Do you think the breast cancer has affected your chance of having a relationship with a woman, getting a partner or...?

I worry about it. I do worry... I also have lost confidence of going out to socialise. I've lost that confidence now, whereas... I mean, I'm ex-army, that's never really bothered me before but I've lost all confidence of going out and socialising, looking for a partner. I don't want to.

Tony (MBC70)

7.7 Women with Breast Cancer: The Embodiment of Cancer, Treatment Effects and Effect on Romantic Relationships

7.7.1 The embodied effects of treatment

There is little data within the women's narratives on the use of hormonal therapy such as tamoxifen. Eight women discussed taking tamoxifen and the menopausal side effects it caused, mainly hot flushes, mood swings and increasing weight. Despite this, all eight said they would continue taking it, as they knew the benefits outweighed the side effects. For example, Hannah (FBC62) had read a lot about tamoxifen and knew it was a drug that was "doing some good" and despite turning into a "blob woman" would continue taking it. Ada (FBC74) was another woman who continued taking tamoxifen despite

describing hot flushes that would cause such severe sweating that her whole body would sweat:

And it [hot flush] can just come on all of a sudden and go away as suddenly, much worse than sort of normally as they would happen. So oh er it's my head, my hair gets soaking, scalp gets very hot, runs down the sides of my face, and the backs of my hands get soaking, arms get soaking, my whole body gets soaking actually but that's where it's sort of most noticeable, and then it all kind of evaporates and you suddenly feel cold. So you're either hot or cold and never right.

Ada (FBC74)

Ada found train journeys uncomfortable as the air conditioning only worked when the train was moving, and she had to anticipate where meetings for work were being held, as stuffy rooms would also cause sweating. She tried complementary therapies (evening primrose) to counteract the effects, however she stopped these, as she did not feel there was any benefit. Despite the hot flushes she continued taking tamoxifen.

Three women had taken hormone replacement therapy (HRT) before their breast cancer diagnosis. All three had to stop taking it when their breast cancer was diagnosed. Two of these women were sad at having to stop the HRT and described their menopausal symptoms returning which made them feel older and they mourned the loss of their youthful selves. Mary (FBC66) was not as explicit in her narrative although she did say she was "very happy on HRT, it was really lovely" and commented that there was "always KY jelly" for the vaginal dryness that she had and "it was lovely while it lasted." It is unclear in her narrative what impact this dryness had but it can be speculated that it may have interfered with her sexual life. In contrast to this, Charlotte's (FBC94) narrative was rich in description on the effect coming off HRT and starting tamoxifen had. Her breast cancer diagnosis had been a huge shock to her and her long-term relationship broke down:

And being a woman of my age I, I was having a pretty good life thanks to hormone replacement therapy, it's sort of bog standard prescription for every woman in her late 40s, early 50s. And I personally feel that that was linked to my breast cancer because there is no family history. So I immediately came off that and suffered for the first time very acute menopausal symptoms. And I felt and believed that the romance in my life was completely over, that I was never going to be desired or feel desirable or have any sense of desire myself, that I was going to have something awful done to my breast, I would not be a woman in that sense any more and the coming off the HRT reminded me most horribly of how menopausal I was, which is a word I just hate.

Charlotte (FBC94)

Charlotte said she "came out the other side" by using natural progesterone cream that alleviated some of her symptoms.

The narratives of three women suggested chemotherapy was more of a threat to their body image and femininity than the surgery they had. For example Fara (FBC90) described her chemotherapy experience as "very, very bad." She did not want to have chemotherapy and had thought surgery (a mastectomy) would be sufficient. During a break in chemotherapy she had radiotherapy and her hair started to grow back and she started to feel better. She then refused more chemotherapy and decided to leave her fate in the hands of God. Another woman Hannah (FBC62) said she found it difficult to accept she needed chemotherapy and eventually managed to think of the treatment as "a little army coming in to zap the enemy, the cancer." Although Hannah described the treatment as necessary she found the effect it had on her body difficult to cope with:

I didn't have a chemotherapy that I lost my hair, my hair thinned considerably and that did upset me quite a lot because I hadn't got very much hair anyway and every time I brushed my hair more came out but I didn't, it just thinned I didn't go bald. I thought I was going to become thin and waif-like and interesting but I found out that wasn't the case, that I actually put on weight so that was, that has and is still a little depressing. But I'm living and I'm here and the drugs are helping me so, you know, it's a small price to pay, I feel.

Hannah (FBC62)

Amelia (FBC78) dreaded chemotherapy and described the effect it had on her femininity vividly. She used the cold cap, which she found very painful to

preserve her hair although it had little effect and the steroids she took to alleviate the sickness increased her appetite and she put on weight. She struggled to cope with the cancer diagnosis and the attack on her body image:

...And my hair, despite the cap, was thinning and I had two areas of about an inch round the ears where it's not close to, where the cap doesn't, well it's sort of pushed out by the ears, so I had bald bits there and there, and I used to have to pull the hair down over it. And my hairline receded and you just begin to look very different, no eyebrows, no eyelashes, and I was fatter, so it really was quite devastating, you felt your femininity was coming out with the sickness really. And it's very difficult to think of yourself as having any good inside when all this dreadful stuff has been pumped into you. It's bad enough to feel that you've got this cancer, there's something bad, these cells that are going all into crooked ways inside you but on top of that to, you know, lose your looks.

Amelia (FBC78)

Once treatment was complete, her hair and eyelashes grew back and she "made sure everyone in sight knew that [she] had those eyelashes."

7.7.2 Sexuality

There was little discussion in the women's narratives about the effect breast cancer had on their sexuality. As presented earlier (7.7.1), Ada (FBC74) alluded to changes in her body once she had stopped HRT. Only one woman talked about sexuality following breast cancer. Jennifer (FBC50) described her husband as a "boob man" and was uncertain she believed him when he said her mastectomy did not bother him. He said he would rather have her alive than not and if that meant with one breast that was fine. Jennifer had numerous scars on her body following one failed reconstruction where tissue was used from her stomach, and one from her back that had become infected after surgery. Jennifer said she had noticed her husband did not watch her getting undressed anymore. Furthermore, before the mastectomy when they were physically intimate he would normally have removed her nightdress but now does not. Jennifer said this made her upset and thought he must think her ugly:

If I ever talk to him about it now all he'll say is that he would rather have me with one breast or no breast than not have me at all. But that's what he says to me er, I don't think that is necessarily what he thinks. Er before all this happened if I was getting ready for bed at night, may be I was getting changed in the sitting room and he was sitting on the settee, he would put down his paper or stop watching television, fold his arms and just sit and watch me getting undressed. And that stopped er after I had the mastectomy. And I did mention it to him one time and he said "Well I'm not conscious of it, I'm not conscious of it," and then for a while he would do the same thing but you could tell it wasn't spontaneous, it was because I had said something.

Jennifer (FBC50)

However, Jennifer's narrative goes on to talk about her relationship with her husband. She said she found it difficult to talk to him because he was a "private person" and she did not really know what he thought about her body since her mastectomy. She said she knew he loved her and demonstrated it by showing affection. She said they had become closer since her breast cancer and he was also more helpful around the house. However she also felt her breast cancer had changed their relationship:

I mean he's very demonstrative in that he's always giving me kisses and cuddles and he always tells me he loves me, virtually daily er, and I'm the most important thing in his life. And I know that, but it's, you still feel er rejected in a way because you just feel that it can't be the same any more no matter how much he says that it doesn't matter, because it must matter, it must make a difference... It's brought us, it's brought us very, a lot closer together. We had, quite a number of years ago now, we had a sort of bad patch and we got through that. But this has definitely brought us a lot, lot closer together and it must be visible.

Jennifer (FBC50)

7.7.3 Body Image

Ten of the women interviewed had had a mastectomy while thirteen had had a lumpectomy. The findings do not suggest that an altered body image is exclusively a problem for mastectomised women. For example, Charlotte (FBC94) described her lumpectomy as "an invasion of a precious part of you" and went through a "patch of self doubt" wondering if her breast size had been reduced following the surgery. Hannah (FBC62) also talked of the early emotions that the scar on her breast brought back every time she saw it and the changes she made to her routine to cover her body up when she was getting changed at the gym:

...I found it very difficult even having a scar on my breast and having a scar under my arm. But I found that was, when I went swimming I would not do what I normally do which is take my swimming costume off under the shower, I do now, I've got over that but initially I found it very difficult. And the fact that you look in the mirror and every time you look in the mirror you've got a scar and you've just got to sort of, you know, and that's sort of, well that's cancer. But I don't do that so much now I don't think as I probably did. Er it's just a battle scar really, but I don't think I, I don't think I would've coped with a mastectomy. But then I've not had, again I've not had to face it [a mastectomy] so you, if that was your option of living or dying you'd take it.

Hannah (FBC62)

There were five women who were given a choice between a lumpectomy and a mastectomy. Four of these women chose to have a mastectomy and another woman requested a bilateral mastectomy despite not clinically requiring one. For example Lesley (FBC70) opted for a mastectomy as she had previously had some calcification (pre-cancerous cells) in the affected breast and said her "breasts had served their purposes" breast feeding both her children and it "didn't worry" her to lose a breast. Catherine (FBC52) had breast cancer twice and the first mastectomy "broke her heart". She could not look at her body for a month after. Dressing she would turn her back on her husband and thought a one breasted woman was "the funniest thing." She wore a prosthesis in her bra and refused to tell anyone she had had a mastectomy, as she "wanted to be normal." Fourteen years later she was diagnosed with breast cancer in her remaining breast and despite being told she did not need a mastectomy, a lumpectomy would suffice, she wanted the whole breast removed to balance her out and to eliminate the need for any further treatment. She said her husband was supportive throughout and her mastectomies never "bothered him" and they would joke about her "boyish" body:

I mean he'll strut in front of me, it's just nature and I know I mean I'm like a young boy now with nothing, so it doesn't bother me (laughs). In fact he used to kid me on, he'd say, "I don't know why you wear a bra," he said "because a string vest would do you," you know one of these Rab C Nesbit vests (laughs), one of them because I had nothing anyway. So it doesn't really bother him, in fact we make a joke of it sometimes, so you've just got to. I mean as I say you can't dwell on these illnesses all your life, you know what I mean.

Catherine (FBC52)

Another example was Margaret (FBC54) who wanted a bilateral mastectomy to prevent any further back injury that having one large breast may cause. Like Lesley, she also felt that her breasts had served their purpose and were not attractive anymore:

I chose to have both breasts off and if you're asking was I grieving over the loss of my breasts frankly, no. Er I'd had then for the best part of my whole 70, 60 years er they'd been pretty young things at one time just as I was er but they've served their purpose. Er, no I'm not, I'm more than a pair of boobs on legs for heavens sake. I've never had a great big thing about it, I really couldn't care less frankly (Laughs).

Margaret (FBC54)

There were five women who said that they would have felt differently about their mastectomies if they had been younger, and Margaret was one of these women. While Margaret was comfortable with her decision and felt that as a society we had been "brainwashed" to think that having a breast off was "mutilation" she did acknowledge that she "totally comprehended" this may be different for a younger woman but at her age, she was "a bit old for that now." Another example was Emma (FBC86) who did not think the scar on her breast following a mastectomy affected her body image although she laughed that she was "63. If I was 30 it would be very different."

Layla (FBC82) was divorced from her husband and did not have a partner at the time of being interviewed. She did not like to see her mastectomised body when she was undressing and did not think she would find a man who would be interested in a one breasted woman. She said this did not worry her as she had six children that she was grateful for and she found the prosthesis very comfortable. Her priority was to be well and able to work again:

Did anyone ever discuss reconstruction with you?

No I don't want it...At my age I don't think I would bother with it, maybe if I was younger I would do it, but I wouldn't do it again now, I'm happy as I am. The only thing that I want to do now is to get well again and get back out to work.

Layla (FBC82)

7.7.4 Intimacy and Romantic Relationships

Six women said their relationship had not changed since their diagnosis and they felt supported by their husbands. Ada (FBC74) said her husband supported her treatment choices and did not mind what she chose as long as she was happy. Jane (FBC68) said her husband had coped “better than most husbands” and Camilla (FBC84) said her relationship had not changed despite feeling she snapped at her husband more since her diagnosis.

Two women (FBC52 and FBC66) said they wanted to protect their husbands from their cancer and its treatment. Catherine’s (FBC52) husband had already witnessed and helped care for her sister who had died of breast cancer and she worried about the effect her diagnosis would have on him. Mary (FBC66) wanted to protect her husband from her diagnosis because his first wife had died of cancer and did not want to worry him.

Two women talked about their relationships breaking down following their breast cancer diagnosis. Charlotte (FBC94) had been having doubts about her relationship and realized soon after diagnosis that her partner could not cope. She said she feared her romantic life was over. However, Charlotte said she had a “happy ever after story” and had met a man that could cope with her diagnosis and with whom she could share her life. Hannah (FBC62) said her husband was supportive at diagnosis and reassured her that she would be alright. She said she knew during her chemotherapy treatment that her husband had “emotionally left her”. She said he was distant and depressed and their relationship was strained. Four months after her treatment was complete, her husband left her:

Before I started radiotherapy and I suppose at that point, I knew at that point that my husband emotionally had left me at the end of the chemotherapy... he found it so difficult and from that moment, before I started radiotherapy he wasn't there for me, which was very traumatising at the time. And I knew he was depressed and I knew he wasn't coping but he wouldn't, he wouldn't go and see anybody and he, I gave him, I found out, there's, there was one of the breast cancer help lines, they actually have a relative's support line but the person who needs the help has to phone themselves and he wouldn't do that... and I just feel quite, I feel very, very sad about what happened, but it did and I have to get on with my life now.

Charlotte (FBC62)

7.8 Discussion

Doyle's (2008) concept of cancer survivorship as an uncertain, life changing experience was found within the men and women's narratives. The enduring effects cancer and its treatment had on their bodies were similar, yet the men discussed their relationships in more positive ways than the women. It was difficult to make direct comparisons between the men and the women in these aspects of this thesis because these were areas, which most strongly revealed their different circumstances. Most men were married whereas approximately half of the women were married. It is not known whether women talked specifically about their relationships in their interviews. Data on relationships, sexuality and intimacy were minimal, which may have been the result of these areas not being discussed during the interview process or consent for these sections being declined for further use in secondary analysis. A summary of the similarities and differences in the findings available are presented in box 4.

Similarities Between Men and Women

- Both men and women experienced embodied effects of breast cancer and its treatment.
- Both men and women experienced an altered body image regardless of surgical treatment (mastectomy or lumpectomy).
- Both men and women described their intimate relationships as unchanged or better since their cancer diagnosis.
- Some men and women said they showed their partners love in other ways, such as holding hands or buying gifts, following the loss of libido.

Differences Between Men and Women

- Some men attributed "getting through" their breast cancer treatment to the support they received from their wives.
- A few men (no women) described deterioration in their intimate relationships because of changes to their personalities or problems controlling their anger.

Box 4. Summary of Similarities and Differences in The Embodiment of Cancer, Treatment Effects & Romantic Relationships in Men and Women

Breast cancer treatment in men and women had some similar effects on their bodies. Both said they had hot flushes, mood swings, and loss of libido, in line with current understandings of breast cancer treatment side effects (Fentiman et al., 2006, Ottini et al., 2010, Janz et al., 2007). The reflections from the men and women on their treatment however were different. Some men wondered

what the treatment was doing to their male bodies because there was no research to validate the side effects they were experiencing. Treatment uncertainty among men has also been reported elsewhere (France et al., 2000). In contrast, some women said that despite uncomfortable side effects they knew it was in their interest to keep taking the treatment to improve their chances of survival and stop recurrences. Chemotherapy appeared to pose more of a threat to a small minority of women's femininity than surgery, concurring with other studies (Wilmoth, 2001, Richer and Ezer, 2002, Browall et al., 2006). Hair loss and steroid use were particularly difficult for these women to come to terms with. Men who had chemotherapy discussed the side effects in relation to their disclosure and inability to hide the physical effects on their bodies.

Unlike Chapple and Ziebland's (2002) study of men with prostate cancer taking hormonal therapy who reported mourning the loss of their sex drive and sexual frisson they enjoyed with women, only one man said he was planning on seeing his GP to discuss treatment for his impotence. The other men, although talking about their impotence as a concern, said it was not important to them. They compensated for their lack of physical intimacy in other ways, such as holding hands, cuddling and kissing, telling their partners they loved them and buying flowers. In addition, some men said they were too old to maintain an active sex life (see similar findings in men with prostate cancer (Boehmer and Babayan, 2004, Fergus et al., 2002)). These findings concur with Connell's (2002) rejection of men's sexuality being phallocentric and based on the biological act of sex. Connell (2002) suggests that "in sexual practices, bodies are drawn into social processes...they are drawn into a social world that is structured by gender relations" (p 94). In this study the men renegotiated their sexual identities to construct an alternative masculine identity that included traditional feminine characteristics such as emotional expressiveness.

The initial response from most of the men in this study was to report no problems with their body image. Over the course of the interview it became apparent they did in fact have concerns about their bodies. This initial denial of body image concerns and later confiding was also found by Iredale et al (2006). A few men also down played the effect their mastectomy had on them as being insignificant to what a woman must go through having a mastectomy. Naymark (2006) also found her the men she interviewed said they thought a

mastectomy would be worse for a woman and “breast cancer means *more* to a woman than a man” (p 162, italics Naymark’s). Naymark (2006) attributes the men’s feelings to (western) society’s association between the female breast and a woman’s sexual attractiveness. Another explanation may be that because there is so little information and support available to men with breast cancer, they assume their breast cancer is less important than women’s. McCaughan and McKenna (2007) suggested men did not ask for information because they felt uncomfortable within the hospital and ‘out of place’. It may be men with breast cancer feel ‘out of place’ within the predominantly female arena of breast cancer and rather than drawing attention to themselves downplay the effects breast cancer has on them individually.

An altered body image was found in some of the men and women (Figueiredo et al., 2004a). Some men did not want others to see their scar and kept their chest covered at all times. Some men changed their leisure activities to ensure they were never topless, concurring with other studies (Pituskin et al., 2007, Naymark, 2006, Donovan and Flynn, 2007). However, not all men now hid their chests because of their scars. Three men said they did not like their ageing bodies and due to a lack of exercise had lost their youthful, toned physiques. Some women who had a mastectomy also talked about their bodies having “served their purpose” and their breasts were not necessary anymore, concurring with Reaby’s (1998) findings. Not all women however had accepted their new body image, including women who had lumpectomies. These women found their lumpectomy scar “ugly” and reminded them of their cancer diagnosis every time they saw it. One man described his scar as his “Vietnam war wound”. France et al (2000) also found some men used this embattled imagery to describe their scars. One woman also described her lumpectomy scar as a “battle scar” that reminded her every day of the life saving surgery she had gone through to stop her cancer spreading.

In contrast to other studies (Boehmer and Clark, 2001, Bokhour et al., 2001) despite the loss of sex drive, most of the men said their relationship with their wife was either the same or had got better since their breast cancer diagnosis. The women’s narratives did not discuss their marital relationships in as much detail, but some said they had felt supported by their husbands and their relationship had not changed. According to Tolstedt and Stokes’s(1983) there are

three key elements of intimacy (verbal, affective and physical). The findings in this study suggest deterioration in one element (physical capability) can be compensated by increasing another element to maintain, and sometimes improve intimacy in lasting relationships.

Not all the men however reported continuing good relations with their wives. Four men who said their relationships had deteriorated since their diagnosis described changes in their character and mood swings. Bokhour et al (2001) found the loss of physical intimacy led to the deterioration of their participants' relationships and the men withdrew their emotional intimacy to protect themselves from the disappointment of not being able to perform sexually. Similar findings reported by Emslie et al (2009) and Boehmer and Clark (2001) suggest that often couples stop communicating to protect their partners from their fears and treatment experiences. Using Tolstedt and Stokes (1983) elements of intimacy, the deterioration of two elements of intimacy (physical and verbal) may not be compensated by the one remaining element thus relationship quality is affected (Tolstedt and Stokes, 1983). In this study although some men said their relationship had been altered, none said their relationship had broken down. In contrast, two women said their relationships had broken down. Fergus and Gray (2009) reported the husbands in their study had felt ill-equipped to deal with their wives breast cancer diagnosis which caused a strain on their marriages.

8 Discussion

8.1 Introduction

This discussion chapter will bring together the main conclusions from the previous findings chapters, providing answers to the research questions posed in Chapter 1. The study's limitations will be considered, and recommendations for future research and practice will be presented.

The aim of this piece of work was to explore men's experiences of having breast cancer and to compare their experiences with women's. Such a comparative approach is novel in this area, being the first systematic comparison of how the experiences of men are similar or different to those of women with breast cancer. What are men's experiences of having breast cancer, a disease that is so much more common amongst women? How do the experiences of men compare with the experiences of women, given this context that? What effect, if any, does having a 'feminine' cancer have on a man's identity and masculinity?

8.2 How do men's experiences of having breast cancer compare with women's experiences of having breast cancer?

8.2.1 Help-seeking

Less than half of the men reported seeking professional for their symptoms promptly. There is a widespread stereotypical characterisation of men as reluctant help-seekers, often relying on their wives to persuade them to see their doctor (Galdas et al., 2010). This stereotype has been reported in relation to men with breast cancer: Williams et al, (2003) suggested the prompt help-seeking of men with breast cancer in their study were due to wives 'prompting' their husbands. In the current study, despite there being a few wives that pushed their husbands, most of the men's narratives suggested their wives played a supporting role. They discussed the need to see a doctor and a joint decision being made.

Another assumption challenged by this study, is that women are necessarily frequent and prompt users of health services (Galdas et al., 2010). This comparative analysis suggests that in fact, women's help-seeking behaviour is

very similar to men's, and some women delayed seeing their doctor for breast symptoms. This supports the assertions made by others (Galdas et al., 2010, Hunt et al., 2010) who suggest the preconceptions of the 'reluctant male' compared to women as frequent healthcare users is incomplete and only serves to perpetuate the myth that men are not interested in their health.

Examinations of the process of help seeking should explore what encourages and inhibits both men and women to seek help rather than explore why men delay and women seek help promptly.

8.2.2 Disclosure

Findings in relation to disclosure were more complex although overall, the men and women shared similar strategies to tell others of their diagnosis. It was unsurprising in this study that few men or women discussed not telling anyone about their diagnosis considering the recruitment methods using a third party to recruit and the men having to be proactive in volunteering and the fact that participants knew that their interviews would contribute to the development of a freely available online collection of people's experiences of having breast cancer, albeit with an option to remain anonymous. This did not preclude men and women however from having problematic encounters with others whilst telling them of their diagnosis. Using Charmaz's (1991) description of disclosure strategies (non-disclosure, limited, strategic and spontaneous) the men's and women's accounts of their reasons for telling people were outlined. Reasons for disclosure or non-disclosure were not static within some individuals' accounts and a few men and women changed their disclosure behaviour either in response to people's reactions or to move on with their lives beyond their diagnosis. Negative reactions from others were not exclusive to men with breast cancer. Some women also described negative experiences.

Although both men and women described using 'strategic announcing' to tell others, this appeared to be more a common strategy amongst the men.

'Strategic announcing' was one way in which men maintained control over who they told they had breast cancer, and also how they told them. Similar findings in relation to other health conditions were reported by O'Brien et al (2007); they reported that their participants with prostate cancer actively engaged with men to educate them about prostate cancer, although this may reflect their recruitment via a prostate cancer support group.

In addition, a few men used their mastectomy scar to prove to sceptical others that they had been diagnosed with breast cancer. Revealing the physical scars on their bodies stopped men doubting them and was also a powerful tool to educate others that men can get breast cancer. This is not something women have to do. Population awareness that women can develop breast cancer is high despite general knowledge of the disease being poor (Moser et al., 2007, Grunfeld et al., 2002b). It is doubtful any woman would feel it necessary to reveal their mastectomy scar in response to someone doubting their diagnosis, and this was never spoken about within the women's narratives.

Another difference between men's and women's reported disclosure was that a few men talked about their inability to hide their diagnosis and having to tell rather than wanting to tell. Looking like a 'cancer victim' whilst undergoing chemotherapy appeared to be more difficult for men to hide than women. Women used wigs and prostheses to conceal changes to their appearance but these options did not appear to be readily available to men with breast cancer. Similar findings of looking like a 'cancer patient' in relation to hair loss has been described in younger (aged 18-38 years) people (Hilton et al., 2007). No study has been found exploring this in older men, and no studies in men with breast cancer explored this. Despite the different ages in the sample used in this study and in Hilton et al (2007), both found hair loss in some participants led to feelings of vulnerability and having no choice in who they told.

8.2.3 Experiences of and Needs during Active Treatment

Treatment choice and having a role in the decision-making process has been established as important for women with breast cancer (Deadman et al., 2001, Keating et al., 2002, Sabo et al., 2007). Patient involvement in treatment choice has been shown to be complex. Information and time are required (Husain et al., 2008) but there are psychological benefits to participating in the decision-making process (Deadman et al., 2001). In contrast, there is no existing evidence on men's experiences of treatment decision-making once diagnosed with breast cancer. Most of the men in this study did not receive a choice in treatment and in most narratives this did not appear to be problematic for them. However, a lack of choice was problematic for one man who did not question his treatment until discovering the choice of treatments available to women and the trials they may enrol for. Although in this study this was not a major theme, it highlights

the wider issue of the lack of research currently being undertaken in men with breast cancer and the subsequent limited availability of treatment options to men (Ottini et al., 2010). It also suggests that an overall agreement and acceptance of treatment can be undermined when men realise there is no treatment choice for them, but there is for women with breast cancer.

Most men and women with breast cancer experience the embodied effects of adjuvant therapies such as chemotherapy and hormonal use (Ottini et al., 2010, Janz et al., 2007, Fentiman et al., 2006). This study found similarities in side effects between men and women with breast cancer. Findings highlighted the plight of men who are treated with drugs that have little clinical evidence for use in male patients. France et al (2000) reported concerns by the men in their study about the suitability of using tamoxifen when no information was available on its effectiveness. However, my research also found the women knew that despite the side effects, the treatment for breast cancer in women had been shown to have benefits. Within the women's narratives were justifications for continued treatment use to ensure they had the best chance of survival. This reassurance was not present within the men's narratives because there is no evidence to provide this reassurance to men.

The findings in this study suggest the support needs of men and women with breast cancer are similar. Concurring with other studies, partners are often cited as the main source of support to men with breast cancer (Pituskin et al., 2007, Iredale et al., 2006). However this did not stop the men wanting additional support from other sources. Some men said they would have attended a support group if they had been offered the opportunity or ideally would have liked to have met another man with breast cancer. Similarly, the women's narratives suggested that despite having support from friends and family, most women shared their breast cancer experiences with other women with breast cancer. The women discussed various places they met other women with breast cancer (in support groups, in hospital, existing friendships); by contrast, due to the rarity of breast cancer in men, there are few opportunities or places for men with breast cancer to meet and share experiences. The existing literature focusing on men with prostate cancer suggests that support group attendance for men is primarily to gain information (Gray et al., 2000) and men only attend because their wives encourage them to go (Bottorff et al., 2008). Furthermore,

Williams et al (2003) found the healthcare professionals who participated in their study perceived the support needs of men with breast cancer to be different from women and did not think similar support networks would work for men. Therefore despite having similar support needs, compared to women, men with breast cancer have fewer opportunities to access similar sources of support.

One major difference between men and women with breast cancer is the experience of healthcare during treatment. From this study it is impossible to argue whether the assertions from others that men's health (similar to women's) is disadvantaged by the current healthcare structure (Banks, 2004, Doyal, 2001). For example, there is no evidence to suggest men with breast cancer receive sub-optimal treatment leading to higher death rates. What is certain however is men with breast cancer are absent in the planning and implementation of breast cancer healthcare delivery. This is evident in the current national clinical guidelines (NICE, 2002, SIGN, 2005) and in the individual narratives within this study. Problematic healthcare encounters appeared to start at the time of their hospital referral from their GP. In this study all but one man said they were referred promptly and first hospital appointments were arranged quickly. From this point on, all the men in this study experienced problematic encounters in the hospital setting.

A potentially unique experience was one man's treatment within a 'women's' centre. The provision of healthcare in a newly built centre providing one stop specialist care to women including breast, gynaecology and maternity services should improve the healthcare experience - of women. Of course, men do not require gynaecology or maternity services, but some men do require breast care. This man's narrative suggests that there was no provision for him, as a man, and he did not like being tagged as 'special' within this female environment. In the current cost cutting climate within the NHS it is understandable that this model of providing care to women in specialist centres may be appealing, however it is at the expense of the delivery of treatment to men.

The men in generic hospital settings also reported problematic experiences, including wives being mistaken as the patient, being called Mrs instead of Mr, women challenging their presence, being asked to wear pink gowns, and wards providing plastic bags to men and embroidered shoulder bags to women. This is

evidence that consideration and change is required in the healthcare delivery of care to men with breast cancer at all levels of healthcare, from reception staff to doctors and nurses. Naymark (2006) suggests, “men with breast cancer are treated within a well defined gendered conception of breast cancer management... that is not conducive to [men’s] needs, values or bodies” (p 163). She goes on to suggest the lack of evidence on how this impacts upon men has led to the further development of services that do not meet the needs of men with breast cancer. These findings support her argument and present further evidence of inappropriate care for men with breast cancer.

In addition available resources do not consider the needs of men with breast cancer. Information was often written specifically for women, for example by discussing the need for a soft bra after surgery, side effects of treatments and living beyond their cancer diagnosis. These men did not want to be ‘special’ and did not expect exclusive services for men with breast cancer. The men acknowledged breast cancer is a predominantly female disease, and their narratives reflected the aims of the Gender Equality Duty, which outlines the need for equality amongst men and women, not equity of service provision. Including a section within current information written specifically for men, or simply acknowledging women and men are at risk of breast cancer may go some way to address these issues. The narratives from the men in this study suggest that healthcare provision to men with breast cancer is not fulfilling the requirements of the Gender Equality Duty.

8.2.4 The Embodiment of Cancer, Treatment Effects and Romantic Relationships

Gerschick and Miller (1995) contend that “the body is a central foundation of how men define themselves and how they are defined by others” (p 183). This interaction between the body and other people contributes to the ‘doing’ of gender, described by West and Zimmerman (1987). Pituskin et al (2007) found their participants felt their bodies reflected their masculinity and experienced an altered body image following breast cancer. Similar to Pituskin et al’s (2007) findings, some men in this study talked about how changed their activities to ensure their chest was never exposed, or kept a top on while on holiday. However, there is little evidence to support the assertion that the male body was central to their masculinity. Unlike Pituskin et al (2007) who had a broad

age range within their sample, the men in this study were aged over 50 years. Some men in this study discussed bodily changes prior to their diagnosis due to the ageing process or other illnesses. This finding concurred with Iredale et al (2006) who suggested an altered body image was more apparent in the younger men in their study, and the older men were more aware of their mortality.

Age-related differences in impact on body image has also been reported in women with breast cancer (Fallowfield, 1997), and the women's narratives included similar findings. Some women said their breasts had already served their purpose to nurture their children, and they did not find it a difficult decision to opt for a mastectomy. Although most of these women conceded had they been younger they may have viewed the decision differently. However, Charmaz (2000) suggests that attributing illness to the ageing process is a strategy that enables men, and in this study, women also, to maintain their masculine and feminine identities unchallenged. In older age illness is more likely and 'more normal' than at younger ages. The narratives did include references to family members, friends and colleagues who had experienced illness and therefore the men and women in this study may have been aligning themselves with their peers. This may be a useful strategy for men with breast cancer to 'normalise' their illness and share illness experiences with other men who are, or have been, unwell.

A novel finding in this study is the effect a breast cancer diagnosis in men has on a couple's relationship. Using Tolstedt and Stokes (1983) description of intimacy it was found the reduction in physical intimacy could be overcome by displaying affection in other ways. Most of the married men in this study said the quality of their relationships with their wives either stayed the same or improved. While the comparative evidence within the women's narratives was limited, there was evidence of this occurring also. Bottorff et al (2008) have described prostate cancer as a "couple's disease" and this may be an appropriate term to use in couples where men have breast cancer. Furthermore, similar findings by Porter et al (2005) who studied men with gastrointestinal cancer, suggests it may be possible to generalise it to men with any form of cancer.

While it is encouraging these men reported improved relations with their wives, this finding should be interpreted with caution. Other studies have suggested

problematic communication within couples coping with a cancer diagnosis (Emslie et al., 2009, Fergus and Gray, 2009) and without exploring the wives' experiences it is impossible to corroborate these findings. Detrimental changes to marital relations featured in a few of the men's narratives. These men attributed these problems to changes in their personality as a result of treatment. However there is no research available to confirm or challenge their assumption. No other explanation was given by these men to explain this change. Another possible explanation for a change in these men's personality may be increased distress or depressive symptoms following their breast cancer diagnosis. Brain et al (2006) surveyed men with breast cancer for psychological distress (n=161) and found a small proportion of their sample reported clinical levels of anxiety (6%) and depressive symptoms (1%). The rate of depression reported by Brain et al (2006) is lower than other estimates of depression in adults with cancer. Irving and Lloyd-Williams (2010) reported prevalence estimates of depression in people with advanced cancer to be between 5 and 26%. Brain et al (2006) surveyed men who had been diagnosed with a variety of stages of cancer. In the current study more men may not have felt able to discuss detrimental changes to their relationships and in some cases their wives presence during the interview may have deterred them from speaking out.

Despite studies finding wives are the main support of men with breast cancer, unlike my research, none explored the extent to which wives were involved in their husbands' experiences (France et al., 2000, Pituskin et al., 2007, Williams et al., 2003). In this study, the wives were found to be present throughout the men's narratives from first finding a symptom to living beyond their cancer. The husbands of the married women did not feature in the narratives of women's breast cancer experiences anywhere near as strongly. The women appeared to use wider support networks for gathering information and support, such as children, friends and work colleagues. Pistrang and Barker (1992) also found women used a variety of sources for support, but named their partners as their main source of support. The difference to our findings may be due to the high number of single women interviewed, compared to Pistrang and Barker's sample who were all in long-term relationships.

Interestingly, it is the wives' role in searching, retrieving and sharing information with their husbands that emerged as an important finding.

Discussion of information seeking was an intriguing part of the interview. While some men felt they received enough information, most acknowledged the lack of male-specific information available to them, and showed an apparent lack of interest in sourcing information themselves. The lack of information for men is a universal finding in all the studies in men with breast cancer although there appears to be more becoming available (France et al, 2000; Naymark, 2006; Iredale et al, 2006; Donovan and Flynn, 2007; Pituskin et al, 2007; Williams et al, 2003) but none have reported men's wives having a role in the collating of information. From the narratives it is unclear exactly why these men do not appear to look for information. One explanation may be the minimal content available for men, and feelings of isolation and misplacement within a female dominated environment. Wives reading and sifting through the information may be one coping strategy to preserve their masculine identities. Furthermore, it enables the men to successfully negotiate Robertson's (2003) dilemma of 'don't care, should care' (p 112). These men are able to construct identities that suggest they do not care or need any more information while their wives are collecting it for them, thus meeting their needs.

There is a paucity of evidence of the experiences of single men with breast cancer. No study was found to date that explored their experiences. In light of the role wives played in the married men's experiences, it may be assumed single men have poorer experiences and Brain et al (2003) found higher cancer specific distress levels in single men than married men. In this study the narratives of single men were not analysed independently from the married men, because of the small number in the sample. No conclusions can therefore be drawn from the findings comparing single and married men.

8.3 What effect, if any, does having a 'feminine' cancer have on a man's identity and masculinity?

Lyons (2009) presents masculinity as "a social location, a set of practises and characteristics that are understood as 'masculine' which have effects on bodily experience, individuals, relationships and social structures" (p 395).

'Masculinity' cannot occur in isolation and is continuously being renegotiated in different ways and in different communities (Paechter, 2003, Connell, 1995).

The experience of each man with breast cancer was unique and their masculine

identities constructed in different social contexts interacting with those around them. The findings highlight the fluid and interchangeable concept of what gender is and what it means (Connell, 1995, Courtenay, 2000a). The men and women with breast cancer did not construct a binary concept of what it meant to be a man or woman (Annandale and Clark, 1996). Instead they constructed identities using both traditionally male and female characteristics (Oliffe, 2005, Paechter, 2003). The men often described examples of stoicism, independence and leadership whereas the women endorsed their caring, protective and loving characteristics, however no characteristic was exclusive to men or women and traditional masculine and feminine characteristics were evident in both sets of interviews (Seem and Clark, 2006, Broverman et al., 1972).

Cultural constructions define men as more powerful than women (Kimmel, 1994). A theoretical framework outlined by Schippers (2007) suggests multiple femininities are always subordinated to all forms of masculinity. In addition, men who embody or adopt feminine characteristics may be socially isolated and stigmatised. Similar to findings by Donovan and Flynn (2007) the men in the current study assigned breast cancer a feminine status rather than being gender-neutral. Furthermore, the men often downplayed their experiences as less important than those of women with breast cancer. The challenge for men with breast cancer is how they construct masculine identities within their social context while experiencing a predominantly female illness. In this study there is evidence of men constructing their identities using traditional male stereotypes within their narratives. Some men referred to being a 'typical man', others referred to their past behaviour such as being reluctant to see their doctor and a few used regional stereotypes (Glaswegian or Yorkshire man) when discussing their past health behaviours. The use of traditional gender stereotypes helped men with breast cancer construct a masculine identity to counteract any threat to their masculinity from breast cancer. De Visser and Smith (2007) described this as trading masculine competence, using one aspect of their masculine identity to compensate for the loss of masculinity in another domain. Other researchers suggest this is 'masculinity insurance' at work: weaker, subordinated masculine traits compensated by idealised, hegemonic masculine traits (Lyons, 2009, Schippers, 2007, Anderson, 2002). The success or failure of men with breast cancer to successfully renegotiate their masculine identities was determined in part by their 'masculinity insurance'. Men with successful careers,

close families and being financially well off appeared to be more successful than others in renegotiating their masculine identities.

This did not exclude these men from negotiating new masculine identities. O'Brien et al (2007) found the men in their study recovering from a heart attack had renegotiated their identities to include heavy physical activities to replace work. However, they were regularly subjected to challenges by family and friends to the appropriateness of these activities. They did not appear to agree they were physically able to undertake these activities. O'Brien and colleagues suggest that despite these men recovering from their heart attack, friends and family permanently viewed them as "changed by their illness" (p194). Men with breast cancer are able to renegotiate their identities to include old and new activities, however they are also regularly challenged by others who question the validity of men's claims to have breast cancer. The identities of men with breast cancer remain fragile and can be challenged long after their illness and recovery. To overcome these challenges there is evidence of the men constructing masculine identities including coping mechanisms such as prompt help-seeking, strategic announcing, and even taking part in this study to inform a new source of information for other men with breast cancer.

Breast cancer in men however remains invisible in the wider context of breast cancer awareness. Kaiser (2008) outlines the transition of breast cancer in women from a hidden, shameful disease, to one that is highly visible and openly embraces the positive dimensions of survivorship. Beyond the personal narratives, breast cancer campaigning is now a powerful marketing and political movement and the pink ribbon has become a global symbol of breast cancer in women (Ehrenreich, 2009). The overwhelmingly pink campaigns run by breast cancer charities do not include men when raising awareness of breast cancer. Some men suggested raising awareness of breast cancer in men by adding a blue flash on the pink ribbon. This would visibly demonstrate that breast cancer is a disease that mainly affects women, but is also experienced by men.

8.4 Limitations of Study

This study has many strengths. It is an original piece of work exploring the social construction of men's and women's identities following a diagnosis of breast cancer and has added to the growing literature on how men renegotiate their identity in relation to illness. The use of secondary analysis alongside primary data collection (using the same methodological approaches) is also a unique feature of this study. This study has shown using these methods in combination can be successful and is an economic way to undertake new research. There are however, limitations to this study.

First, to ensure comparability between the primary and secondary data, the primary interviews had to be undertaken using the same methods that were used to collect the women's interviews. The women's interviews were also undertaken several years (in 2001) before the men's interviews and it is not known how different the women's experiences would have been if they had been carried out more recently. In addition, the research aims of the original study and this study may have differed and I had no control over what was asked during the women's interviews. Areas of interest, to me, may not have been an area of interest to the original study. Furthermore, the women may not have given consent for some parts of their interviews to be used for further research purposes such as secondary analysis.

The men had also volunteered to participate in this study. This may have yielded a more proactive and open group of men. Men who were embarrassed or who struggled with their diagnosis may have decided not to participate but their reasons for not taking part were not systematically collected. The proposed use of the interviews for a new Healthtalkonline module on Breast Cancer in Men may have stopped men participating despite assurances they could remain anonymous if they wished. Some men however, were clearly embarrassed talking about their experiences. Their desire to meet another man with breast cancer or strong feelings that more information should be available to men with breast cancer motivated some to participate in this study. Another possible reason for non-participation may have been poorer health of the individual. Men currently undergoing chemotherapy, those with secondary disease or at the end of life may not have felt well enough to participate. Also, the experiences of younger

men were not included in this study. The findings from this study are not representative of these men's experiences and therefore cannot be generalised to all men with breast cancer.

8.5 Recommendations and Practice Implications

Using a gender comparative approach, this study has highlighted some of the many hurdles men have to overcome when diagnosed with breast cancer. There is little awareness in the general population that men can, and do, develop breast cancer. They are often met with disbelief when telling people their diagnosis, undergo treatment that has little clinical evidence of its effects on a male body and have few resources available to help cope with a life threatening illness. It would have been interesting however, to directly compare men with breast cancer to men with prostate cancer (in addition to the comparison with women with breast cancer), to further explore the impact of disease at polar ends of the gendered construction of illnesses on men's identities. This would have further enriched the data and subsequent findings. However the time constraints of the PhD did not allow this to happen.

Another finding of this study was the role of the men's wives throughout the men's experiences of having breast cancer. To date, there has been no study found that has explored the wives experiences of their husbands' illness. Their experiences would further illuminate men's experiences of having breast cancer.

Within the healthcare setting there is little evidence of gender equality for men with breast cancer. This is reflected in the national guidelines for treating breast cancer where there is little mention of men with breast cancer (NICE, 2002), and the Scottish guidelines are titled management of breast cancer in women (SIGN, 2005). There is no guideline available for treating men with breast cancer. Exclusion from national guidelines can only perpetuate the myth that breast cancer is a women's disease and leave clinicians unsure of what are the most effective treatments for breast cancer in men.

At a service level, services must adapt to provide men with breast cancer with the same level of care many women experience. The conundrum is, how do you provide gender-appropriate services to a minority of cases? In the case of men

with breast cancer, each hospital may diagnose one man every one to two years. The findings in this study suggest a variety of measures that may help improve the experiences of men with breast cancer. They include:

- Information leaflets talking about breast cancer in women and men.
- Including male-specific sections in general breast cancer leaflets.
- Raising awareness in the general population during media campaigns.
- Include a blue flash on the pink ribbon.

The men in this study acknowledged the rarity of breast cancer in men. They did not want to be 'special' instead they wanted to be included.

Appendix 1 – Search Strategy

Table 1. Databases searched

Medline 1996-2010	Web of Knowledge
Embase 1996-2010	IBSS
PsychInfo 1987-2010	Socindex
British Nursing Index 1994-2009	SSA

Table 2. Search Terms Used

Male breast cancer	Cancer and masculinity	Cancer and family
Men with breast cancer	Social support and disclosure	Patient satisfaction and health service
Men and breast cancer	Disclosure and cancer	Patient satisfaction, health service and cancer
Prostate cancer and masculinity	Disclosure of a cancer diagnosis	Intimacy and cancer
Gender and female breast cancer	Social support and breast cancer	Body image and breast cancer
Femininity and breast cancer	Coping and breast cancer	Social support and masculinity
Experiences and breast cancer	Patient satisfaction and hospital environment and cancer	Men, cancer and anger
Help-seeking and masculinity	Marital adjustment after breast cancer	Anger expression and breast cancer
Help-seeking	Formal support	Anger and breast cancer
Help-seeking, cancer and men	Support group	Survivorship
Symptoms and gender	Experiences of breast cancer	Living beyond a cancer diagnosis
Response to symptoms and gender	Healthcare environment	Survivorship and marital relationships
Disclosure	Healthcare environment and NHS	Survivorship
Communication disclosure and cancer	Patient experience and hospital environment	Men, survivorship and breast cancer
Masculinity and disclosure	Patient experience and hospital	Men and survivorship
Disclosure family and cancer	Patient experience	Survivorship and breast cancer
Telling others about a cancer diagnosis	Patient experience and clinic setting	Men, cancer and survivorship
Communication and disclosure		

Appendix 2 – Copyright Consent



PERSONAL EXPERIENCES OF HEALTH & ILLNESS

DIPEX Research Group
Department of Primary Health
Care
University of Oxford
Old Road Campus, Headington
Oxford OX3 7LF

Tel: +44(0)1865 289328
Fax: +44(0)1865 289287
dipexadmin@dphpc.ox.ac.uk
www.dipex.org

Future use of my DIPEX interview

It is intended that the content of my interview, anonymised according to my wishes, will form part of the DIPEX website which will be available for use by other people with an interest in my condition including patients and their relatives and researchers. It will also be available for use in publications, education, lectures and broadcasting.

Consent includes use of independent service providers for any part of the DIPEX activities, including hosting of the material on the web site. The DIPEX database will not be used for personal profit or commercial gain. I note that access to the website cannot be restricted

I consent to the inclusion of my DIPEX interview in the database in the following format(s).
Tick all that apply:

- ☐ Video of interview
- ☐ Audio tape of interview
- ☐ Written transcript of interview

To enable the full use of my contribution, I assign my copyright in my contribution to the DIPEX database to the University of Oxford for use in the DIPEX project. In return for my assignment, the DIPEX project will only use my contribution in the manner set out above. If I decide that I no longer want my contribution to appear on the database, it will be removed, although I accept that it will not be possible to remove all existing copies from circulation.

Name: (block capitals) _____

Signature: _____ **Date:** _____

Age: _____ **D.O.B:** _____

Address: _____

Office use only:

Signed: _____ **Date:** _____
(DIPEX)

Interviewer: _____ **Date:** _____

Recording available as: ☐ Video ☐ Audio

Number of interviews with this respondent: _____ Database reference number: _____

Series title: _____

Appendix 3 – Ethics Approval

Dr S Evans - Chairman Eastern MREC All correspondence to: Anne Burnley House No. 1 Papworth Hospital NHS Trust Papworth Everard, Cambridge, CB3 8RE Tel: 01480 364757 Fax 01480 364887 Email: EasternMREC@aol.com	Dr M Wilkinson - Vice Chairman
--	---------------------------------------

Our ref: catD04511caapril04

4th May 2004.

Ms S Ziebland
 DIPEX Research Group
 Dept of Primary Health Care
 University of Oxford, Old Road Campus
 Headington, Oxford, OX3 7LF

Dear Ms Ziebland

MREC 04/5/11
Expansion to DIPEX

USE YOUR MREC REFERENCE ON ALL CORRESPONDENCE AND QUOTE IT WHEN MAKING TELEPHONE ENQUIRIES

The Chairman and lead members agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC response form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the establishment of a new disease or patient database for research purposes/the use of an existing database collected for previous research or other purposes with subsequent patient contact. **For this reason you are asked to read carefully the sections concerning LREC involvement and local NHS management set out below as there are specific requirements involved when undertaking such research.**

MREC Conditions of Approval.

- The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
- You must complete and return to the MREC the annual report form (progress of study) that is enclosed, and the final report form when your research is completed. (use the progress of study report form for the annual and final report).
 - You must promptly inform the MREC of:
 - (i) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
 - (ii) any new information that may affect adversely the safety or welfare of the subjects or the conduct of the trial.
 - You must complete and return to the MREC the enclosed annual review form once a year, and when your research is completed.

LREC involvement

When undertaking the review of your project the MREC observed that there is/ limited patient contact by a local clinician who is performing technical procedures or additional data collection as described in the MREC approved protocol/ initial contact by a local clinician for purposes of recruitment. It is felt that these tasks appear well within his/her routine professional competence and adequate facilities for such procedure are available as part of his/her normal professional practice.

For this reason you are asked to only inform the appropriate LREC of the project by sending a copy of this letter and also **giving the name and contact details of the local clinician involved**. If (unusually) the LREC has any reason to doubt that the local clinician is competent to carry out the tasks required, it will inform the clinician and the MREC that gave ethical approval giving full reasons.

You are not required to wait for confirmation from the LREC before starting your research.

Local NHS Management

The local clinician must inform his/her NHS organisation of their co-operation in the research project and the nature of their involvement. Care should be taken to ensure with the NHS organisation that local indemnity arrangements are adequate.


Legal and Regulatory Requirements

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and Statement of Compliance are available with the application form and guidelines for researchers and on the Internet at www.corec.org.uk.

Yours sincerely



Anne M Burnley
MREC,

Enc. Response form
Progress of study form

Appendix 4 – Information Sheet

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by **Multi Centre Research Ethics Committee for health research**
- The University of Oxford has a specific insurance policy to protect patients and healthy volunteers who take part in research. The insurance provides for 'no fault compensation' consistent with that provided through the Association of British Pharmaceutical Industries (ABPI), as well as for legal liability. The MRC will provide indemnity in the case of negligent harm for research conducted through its Units when it is Sponsor and for employees or others acting on behalf of the Council. Care organisations continue to be responsible for any breaches of the duty of care they owe with respect to participants of this research.

Many thanks for reading this information sheet.

Caroline Sime

Note: *Consumers for Ethics in Research (CERES)* publish a leaflet called 'Medical Research and You'. This leaflet gives you more information about medical research and can answer some questions. You can get this leaflet by writing to CERES PO Box 1365, London N16 0BW.

DIPeX is a registered charity number 1087019 and a company limited by guarantee, company number 04178865, whose registered office is at 41 Cornmarket Street, Oxford OX1 3HA.

DIPeX Charity Office
P O Box 428
Witney, Oxfordshire
OX28 9EU

Taking Part in Research For
A Healthtalkonline module on
Male Breast Cancer



DIPeX Health Experiences Research Group
Dept of Primary Health Care,
University of Oxford



Social and Public Health Sciences Unit
4 Lilybank Gardens
Glasgow
G12 8RZ

Tel: 0141 357 3949
caroline-s@sphsumrc.ac.uk

Taking Part in Research A healthtalkonline module on Male Breast Cancer

DIPEX – Personal Experiences of Health & Illness

Hello

My name is Caroline Sime. I am a researcher from Glasgow University. I am asking you to take part in research. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please read what I have to say carefully. Talk about it with friends, relatives and your GP if you wish. Ask me if you have any other questions. Please take as much time as you like to decide.

Consumers for Ethics in Research (CERES) publish a leaflet called '*Medical Research and You*'. This leaflet gives you more information about medical research and can answer some questions. You can get this leaflet by writing to CERES PO Box 1365, London N16 0BW.

Thanks for reading this.

Who is organising and funding the research?

This research on male breast cancer is being funded by the Medical Research Council and supervised from the MRC Social and Public Health Sciences Unit at Glasgow University. In order to produce the Healthtalkonline module on male breast cancer we are collaborating closely with the DIPEX Health Experiences Research Group which is based at the Department of Primary Health Care, University of Oxford.

Contact for further information

I hope that this information sheet about Healthtalkonline has told you what you need to know before deciding whether or not to take part. If you have any queries at all about the project or wish to make a complaint please telephone Caroline Sime or Professor Kate Hunt on 0141 357 3949 or Sue Ziebland of the DIPEX team on 01865 289302.

What is the purpose of the study?

www.healthtalkonline.org is a website that has:

- people's stories of health and illness
- information about tests and treatments,
- helpful support groups & other materials (e.g. self-help books).

The idea is that Healthtalkonline will help people to:

- understand & cope with health problems and issues
- know what really matters to people when they are ill or are facing health issues; and answer common questions and provide information.

People who are faced with difficult choices (e.g. which tests or treatment to choose) will be able to go to the Healthtalkonline website for this kind of help. Health professionals who want to understand what it is like for people to have an illness or face health choices can also visit the website. To develop each Healthtalkonline topic (such as this one) takes about one and a half years.

Anyone who has access to the Internet can use Healthtalkonline. The interviews will not be used for profit or commercial gain.

Why have I been approached?

You have received this brochure because we want to interview people who have had experience of male breast cancer. I will be interviewing around 40 people who have had such experiences. Your name has not been given to us at the MRC Social and Public Health Sciences Unit or the DIPEx Health Experiences Research Group, so **I will only be able to contact you if you fill in the patient 'reply slip' (in your information pack) and post it to us in the reply paid envelope.**

Do I have to take part?

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign a 'consent form'. If you decide to take part, you are still free to stop at any time without giving a reason. No questions will be asked if you stop. If you do not take part, or stop taking part, the care you get from your doctors and nurses will not be affected.

What will happen if I take part?

If you complete and send back the enclosed 'reply slip', I will contact you to arrange an interview at a time and place that suits you. Most people prefer to be interviewed in the comfort of their own homes. However, if the interview does not take place in your home, an alternative location will be chosen for your convenience and you will be paid for the cost of your travel. I will try to answer any questions you may have about the interview or the Healthtalkonline project.

Before the interview I can show you the Healthtalkonline website on a portable computer. You can see how other people's interviews look in video, audio and written formats.

What would the interview be like?

I will ask you if you are willing to have the interview video or audio taped. You will be given the "consent form". You only sign this form if you agree to take part in the interview. You will be given a copy of the consent form to keep.

The interview will be a little like a conversation, but I will help you talk about yourself in your own words. I will ask you to talk about your experiences of breast cancer. I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have got information, what you have done, and what have been the good and bad parts of the experience.

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, I will give everyone a list of useful contacts which can be used to get more help if you want.

Can I choose how my interview will appear on the Website?

You will have a choice about whether a video, audio or just a written version of your interview is included. If you want to be anonymous, you will be invited to use an alias for yourself and others, and you can keep out of the interview anything which might identify you. You may wish to discuss this with members of your family, since they might possibly be connected to your appearance on the screen.

If you are recognised on a website, this would be a little like appearing on the TV. And as with TV, other people can record what they find there, and show it to others. If you have any doubts about how you want the interview to be included, talk to me, or I could find an independent adviser for you to talk to if you prefer.

How would the researcher use the interview tape and transcript?

You will be asked to sign a form '**Further use of my interview**'. If you sign this form, you give copyright of the interview to The University of Oxford. It is very important that you take time to think about and discuss the copyright form before you sign it. This form is also used to spell out any limits that you wish to place on its use. You will be given a copy of this form to keep.

If you do decide to allow your interview to be used for the Healthtalkonline website, it would be used along with interviews from other men who have experiences of breast cancer. A summary of these interviews would be prepared. People who use the database would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. All data use is strictly within the terms of the Data Protection Act (DPA 1998).

How long would the interview take?

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

What if I decide to withdraw after the interview has taken place?

You are free to leave the study at any time. If you decide to leave after an interview has taken place, all video, tapes, transcripts and typing of your interview would be destroyed. However, if you decide to leave after the Website has been finished, we would remove your contribution from all later versions, but we would not be able to destroy existing material, which other people could copy from the Website.

What would happen after the interview?

I will label the interview tape with a code number and give it to a typist who will type out everything you said in the interview. The typist signs an agreement to keep everything you say in the interview secret. The video, sound file and the typed up record (transcript), identified only by the code number, would be kept in a secure place at the Social and Public Health Sciences Unit in Glasgow.

I will send you a copy of the interview transcript to help you decide whether you want your whole interview to be made available to Healthtalkonline (a video copy of the interview can also be provided if requested). You would be asked to read or listen to the interview and consider if there was anything you would like to change or remove, to keep anything secret or hide your identity, or to delete or change some of your interview. You can take as long as you need to do this. You can also choose how your interview will appear on the Website (see next section).

Appendix 5 – Patient Reply Slip



Reply slip for Module: Men with Breast Cancer

Yes, I am happy for a researcher to contact me about this project.

Name:

(Block Capitals)

Address:

.....

..... Post Code:

Telephone number: Day: Evening:

Best time to contact me:

Age:

Date or year of diagnosis:

Occupation:

(if retired please state and give last occupation)

Ethnic Background.....

(It is important for us to include perspectives from a range of ethnic groups in our research).

Please return to:

Caroline Sime
Social and Public Health Sciences Unit,
4 Lilybank Gardens,
Glasgow,
G12 8RZ

Tel: 0141 357 3949

Appendix 6 – Consent Form



MRC Social & Public Health Sciences Unit,
4 Lilybank Gardens,
Glasgow,
G12 8RZ.

Tel: +44(0)141 357 3949
Fax: +44(0)141 337 2389

www.healthtalkonline.org
dipexadmin@dphpc.ox.ac.uk

Database reference number: _____

Series title: _____

Consent Form

Title of Project: Healthtalkonline – personal experiences of health & illness

Name of Researcher: _____

Please initial
box

- | | | |
|---|---|---|
| 1 | I confirm that I have read and understand the information sheet dated _____ (version _____) for the above study and have had the opportunity to ask questions. | □ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons, without my medical care or legal rights being affected. | □ |
| 3 | I agree to take part in the above study. | |

Name of Participant (block capitals)	Date	Signature
--------------------------------------	------	-----------

Name of Person taking consent (if different from researcher)	Date	Signature
--	------	-----------

Researcher	Date	Signature
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Version 09, October 08

Appendix 7 – Topic Guide

RATIONALE INTRODUCTION Narrative Q – to allow the interviewee to construct their experience in a meaningful way which allows them the chance to understand what has happened to them and adapt to an altered life (Bury, 2001). DIAGNOSIS Some researchers have suggested men delay seeking medical help once they find a change in their breast (France et al, 2000; Giordano et al, 2002). May be due to men being unaware they are at risk of BC (Pituiskin et al, 2007). Iredale et al (2006) found no delay among men, and family history of BC may help reduce delay times (Goss et al, 1999). Men may experience provider delay as they may not be immediately referred on to specialists if their GP is not aware of men having BC (Pituiskin et al, 2007). FBC lit reports fear and lack of knowledge/awareness of personal risk of BC as primary reasons why women delay (Bish et al, 2005; Burgess et al, 2001; Grunfeld et al, 2002; Lugton 1997; Richards et al, 1999). Own reaction to diagnosis: The initial reaction women appear to have is fear (of dying), concern for partners and children/family, grief. Men have been described as being stoical after the initial shock of diagnosis and wanting information and to know what the treatment plan is to prepare for it. Reaction of others to diagnosis: The use of humour by men to either deflect the seriousness of their situation or by others using it as a means to deal with an uncomfortable topic. Some men only disclose their diagnosis on a 'need to know' basis. They do not want to be stigmatized as being ill, and voice a need to be treated as 'normal' (France et al, 2000; Gray et al, 2000; Iredale et al, 2006). Some men do not disclose their diagnosis immediately, and wait until they have come to terms with it before telling others, usually with their partners with them (Gray et al, 2000).	QUESTION <ul style="list-style-type: none"> Can you describe everything that has happened since you first suspected there was a problem. Before you were diagnosed with breast cancer, were you aware that men could have breast cancer? Why did you go to your GP? At what point/when was this? How did you feel when you were told you had breast cancer? Who did you disclose your diagnosis to? What was their reaction to the news? Who didn't you tell and why?
TREATMENT Men are given the same treatment options as women. Lymphodema can be problematic post mastectomy, reactions to chemo/radiotherapy and tamoxifen (Q re hormonal tx affecting a man's masculinity in masc. section)	<ul style="list-style-type: none"> Can you tell me about the treatment you have had? How much choice did you feel you had about treatment(s) to have?

<p>can also have long term side effects, but each person can be affected to varying degrees, if at all depending, on tx plan of the individual.</p>	<ul style="list-style-type: none">• How do you feel about the treatment you were given?
<p>INFORMATION & SUPPORT</p> <p>Information needs:</p> <p>Previous studies suggest that men are given inadequate information and are not offered support services such as Nurse Specialists (Brain et al, 2006; France et al, 2000; Naymark, 2006; Pituskin et al, 2007). Men may not have been given any information on the effect that hormonal tx may have on their libido and sexual function (Chapple & Ziebland, 2002).</p> <p>Support:</p> <p>Some men would appreciate meeting other men with BC but most declined attending support groups as they are considered to be for women (Pituskin et al, 2007). Men are also less likely to identify themselves as needing support (Iredale et al, 2006). Gray et al's (1997) study of men with PC showed that men can enjoy using support groups, but advocate their use for gaining information, not for emotional support, although they admit to enjoy the friendships they had built up by attending the groups.</p> <p>A range of coping strategies may be adopted by men and women. Attending support groups, having a supportive partner/friend, talking to another man, and need for normality are some of the ways people cope with a cancer diagnosis (Iredale et al, 2006; Kiss & Meryn, 2001; Williams et al, 2003).</p> <p>IMPACT ON IDENTITY/MASCULINITY</p> <p>Financial implications:</p> <p>For many men, providing for their families through work is an essential part of being a man. Once the shock of their diagnosis has worn off, many men are concerned about the financial implications that their illness may have for their wives, and children (Chapple & Ziebland, 2002).</p> <p>Body image:</p> <p>Men's body image may be altered by their surgery and they may wish to conceal their mastectomized bodies for fear of being questioned and people staring at them (France et al, 2000). Men often see their bodies as reflecting their manliness and their scars detract from their perceived masculinity (Pituskin et al, 2007).</p>	<ul style="list-style-type: none">• What kinds of questions did you have?• What sort of information were you given?• What information were you given when you started hormonal treatment? What side effects were you warned about?• What sorts of information do you think would have been helpful to you after receiving your diagnosis?• Were you offered any support by the hospital or by the doctors or nurses you came across when you were diagnosed or being treated?• Did anyone else give you support?• Did you need/want more support than you received? What kind?• What were your reasons for attending (or not) a support group?• Have there been any financial implications of being diagnosed with cancer?• (For men following mastectomy) Can you tell me about how you feel about having had a mastectomy?• It can happen that the relationship with a wife/partner is affected. Has this happened in your case and can you tell me about it?

<p>Anger: During the first 5 interviews undertaken, some of the men have complained about a change in their character, and uncontrollable anger that can happen quickly. They feel they need to remove themselves or take a breath before responding and their partners have to absorb a lot of this anger as it is usually directed at them.</p> <p>Sexuality: Although sexual function declines over time, sexuality remains a significant aspect of many men's lives well into old age (Bokhour et al, 2001). The relationship a man with PC has with his wife may be affected in different ways. Treatment may lead to erectile dysfunction that restricts the physical intimacy once experienced between a couple. Men taking hormonal treatment can also experience a lack or arousal and sexual thoughts that can impact on their intimate relations with their partner. If they are unable to get or maintain an erection some men do not wish to initiate any intimacy (cuddling, kissing etc) as they find the disappointment and frustration of not carrying on to full sexual intimacy too difficult to deal with (Bokhour et al, 2001; Chapple & Ziehlend, 2002).</p>	<ul style="list-style-type: none"> Do you associate this anger/change of character to the hormonal treatment, or do you feel differently as a man since having the breast cancer diagnosis? (For men on hormonal treatment) Can you talk about what affect (if any) taking hormonal therapy has had on yourself and your relationship with your wife/partner?
<p>SURVIVORSHIP Uncertainty: The FBC lit suggests that many women live with a constant fear of recurrence post-treatment (Breaden, 1997; Doyle, 2008; Manderson & Stirling, 2007; Mishel, 1981). For men with PC none of the treatment options have been shown to be more or less effective than others, and 'watchful waiting' is also an option for some men with early disease (Chapple & Ziehlend, 2002). Living with the effects of radical treatment options may be a small price to pay for some men to have the assurance that their cancer is controlled. For others, the side effects, such as ED and loss of libido may be too great a price to pay. The experience of being diagnosed with a life threatening illness can lead some people to re-evaluate their lives and change their priorities (Breaden, 1997; Doyle, 2008)</p>	<ul style="list-style-type: none"> How do you feel about the future? What (if anything) have you changed in the way you live since being diagnosed with cancer?
<p>Language used to discuss MBC Through emails with a potential participant, it has emerged that men appear to loath the used of the word 'male' when discussing MBC. 'Female' breast</p>	<ul style="list-style-type: none"> In the research literature and in the media people use both 'men with breast cancer' and 'male breast cancer' when talking about the disease in men. Do you have any feelings about which

cancer is not used, but maybe 'women' with BC. Contention is with the use of gender terms when it is the same BC that affects men and women. Thread on BCC website also found from 2006 discussing issue (and women complaining of the aggressive nature in which men were raising this issue).	<ul style="list-style-type: none">terms you are most comfortable with yourself?Breast cancer campaigns appear to be very 'pink' and feminine, have you noticed this and what are your thoughts on it?
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CONCLUSION

- What advice, if any, would you give to another man who has just been diagnosed with breast cancer?
- Is there anything else you would like to add?

Abbreviations used:

BC – breast cancer

ED – erectile dysfunction

FBC – female breast cancer

PC – prostate cancer

Tx – treatment

Appendix 8 – Short Biographies of Men with Breast Cancer

Background	Biographies
MBC76: (52) Hindu London Lecturer Married Diag 2006	After finding a lump in his breast it took his wife's nagging for him to go to the Drs. He had a mastectomy, radio and chemo. He didn't want chemo but felt pressured into having it so that he didn't jeopardize his chance to have Herceptin, which was a new treatment at the time. He managed to have a course of Herceptin. He is fearful for his family's future should anything happen to him, and he bottles a lot of emotions up to protect them. Hates when he goes to clinic they shout "Mrs" instead of "Mr".
MBC89: (68) White British London Retired Health & Safety Officer Married Diag 2003 & 2006	First found a lump in his breast whilst washing. Sought medical advice straight away and had BC diagnosis within 2 weeks. Had mastectomy and tamoxifen until a DVT led to the discontinuation of tamoxifen. He then had a recurrence of the BC in same breast. Had further surgery then radio and chemo. Commenced arimidex but suffered terrible side effects including hot flushes and mood swings. Changed onto zoladex and side effects diminishing. Had knowledge men could get BC.
MBC52: (67) White British Yorkshire Retired Engineer Married Diag 2003	Found a lump in his breast washing and wife prompted him to go and see the GP. Very embarrassed by his BC diagnosis and felt there was a stigma attached to men having breast cancer. Had a mastectomy and tamoxifen. Wasn't offered any support from BC nurse, support groups and given little written information. Keen to educate other men to seek medical help promptly.
MBC73: (57) White British Yorkshire Stock Analyst Married Diag 2003	Had no knowledge that men could get BC. Found lump in the shower and delayed seeking help until wife and daughter thought he should have it checked. Diagnosis took a couple of months and when he was given the news was unsuspecting and unprepared. Had mastectomy, chemo and radio. Commenced tamoxifen but complained of fluctuations of body shape, terrible mood swings and a change in character. Took it for 2 years then stopped. Given no treatment choice or reconstruction. Disillusioned by charities and healthcare on their treatment of men who have had BC.
MBC67: (78) White British Devon Retired Site Engineer Married Diag 2001	Had no prior knowledge men could get BC. Had mastectomy, radio and chemo. Had diagnosis within 2 weeks of finding a lump. Took tamoxifen but complained of terrible flashes of uncontrollable anger. Unclear medical reason why tamoxifen was stopped (?pains in legs being mistaken for side effects then eventually diagnosed with polymyalgia). Tells everyone about his diagnosis and feels

	<p>compelled to tell everyone that men can get BC. Finds men's reactions quite odd, they stop talking to him, never ask questions and he feels they want to ignore the issue that they are at risk too.</p>
<p>MBC70: (51) White British Cambridgeshire Unemployed Divorced Diag 2007</p>	<p>Noticed that one of his nipples had inverted but had no pain or other symptoms so did not think it important. He had no prior knowledge that men could get breast cancer. Mentioned to GP approximately 7 months later at a medical. GP referred him straight to a specialist and he had his diagnosis within 2 weeks. Had a mastectomy and although lymph nodes clear was strongly advised to have some radiotherapy as lump was quite large. Received very good medical care and continues to see his Macmillan Nurse who invited him to join a support group, which he attends and feels supported by the women in this group. He has met other men but does not feel gender has been a barrier to him receiving or giving support. Having a cancer diagnosis has changed his life and the way he lives. He appreciates his family much more and tries to live a better life.</p>
<p>MBC86: (58) White British Scotland Unemployed Divorced Diag 2003</p>	<p>First noticed one of his breasts was larger at the age of 15. He felt it was considerably bigger than the other and was ignorant that men could get breast cancer. There had been many close relatives that had cancer (breast, bowel) but had hidden their illness. Feels quite bitter about this as felt if he knew he would have been more vigilant. Attended GP for another reason, but mentioned that nipple had started to invert. Required mastectomy, chemo and radio. Found the fatigue with chemo dreadful and lost his appetite. Continued to lose weight on tamoxifen and cried all the time. Managed to last 3 years on tamoxifen, but weight was very low and had to stop it. Sex drive went completely which he found very hard to cope with. Has returned somewhat but now feels is too old to have a relationship now and is content on his own. Was told in Oct '08 that the cancer would return at some point and lives each day as it comes.</p>
<p>MBC75: (59) Jewish London Unemployed Married Diag 2008</p>	<p>Had what he thought were recurring cysts in his breast for over a year that would come and go causing pain and discomfort. Didn't know men could get BC and delayed seeing his GP until the problem was becoming more regular and painful and at his wife's insistence. Was shocked at diagnosis and wanted to know how bad it was. Had private health insurance so has had all treatment privately. Has been supported by wife, family (disclosed his diagnosis to everyone) and hospital. Found chemo a dreadful experience with terrible side effects (neuropathy and oedema which severely limited his</p>

	<p>mobility) and was unsure about completing course. Had last chemo at a reduced strength. Currently undergoing radio which he doesn't find too stressful and is feeling his health is improving since stopping the chemo. Has just started tamoxifen a few weeks ago and hasn't had any problems with it as yet. Has had to deal with being made redundant recently which was an issue before getting his diagnosis, and worked throughout his chemo. Is very concerned about his future employment issues (due to age, cancer history and current economic climate), but is starting to feel more positive about his health and is planning a holiday in the summer.</p>
<p>MBC83: (71) Christian Scotland Retired Married Diag 2008</p>	<p>Had noticed some months previously a small wart-like growth on the skin just under his left nipple. While at the GP's for another issue took the opportunity to ask about it. GP was concerned and referred on to the hospital. Was seen promptly and had a diag within 2 weeks. Was shocked at the diagnosis as everyone had reassured him he would be ok (including a close friend who was a breast surgeon). Tumour was a grade 2 and only 1 lymph node affected. Advised to have radiotherapy and taking tamoxifen for 5 years. No side effects with tamoxifen and carries on with life as before. Has a strong Christian faith that has given him enormous comfort and has a close and loving family. Felt overwhelmed with information at hosp and felt a lot of it was unnecessary. Was given choice in tx which he didn't like (just wanted told) and received specific MBC info. Felt embarrassed telling people he had BC but did not hide his diag. Found reactions of others difficult to deal with as they were shocked. Women were more sympathetic but both men and women didn't ask anything about it. He thought this was because they didn't want to intrude.</p>
<p>MBC87: (60) White British Essex Retired Divorced Diag 1999</p>	<p>Delayed seeing his GP for 4 or 5 months because his dog was unwell and had nobody to look after him. He eventually went when the dog had died. Was shocked by his diagnosis but thought it was interesting to have such an unusual illness. He first had a lumpectomy, which was found not to be enough and had to have a mastectomy. He then had a blood clot in his wound that required further surgery. Did not think having breast cancer affected the care he had, but his profound deafness caused issues with hospital staff ignoring him. He did not require any further treatment apart from tamoxifen for 5 years, which caused major side effects. He received some written information on breast cancer and looked on the internet for more. He was wary about taking his top off at the beach, and decided to try walking along the sea front to gauge people's reactions. He found</p>

	noone noticed and has felt comfortable with his top off since. He participated in online support groups but found the tension between the men and women participants to be off-putting and stopped using the site. He told everyone about his diagnosis and now does awareness sessions for deaf people.
MBC55: (72) White British Scotland Retired Single Diag 2008	Had found a lump in his breast as a young man 50 years ago. At the time he squeezed it and some pus came out. There was no change until it suddenly grew several years before diagnosis. It stopped growing and remained unchanged until again it started growing. When it doubled in size he decided to see his GP. He was frightened of his diagnosis but felt relief it hadn't spread to another part of his body. He was later found to have the genetic mutation BRCA1. He had no family of his own but warned his cousin. He was generally very open about his diagnosis, but there were a couple of people he did not tell as he thought they would laugh at him. He required radio and tamoxifen which killed his libido. He reflected that it was ironic that since his diagnosis he had met a woman he was very attracted to, however their relationship had remained platonic due to his impotence. He said his wound did not bother him, but described it as being "ugly" and did not let anyone see it. He also referred to himself as a "good Glaswegian boy" despite being health conscious and using alternative medicine to remain healthy.
MBC59: (71) White British Yorkshire Married Diag 2008	Attributed his breast swelling and discoloration to previous knocks to his breast. His daughter saw his chest by chance while at his allotment and insisted he see his GP about it. She phoned him every day until he made an appointment. He felt shock at his diagnosis and had surgery, radio and tamoxifen with no side effects. His wife had been diagnosed with incurable lung cancer before his diagnosis and throughout his interview he downplayed his breast cancer experience. He felt he had been cured while his wife would never be free from her cancer. He did not like to show his scar so that he did not offend anyone and now kept his top on at his allotment. He was offered reconstruction surgery but declined because as a man his mastectomy scar did not matter. He told everyone about his diagnosis and received the BCC information booklet for men, which he felt was more information than his wife ever got about her cancer.
MBC77: (65) White British Yorkshire Married Diag 2004	Had knocked his breast at work and assumed the bruising and swelling was due to that. His wife noticed his nipple inverting 2 months later and told him to see his GP. He was very surprised when he was told he had BC. He required chemo but said he didn't

	<p>have any adverse side effects. He cut his hair very short to minimize the change to his appearance. The arimidex led to a loss of libido but he felt fortunate that he had a loving wife and showed their affection in different ways. Did not receive any male-specific literature and tells everyone he had breast cancer to raise awareness. If people don't believe him he shows them his mastectomy scar as evidence.</p>
<p>MBC71: (68) White British Yorkshire Married Diag 2005</p>	<p>Found a lump in shower one day and showed it to his wife immediately who advised him to see his GP. Was unprepared for his diagnosis and was on his own. He had to phone his wife and tell her as he was meant to be going on to his work after his appt. Did not require any further treatment other than tamoxifen. He worries about the cancer returning and is looking forward to his 5-year clinic appt when he will be discharged. Is not embarrassed about his scar and still showered at the rugby club and told everyone about his diagnosis. Most people were supportive but had some make comments about being "soft" or asking if he was "queer". Received some male-specific leaflets and the BC nurse visited his home to answer his family's questions.</p>
<p>MBC79: (65) White British Yorkshire Married Diag 2005</p>	<p>Had noticed a change in his nipple and while at the hospital for an unrelated issue was advised by a Dr to see his GP. His GP sent him for an X-ray and refused to send him for a mammogram. This resulted in an argument and he was struck off his GP's list. When given his diagnosis he was totally shocked and unprepared. He was resentful and angry that led to strained relationships between him and his family. Chemo led to a life-threatening infection that had to be treated in hospital. He felt out of place on the ward as it was full of women and they were given nice bags to put their drains in. He was given a carrier bag. He feels angry when he sees advertising for breast cancer campaigns that are pink with no mention of men anywhere and he goes into shops to remind them that men get breast cancer too. He feels his scar is ugly and keeps it hidden all the time. His loss of libido has changed his relationship with his wife, although they are still loving towards one another but he shows it in different ways such as buying her flowers. He is waiting for his 10th anniversary to celebrate beating cancer although he still struggles wondering "why me?"</p>
<p>MBC81: (64) White British Yorkshire Married Diag 2007</p>	<p>Had attributed his inverted nipple to excessive exercise at the gym. After 2-3 weeks he asked his wife what he should do and she encouraged him to see his GP. He was half expecting his diagnosis after his GP had pulled a face and said he didn't like what he saw. Told his immediate family immediately and a few close friends. However, he was quite a private</p>

	<p>person and didn't want some people to know as he thought they would gossip and tell everyone. He didn't feel it was anyone else's business and withdrew from social outings until he looked better and over his chemo so that he didn't draw attention to himself. He now feels he can't go swimming as he's too self-conscious about his body. He also felt he was too young to have lost his libido and is going to see his GP about any treatments that may remedy this meantime. When at hospital his wife often gets called in to clinic and he hates sitting in a pink room which makes him feel very self-conscious when his name is called out. Feels upset when the race for life is a women only event and would like men to be mentioned or included somehow. Was given a lot of information, none male specific but he didn't want to know anything. His wife read the literature and looked on the internet.</p>
<p>MBC85: (73) White British Yorkshire Married Diag 2005</p>	<p>Noticed his nipple had inverted while on holiday. He decided since there was nothing he could do he would not tell his wife until they got home. Dealt with his diagnosis in practical terms of getting on with it. Was sad when his hair fell out and grew back thinner than it used to be. He said his scar didn't bother him and he wasn't one for sunbathing or going swimming anyway. He has read about BC in women and feels his experience was nothing compared to a woman's. He refused breast reconstruction. He told everyone about his diagnosis to raise awareness that men could get breast cancer and they should be checking for lumps.</p>
<p>MBC93: (73) White British London Married Diag 2005</p>	<p>Had been experiencing pain in his nipple for some time before it inverted. He attributed it to jogger's nipple despite not running. 6 months later he showed it to his Dr brother-in-law after encouragement from his wife. Was very surprised when he received his diagnosis as men have 'chest' not breasts. He told his family and friends and although his diagnosis wasn't a secret, he also didn't go around telling everyone he met. He found the loss of his libido depressing and emasculating but didn't feel his BC impacted him as much as it would a woman. Since his diagnosis he has changed his lifestyle, improving his diet, taking supplements and learning reflexology, reiki and participating in a male support group.</p>
<p>MBC91: (59) White British Scotland Married Diag 2006</p>	<p>Had a lump next to his nipple for years and had previously mentioned it to his GP who had reassured him it was nothing to worry about. However it became itchy and would occasionally bleed, so while seeing his GP for another reason, asked his GP about it who offered to refer him. He was seen quickly and reassured it was nothing to worry about. However, the week after the biopsy he was telephoned and</p>

	<p>asked to go to the hospital. He knew then there was something seriously wrong. His family were devastated by his diagnosis but was supported by them and his local community. Has a strong faith that has been a comfort to him and he doesn't fear death. Since diagnosis he's not as outgoing as he used to be and has improved his diet and exercises regularly despite feeling very tired while on tamoxifen. Was given leaflets but none were male-specific and he wasn't interested in knowing about BC anyway. His daughter looks on the internet and tells him what he needs to know. He now won't take his shirt off to go into the pool although he does show people his scar if they don't believe that he has had BC.</p>
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Appendix 9 – Short Biographies of Women with Breast Cancer

Background	Biography
<p>FBC60: 50-59 yrs Oxfordshire White British Divorced Professional/full-time Diagnosed:1998 - symptomatic</p>	<p>First noticed a change in her breast in the shower, but didn't tell anyone or do anything about it for several days. Her daughter was with her when she was given her diagnosis and it came as a complete shock. She told everyone and has received very good support from family, friends and neighbours. She now has bone secondaries and is undergoing treatment and facing an uncertain future.</p>
<p>FBC62: 50-59 yrs Oxfordshire White British Divorced Professional/Part-time Diagnosed:1998 - screening</p>	<p>Recalled to screening but didn't think there would be anything wrong. Was shocked at diagnosis and couldn't recall much of what the doctor told her. She told everyone her diagnosis and realised some people were ignoring her which upset her. The scar on her breast upset her and it reminded her of her cancer. Her marriage broke down soon after treatment finished. She felt her husband could not cope with her illness and became depressed. She feels her cancer has changed her life in many positive ways and she now takes each day as they come.</p>
<p>FBC64: 60-69 yrs Oxfordshire White British Divorced Profession: non-manual Diagnosed 2+ yrs from interview Screening</p>	<p>She had been recalled for regular mammograms but nothing had been found. She later joined a study and was found to have a lump. Initially told everyone but found some people's reactions upsetting as they appeared to "withdraw" from her so now doesn't tell anyone. She had a disabled son that she decided not to tell. She did not think he would cope with the news. She struggled to come to terms with her diagnosis and move on. Had friends and family to support her and always had someone with her at hospital appointments. She refused to read about breast cancer and tried anti-depressants and received some counselling. Attended 3 support groups, but didn't like hearing about all the people who had a recurrence. Needed support once treatment had finished but didn't get any.</p>
<p>FBC66: 70+yrs Oxfordshire White British Married Retired prev profession</p>	<p>Found a lump under her left arm whilst in the bath. Saw her GP that day and was referred onto the hospital immediately. She wanted to protect her husband from her diagnosis as his first wife had died of</p>

<p>unknown Diagnosed 7+ yrs from interview Symptomatic</p>	<p>cancer. He later asked her if she had cancer as she had not explained it to him well enough. Recalled poor experiences in X ray when having her mammography. Care mostly private within NHS setting. Now pays to have extra check ups for peace of mind. She had ongoing problems with lymphodema. She mentioned vaginal dryness during the interview but no further information is available on intimacy or relationship issues.</p>
<p>FBC68: 50-54 yrs Oxfordshire White British Married Profession: non-manual Diagnosed <1 yr from interview Symptomatic</p>	<p>Breast started to feel very hard and as though it was engorged. Got an emergency appt with GP and sent for tests. Found the staff initially insensitive. She was sent home and was phoned the results. She had good family support from her husband and parents. Son was 12 and was very upset thinking she was going to die. Although husband supportive she prefers a friend with her at her hospital appointments. Her niece has also been a very good support whose mum died of breast cancer. She feels her cancer was an interruption in her life although finds it is always present in her thoughts and she is concerned if and how it will return.</p>
<p>FBC70: 50-64 yrs Yorkshire White British Divorced Professional Diagnosed 2+yrs first diag and <12months 2nd diag. 1. Screening 2. Symptomatic</p>	<p>Was first diagnosed at screening and was angry thinking "why me". She was moving area and decided to carry on with her plans. Her second diagnosis followed her finding a lump along her scar. Told everyone her diagnosis. Emailed those she could and phoned the rest. Although she felt there was no point in telling people, she didn't want any rumours starting. Her mastectomy doesn't bother and she rarely uses her prosthesis. Her friends were the main support. Made sure she had enough information before making treatment decisions and consulted widely.</p>
<p>FBC72: 70+ yrs Oxfordshire White British Married Profession: none Diagnosed <1 yr from interview Symptomatic</p>	<p>Had been ignoring a pain in her breast until one day showering she felt a lump in her breast. She immediately came out the shower and phoned the GP for an appointment. Before diagnosis tried to carry on as normal and would check to see if the lump has gone. Found it very hard to tell friends and family as she felt they were "writing her off". Asked her daughter-in-law to tell her son. Hasn't told any of her other children as letting them get on with their lives and will tell them when</p>

	there is no hope. Doesn't want to burden anyone. Was waiting for surgery at time of interview.
FBC74: 50-59 yrs Yorkshire White British Married Professional Diagnosed <2 yrs from interview Screening	Had attended screening and was recalled. Did not expect any problems and felt well throughout. Never thought breast cancer would happen to her. Husband was with her who asked what the prognosis was. Felt her normal life continued in a parallel life to her treatment life. Her husband told her sons and work as she felt she couldn't cope with people's reactions to hearing the news. She could talk to them once they knew though. She had problems with her mastectomy scar and had it drained a few times and a haematoma removed surgically. She had severe hot flushes and sweating on tamoxifen but these side effects were improving. Tried evening primrose but didn't work so gave up. Wanted a mastectomy to get rid of the BC, but found the scar very hard to look at initially. Has so far declined reconstruction as worried about it being such a big operation, and she uses a stick on prosthesis, which she feels is very life-like.
FBC76: 50-64 yrs London White British Married Professional Diagnosed 2+ yrs from interview Symptomatic	Had been ignoring a lump in her breast until she returned from a work trip and went to see her GP. Was referred immediately but thought everything would be ok. Had no prior knowledge of breast cancer. Told everyone as felt it was her "duty" to raise awareness. Is now having problems with changes in her uterus but is not telling people so as not to worry them. She will tell them if there was something important found. Had problems with lymphodema since surgery and felt it was a daily reminder of her diagnosis. Felt able to work throughout treatment and get on with normal life. Still worries about recurrence and will never say she is "cured". Has made sure she has made financial arrangements should anything happen to her.
FBC78: 50-64 yrs London White British Divorced Professional Diagnosed 1+ yr from interview Screening	Didn't ever think she would get cancer as noone in family had it. Felt embarrassed and shame when she was diagnosed. She did not want to lose her hair during chemotherapy and used the cold cap treatment. She found this very painful and felt de-feminised due to the hair thinning and weight gain on steroids. Felt deeply

	<p>changed by her diagnosis both in negative and positive ways. Felt initially that she was going to die but is now getting on with life and going out more. Feelings of loneliness remain and removed from "normal" life as she isn't carefree anymore.</p>
<p>FBC80: 50-64 yrs Kent White British Married Profession: Lecturer Diagnosed 2+ yrs from interview Symptomatic</p>	<p>Had felt a thickening of her breast 4 months previously which she was unsure about so decided to leave it a month to assess. Her father then had a stroke and her priority was helping him come home and looking after him. Later she found a lump that was much bigger than previous. She assumed it was cancer. Checked with husband he could feel the lump then made appointment to see GP. Drs agreed to try and shrink it first by using hormonal therapy. This allowed her to not tell her sons immediately who were sitting important exams at the time. She told her brother and sister and people at work who needed to know. She declined any reconstruction. She now changes in a cubicle at the gym and wears prosthesis. Had time to adjust and come to terms with her mastectomy before the surgery. Her breast cancer has given her a new outlook on life and she tries to find something to take pleasure in every day.</p>
<p>FBC82: 50-59 yrs Midlands African-Caribbean Divorced Profession: unskilled manual Diagnosed 1+ yrs from interview Symptomatic</p>	<p>Found a lump whilst in the bath. She bathed it in hot water and applied antiseptic cream until she realised 3 weeks later there was no change. She was told the only surgical treatment option was a mastectomy. She told her family and some close friends. She didn't want a mastectomy but realised to remain alive she had to have it. Hasn't got a current partner but she is done with men anyway as they won't like her body now. She declined reconstruction because she felt too old. She was also alarmed at the speed her hair fell out during chemotherapy. Her nephew shaved her head for her and she wore a wig. She didn't think anyone could tell the difference. As long as she has her family and roof over her head she feels she doesn't need anything else. She has a strong faith and she prays for health.</p>
<p>FBC84: 50-64 yrs Oxfordshire White British Married</p>	<p>Found a lump whilst in the bath and thought it would go away so delayed seeing GP for 4 weeks. Eventually broke down and told her husband and a friend who said she</p>

<p>Profession: retired Diagnosed 2+ yrs from interview Symptomatic</p>	<p>must see her GP. She told her family eventually. Her daughter angry she hadn't been told earlier and sisters became hysterical as though she was going to die imminently. Once everyone got over the initial shock she felt she could talk to them all about her diagnosis. She had a wide local excision, which changed the shape of her breast, and she doesn't like anyone seeing her without a bra on. Once treatment finished she started living her life again. She worries about the cancer returning and checks herself for lumps. Doesn't think she'll ever stop worrying about it returning.</p>
<p>FBC86: 50-64 yrs Oxfordshire White British Married Profession: voluntary Diagnosed 2+ yrs from interview Screening</p>	<p>She was recalled to screening following a mammogram. Although alarmed to get the letter, was reassured by its content because she knew many women are found to be ok. Had various tests, which were inconclusive and had to wait for results. She was told there was a high probability it would be cancer. Found telling her children the hardest part. She waited until after her surgery before telling her mum. She has been very open about her diagnosis. Her family was very supportive and she always had someone with her at appointments to make sure she picked up the right information. It made her realise she won't live forever and has to face her own mortality. Now undertakes regular breast checks and shares her experiences with others to help them.</p>
<p>FBC88: 50-64 yrs London African-Caribbean Divorced Profession: none Diagnosed 2+ yrs from interview Symptomatic</p>	<p>Had a lesion on her skin near her nipple that kept breaking down. She attended her GP who referred her to the clinic. After several months she was diagnosed with Paget's Disease, a form of breast cancer. She was alone when given her results and was in shock. Her family lived abroad and she had to phone and tell them. She had a reconstruction at the same time as her mastectomy and feels very happy with the results. She also had a nipple reconstructed several months later. Despite having a second cancer, an unknown primary, she continues to get up in the morning and live her life as best she can with the help of others.</p>
<p>FBC90: 50-64 yrs London South Asian</p>	<p>Had attended screening and received a letter in the post to return. Thought the hospital had made a mistake and threw the</p>

<p>Married Profession: business owner Diagnosed 2+ yrs from interview Screening</p>	<p>letter out. Another letter came 2 weeks later and she phoned to tell them they had made a mistake. They said no and she went for the appointment. She was confident she did not have breast cancer when they said she did. She told them she didn't want to be treated and she wanted to die. Her family and GP persuaded her to attend for treatment but she was devastated to have a mastectomy. She struggled with the hair loss and change to her body and was mistrusting of the medical team. She could not cope with the 2nd part of her chemotherapy treatment and refused to have it. Her family was very supportive.</p>
<p>FBC92: 50-64 yrs London African Widowed Profession: none Diagnosed 2+ yrs from interview Symptomatic</p>	<p>Had prior experience of cysts in her breasts and regularly checked herself. When she found a lump she went to her GP who referred her immediately. Was seen that day and given her diagnosis very quickly. She was very upset and thought "why me?" as she already had arthritis and high blood pressure. The doctors tried to reassure her she would be ok, but she didn't believe them and doubted their advice. She found it very difficult to tell people and puts her faith in God to look after her.</p>
<p>FBC94: 50-64 yrs London White British Divorced Professional Diagnosed 2+ yrs from interview Screening</p>	<p>Had a mammography under her work's private health insurance scheme. Was expecting a normal day and by end of it had been told she probably had an invasive breast cancer. She was shocked and felt rushed into decision-making. She felt the first doctor she saw wasn't giving her enough information or supported her choice for alternative treatment and sought out 2 or 3 opinions until she felt comfortable to have treatment. She found it very hard to tell her son and his wife, but found them very supportive. She felt embarrassed telling people, and never heard from some friends again. At the time felt that surgery was an invasion of her private body that wasn't the same anymore. With time, she realised the scarring was minimal and doesn't worry now. She stopped HRT when she was diagnosed and had menopausal symptoms. She felt her desire as a woman had gone and her relationship had ended. She didn't think she would ever find love again, although she did.</p>
<p>FBC96: 50-64 yrs</p>	<p>Received a letter to attend mammography</p>

<p>London African-Caribbean Separated Profession: unemployed Diagnosed 1+ yrs from interview Screening</p>	<p>and took it to the doctor who advised her to go. A couple of months later she was lettered again to go to the hospital for follow up. She underwent more tests and was told she had breast cancer. She didn't want conservative surgery, she wanted the breast off to prevent re-occurrence and have piece of mind. She had severe side effects on chemotherapy including nausea, sickness and tiredness. She had some burning with radiotherapy and felt ill the day of treatment. She didn't want details of her surgery. She read some booklets but felt they couldn't help her with how she was feeling inside. She had very good family support and did not attend support groups because she did not think they would help her.</p>
<p>FBC98: 65+ yrs London South Asian Married Profession: none Diagnosed 10+ yrs from interview Symptomatic</p>	<p>Knew nothing of breast cancer until a woman came to an Indian centre she attended and talked to women about breast awareness. She went home and talked to her daughter as she had a thickening on one of her breasts. Her daughter encouraged her to see her GP who referred her immediately to the hospital. When she was diagnosed she put her faith in God as he is the only one who could decide her fate. She didn't receive any ethnic information and her children interpreted for her. They asked questions and reassured her she would be ok.</p>
<p>FBC50: 50-64 yrs Scotland White British Married Profession: Office Manager Diagnosed 2+ yrs from interview Symptomatic</p>	<p>She had lumpy breasts in the past and ignored a lump in her breast for a couple of months until she noticed in the shower one day that her nipple had inverted. She knew this was something that needed checked out at the hospital and went to see her GP. Her husband had gone with her, but she didn't think there would be anything wrong and was stunned when she told she had breast cancer. She had complications following surgery and the reconstruction of her breast left her with ugly scars on other parts of her body. She feels that despite her husband's reassurances their sex life and relationship will never be back to what it was before and feels rejected sometimes. Feels despite everything her breast cancer has made her a better person as she has found strengths within herself and she's survived the experience. She sees the cancer as a sniper out to shoot people</p>

	down and she's determined she isn't going to get caught again.
<p>FBC52: 65+ yrs Scotland White British Married Profession: none Diagnosed twice: 2nd 5+ yrs from interview Symptomatic (twice)</p>	<p>Her sister had died of breast cancer two years before her diagnosis. She could not believe she had breast cancer too and thought she would die. Her husband was very supportive throughout, and although her family eventually was, they were hysterical when she first told them. 14 years after her first diagnosis she was diagnosed with breast cancer in her remaining breast. At first she couldn't look at her mastectomy scar. She would turn herself away from her husband whenever undressing and thought of her body as ugly and odd without breasts. Eventually she came to terms with it and can now be naked near her husband. She said she wasn't going to let cancer beat her, and put some faith in God.</p>
<p>FBC54: 65+ yrs London White British Married Profession: Nurse, journalist Diagnosed <1 yrs from interview Symptomatic</p>	<p>She had been on holiday when she noticed a thickening of her breast. She did not do anything about it until she returned from holiday and her husband had recovered from an illness. She was seen very quickly at the hospital and given her diagnosis that day. She thought there was a high chance of it being cancer as she had several risk factors including a strong family history. Her reaction was one of dismay but felt there were worse diagnoses than cancer. She decided to have both breasts off as felt being lopsided would be bad for her back and she would be worried about recurrence. She felt at 70 having reconstruction would be "taking vanity to the extreme". She felt she took her diagnosis in her stride and got on with life as quickly as she could following surgery.</p>

Appendix 10 – Coding Strategy

HELP SEEKING

Any awareness that men could get BC. Finding initial change in their breast and seeking medical help from their GP. Includes whether this was done promptly or if they delayed. The symptoms they had and any influencing factors that prompted seeking help.

DIAGNOSIS

Actions taken by GP and referral to specialist services. Diagnostic test carried out and diagnosis given (by whom, who was present, reactions).

EMOTIONS

Any discussion where emotions were described. Including anger, shock and “why me”

DISCLOSURE

Who participant’s told and their reactions. When they told them (immediately, delayed) and discussions on nondisclosure and reasons for this.

TREATMENT

All discussions on the decision-making process, their treatment including surgery, chemo, radiotherapy and hormonal tx such as tamoxifen and arimidex. Any side effects suffered. Reflections on their treatment experience. Any follow up received/not received.

EXPERIENCES OF HEALTHCARE

Positive and negative experiences. Interactions with medical, nursing and voluntary staff.

INFORMATION

Information given (leaflets, internet web links used) Lack of information resources. Offered but not used or declined.

FINANCIAL IMPLICATIONS

The financial implications their BC diagnosis and following treatment had for them.

MASCULINITY

A section where things that appear to have significance to their masculinity has been put. Includes sexuality/intimacy, issues of self-esteem, remarks about women and their position. Anger issues etc (this is a work in progress!)

THOUGHTS ON WHAT CAUSED BREAST CANCER

Includes family history and genetics, lifestyle and environmental issues.

SURVIVORSHIP

Includes the lifestyle changes made since their diagnosis. Their future plans (if they have any). Getting back to ‘normal’ any discussions there were on helping others either by talking to them or taking part in research (‘pay back’).

COPING STRATEGIES

Use of support groups. Whether they talked to other people or distanced themselves.

ROLE & RELATIONSHIPS WITH SIGNIFICANT OTHERS

Particularly wives and children, but anyone else discussed that either helped them significantly or caused them upset.

BODY IMAGE

Includes hair loss, mastectomy scar, changes to lifestyle due to an altered body image.

COMPARISONS WITH WOMEN & MEN

Any experience reflected comparing with women's experience, both positive and negative.

ADVICE FOR OTHER MEN

Answers to what advice they would give other men newly diagnosed with BC.

BC CAMPAIGNS

Thoughts on the feminine and 'pinkness' of BC campaigns

'MALE BREAST CANCER'

Answers to what their thoughts were on the term and other suggestions that they made.

Appendix 11 – LBSS Ethics Application

FACULTY OF LAW, BUSINESS & SOCIAL SCIENCES ETHICS COMMITTEE

APPLICATION FOR ETHICAL APPROVAL

NOTES:

THIS APPLICATION AND ANY ACCOMPANYING DOCUMENTS MUST BE SENT ELECTRONICALLY TO L.Stevenson@lbss.gla.ac.uk

THIS APPLICATION FORM SHOULD BE TYPED NOT HAND WRITTEN.

ALL QUESTIONS MUST BE ANSWERED. "NOT APPLICABLE" IS A SATISFACTORY ANSWER WHERE APPROPRIATE.

INTERNAL IDENTIFICATION NUMBER SSL/06/

Project Title Men's experiences of having breast cancer

Date of submission May 2008

Name of all person(s) submitting research proposal
Caroline Sime

Position: Student or Staff __ student

[If Student: UG or PG __ PG Student No: _0506950s

Full Course Name: _PhD

Department/Group/Institute/Centre

Medical Research Council , Social & Public Health Sciences Unit (MRC, SPHSU)

Address for correspondence relating to this submission:

4 Lilybank Gdns,
Glasgow
G12 8RZ

Name of Principal Researcher (if different from above e.g., Student's Supervisor)

Prof Kate Hunt
Dr Katie Buston

Position held

Head of Programme – Gender & Health, MRC SPHSU
Investigator Scientist, Sexual & Reproductive Health, MRC SPHSU

1. Describe the purposes of the research proposed.

Breast cancer in men remains a rare occurrence in the UK. In 2004 324 men were diagnosed with breast cancer which accounted for 1% of all new cases of breast cancer (Cancer Research, 2007). Because of the rarity of the disease there is a lack of research and literature that concentrates on men with breast cancer (Giordano et al, 2004; Weiss et al, 2005). Indeed, the evidence base that supports the treatment of men has mainly been extrapolated from studies of women, due to the small size of samples of men available (Naymark, 2006). However it is the psychosocial effects of receiving a breast cancer diagnosis and subsequent support for men that has particularly been ignored (Fentiman et al, 2006; Agrawal et al, 2007).

Therefore the purpose of the proposed research is to explore men's experiences of having breast cancer, which is a stereotypically 'female' disease, and to compare the findings with women's experiences of having breast cancer; men's experiences of prostate cancer (a 'masculine' cancer); and men's experiences of having colorectal cancer (a non-sex specific cancer). The main areas of interest will be the reactions of men to their diagnosis; their family's and society's reactions to the diagnosis; their experiences of treatment; and the impact the diagnosis has had on their identity.

2. Please give a summary of the design and methodology of the project. Please also include in this section details of the proposed sample size, giving indications of the calculations used to determine the required sample size, including any assumptions you may have made. (If in doubt, please obtain statistical advice).

Methodology

This is a qualitative study that will be conducted in a manner that is compatible with the production of a DIPEX module (see www.dipex.org). The DIPEX charity was launched in 2001 with the express purpose of providing widespread access to an extensive range of personal experiences of health and illness. To date, there are over 30 'modules' on the award winning DIPEX site, each dealing with a different health issue. The website is unique because the extracts of personal experiences that are presented are based on interviews collected and analysed by experienced qualitative researchers using rigorous methods approved by the UK Multi-centre Research Ethics Committee (MREC).

Sample

A purposive sample of approximately 25-35 men with breast cancer from all over the UK will be interviewed. We aim to recruit men who have been diagnosed within the last five years so that we can identify men at different stages in process of receiving the diagnosis, having treatment and recovering from treatment.

Recruitment

Men with breast cancer will be approached via their GP or their hospital consultant, or through an advert on the DIPEX website, Breast Cancer Care website and snowballing methods. They will be offered the chance to return a reply slip giving their name and contact details direct to the researcher. Only then will the researcher contact the respondent directly.

Interviews

The interviews will be video or audio recorded with the participant's consent. The men will be asked to narrate their stories from when they first suspected a problem. Once they have completed their story, they will be asked some semi-structured questions to explore their reactions to their breast cancer diagnosis; the reactions of family, friends, colleagues, health workers and wider society; their experiences of treatment; and the impact of diagnosis and treatment on their identity.

Secondary Analysis

The men's experiences of having breast cancer will be compared with three other groups of interviews already undertaken for the DIPEX website. These are women's experiences of having breast cancer; men's experiences of having prostate cancer and men's experiences of having colorectal cancer. There is an existing agreement between Prof Hunt and the Research Director of DIPEX that the transcripts from these interviews are available to us for secondary analysis.

3. Describe the research procedures as they affect the research subject and any other parties involved.

WE will carefully follow the procedures which the DIPEX team have established and gained MREC approval for, which is outlined here. The DIPEX site will be demonstrated to participants on a laptop computer before the interview. If they consent to taking part in the interview they will be asked to sign consent forms (see appendix 3). Their interview will be video or audio tape recorded and the interviews will be transcribed in full. Names of healthcare staff and hospitals will then be removed from the tape transcripts and participants will be given the option whether to use their own name or an alias of their choosing. A copy of the interview will be sent to the participant and they will be invited to indicate any sections that they do not want to appear on the internet. After they have approved the interview content and chosen whether they want their clips to appear in video, audio or completely anonymised written version, a form will be signed which gives copyright to the project to use the material in research, teaching, publications and broadcasting. These procedures are well established and have been used for all the existing DIPEX modules.

For the PhD, the transcripts will be analysed using a framework analysis approach to identify anticipated and emergent themes in a structured and comprehensive manner that will allow direct comparability with the secondary analysis data.

4. What in your opinion are the ethical considerations involved in this proposal? (You may wish for example to comment on issues to do with consent, confidentiality, risk to subjects, etc.)

Consent

This study has been designed to ensure integrity and quality. The participants will be given an information sheet (see appendix 1) and will be given time to ask any questions that they may have. They will be answered to the best of the researcher's ability. Potential respondents will also be given the opportunity to ask further questions of Professor Hunt, or Sue Ziebland, research Director of DIPEX at Oxford University.

All subjects will give full, written consent prior to the interviews. They will be given the option whether to use their own name or an alias of their choosing on the DIPEX website, and in the PhD thesis will be anonymised. There will be no coercion to participate. They will be free to withdraw from the interview at any point. There will be no changes to their healthcare should they choose not to participate, or withdraw.

Confidentiality

All tapes, transcripts and field notes will be kept in a locked cabinet. They will be stored using an ID number which will be filed separately from any identifying/contact details.

Risk to Subjects

There will be no invasive procedures used in this study. The interviews will initially be led by the respondent giving a narrative of their experiences. It is anticipated, this may cause some emotional distress to the respondent. The issues raised will be dealt with sensitively and contact details for further support will be given to each individual after the interview. The respondents will be reassured that they can stop the interview at any point and can withdraw from the study completely if they wish. The majority of the interviews will be conducted by the applicant, Caroline Sime, who has extensive experience with patients with cancer.

The MRC will provide in the case of negligent harm for research conducted through its Units when it is Sponsor and for employees or others acting on behalf of the Council. Care organisations continue to be responsible for any breaches of the duty of care they owe with respect to participants of this research (see appendix 2).

5. Outline the reasons which lead you to be satisfied that the possible benefits to be gained from the project justify any risks or discomforts involved.

The benefits of this study will be a greater understanding of men's experience of having breast cancer, which is arguably at the most extreme feminine end of a spectrum of illnesses that men can experience. It is anticipated that by understanding the way men find their identity challenged greater knowledge will be gained about their use of health services, attitudes to treatment, psycho-social well-being and outstanding needs.

The DIPEX module that we hope to produce from the interviews will also be a resource for others to use. It will provide other men diagnosed with breast cancer in the future with the opportunity to find out how other men have experienced the illness. It will also enable health professionals, family members and friends to explore the experiences of other men with breast cancer should a patient or close contact be diagnosed with this rare disease.

6. Who are the investigators (including assistants) who will conduct the research and what are their qualifications and experience?

Caroline Sime, BN, RGN, DN. I am a qualified District Nurse with extensive experience of working with and talking to people who are ill. I have also worked for four years with people who have HIV. The main duties of my former post included supporting and counselling people who were living with a life threatening, chronic disease and supporting them to make informed choices about their treatment options including palliative care. I have carried out a qualitative study prior to this using semi-structured interviews with District Nurses exploring their use of care packages in the last week of life.

I have also attended a qualitative study training day and another course on Interview Techniques provided by the DIPEX team in Oxford. I have recently successfully completed the Qualitative Methods module from the LBSS faculty. I am also currently waiting for final results to complete the Masters in Primary Care at Glasgow University.

Prof Kate Hunt, PhD, MA (Human Sciences), MSc (Dept of Clinical Medicine) Oxford University, is a Senior Research Scientist at the MRC Social and Public Health Sciences Unit. She is responsible for a programme of research on gender and health. She has conducted a wide range of research, using both qualitative and quantitative methodologies and is experienced in PhD project supervision.

Dr Katie Buston, PhD, is an Investigator Scientist at the MRC Social and Public Health Sciences Unit. She has been involved in qualitative research for over 16 years and has worked as a researcher in the sexual health team at the SPHSU for the last 11 years. She is also an experienced PhD project supervisor.

7. Are arrangements for the provision of clinical facilities to handle emergencies necessary? If so, briefly describe the arrangements made.

No clinical facilities will be necessary for this study.

8. In cases where subjects will be identified from information held by another party (for example, a doctor or hospital) describe the arrangements you intend to make to gain access to this information including, where appropriate, which Multi Centre Research Ethics Committee or Local Research Ethics Committee will be applied to.

We anticipate that, because of the uncommon nature of male breast cancer, we will only be able to recruit a minority of our participants from the established DIPEX network of GPs, and that the majority will be recruited from major hospitals and self-help groups. The study will be covered by the DIPEX MREC (Multi centre Research Ethics Committee) approval (MREC 99/5/17, MREC 03/5/16) for studies with adults. DIPEX studies have 'no local investigator' approval and we have cover letters for Hospital Trusts who must be informed whenever a member of staff agrees to recruit for one of our studies.

9. Specify whether subjects will include students or others in a dependent relationship.

The participants will be men with breast cancer who will be able to decide for themselves whether they wish to participate in the project. This will not include any students or others in a dependent relationship to any of the researchers.

10. Specify whether the research will include children or people with mental illness, disability or handicap. If so, please explain the necessity of involving these individuals as research subjects.

Not Applicable

11. Will payment or any other incentive, such as a gift or free services, be made to any research subject? If so, please specify and state the level of payment to be made and/or the source of the funds/gift/free service to be used. Please explain the justification for offering payment or other incentive.

No payment will be made to any of the participants. If it is necessary for the participant to travel to the interview then travel costs will be reimbursed.

12. Please give details of how consent is to be obtained. A copy of the proposed consent form, along with a separate information sheet, written in simple, non-technical language MUST ACCOMPANY THIS PROPOSAL FORM.

Potential participants will be sent a participant information sheet (see appendix 1) and response form (see appendix 3). If they return a completed response form they will then be contacted direct by the researcher and given the opportunity to ask any questions they may

have. Once both the parties are satisfied, a mutually convenient time and place will be chosen for the interview. Before the interview begins the participant will again be offered the opportunity to ask any questions and they will be given a demonstration of how video, audio and written clips are used. They will then be asked to sign a consent form (see appendix 4) should they agree to participate.

13. Comment on any cultural, social or gender-based characteristics of the subject which have affected the design of the project or which may affect its conduct.
This research is gender-specific and only men will be interviewed. Due to the low incidence of MBC, the proposed study will be carried out UK wide to ensure that the sample size is large enough to reach saturation.

14. Please state who will have access to the data and what measures which will be adopted to maintain the confidentiality of the research subject and to comply with data protection requirements e.g. will the data be anonymised?
Once the interview has been completed, the tapes will be transcribed and anonymised to ensure confidentiality. The original transcripts will be kept in a locked unit separate from the tapes that will also be kept in a secure place in the SPHSU MRC unit. On completion of the project the researcher will also make copies of the tapes and transcripts available to legitimate members of the DIPEX team to assist in the preparation of the DIPEX module on male breast cancer. Extracts from the interview, approved by the participant, may appear on the DIPEX website once the male breast cancer module has been completed. The MRC SPHSU will retain the research intellectual property rights, and only the researcher, the supervisors and other legitimate researchers will have access to the full transcripts.
The original list of names and signed consent forms will be kept by the Unit's Survey office and will be kept completely separate from the anonymised transcripts.

15. Will the intended group of research subjects, to your knowledge, be involved in other research? If so, please justify.
To my knowledge, the research subjects will not have been involved in other research.

16. Date on which the project will begin

May 2008 – October 2010.

17. Please state location(s) where the project will be carried out.

Primarily in the respondents' homes, or in the Social and Public Health Sciences Unit, MRC, Glasgow, or in other locations convenient to the respondent.

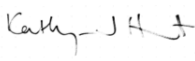
18. Please state briefly any precautions being taken to protect the health and safety of researchers and others associated with the project (as distinct from the research subjects) e.g. where blood samples are being taken

SPHSU MRC has strict guidelines for the safety of its researchers and training is given. During periods of fieldwork, researchers are issued with a mobile phone connected to the 'Communicare' network. This is a support device which monitors travel whereabouts and has a panic mode facility. Travel arrangements and interview times will be left with a colleague at the unit. If the researcher feels at risk at any time then they will remove themselves from the area and contact emergency services if necessary. MRC good research practice guidelines dictate that a full risk assessment is carried out before fieldwork commences.

Name _____
(Proposer of research)

Date _____

Where the proposal is from a student, the Supervisor is asked to certify the accuracy of the above account.


 Professor Kate Hunt
 Name _____ Date 13.5.08
 (Supervisor of student)

COMMENT FROM HEAD OF DEPARTMENT/GROUP/INSTITUTE/CENTRE

This is a sensitive area but Caroline is a trained nurse experienced in dealing with sensitive and life threatening diseases. Both supervisors are experienced quantitative researchers and are familiar with ethical issues arising in health research. DIPEx has its own controls and procedures which have passed rigorous ethics scrutiny. I am confident that this project will maintain high ethical standards.



Professor Sally Macintyre
 Name _____ Date 7 May 2008.
 (Head of Department/Group/Institute/Centre)

Send completed form to Leeann Stevenson

L.Stevenson@lbss.gla.ac.uk



LBSS Faculty Ethics Committee

13/06/08

Dear Leeann,

Thank you for the comments from the ethics committee. I have considered each point and have made the following alterations:

1. I have inserted Prof Kate Hunt's name into the Participant Information Sheet for further contact in case of a complaint or further information.
2. I have completed section 10 of the ethics application to reflect the needs of people with disability.
3. With respect to points 3 & 4 on secondary use of data, Professor Kate Hunt has an existing agreement with DIPEX for her and members of her research team to undertake secondary analysis of certain DIPEX modules, including the female breast cancer and prostate cancer modules. She has already co-authored 3 papers based on secondary analysis of various DIPEX data (please see below) published in academic journals which adhere to the highest ethical standards and require reassurances about the ethics of the research; another two papers are currently under submission with further journals. The commitment to make data from a DIPEX interview widely available (either for members of the public and health professionals via the DIPEX website, or for other bona fide academic researchers through secondary analysis) was a core value behind the establishment of DIPEX. As such, it was an important part of the lengthy negotiations of the ethical framework for DIPEX which were approved by MREC. The potential uses for the data are, of course, made explicit, to potential respondents and they have an opportunity to restrict access to all or part of their transcript if they wish when they have the opportunity to review what they have said in the transcription of the interview.

Hilton S, Hunt K, Emslie C, Salinas M, Ziebland S (in press) Have men been overlooked? A comparison of young men and women's experiences of chemotherapy-induced alopecia. *Psycho-Oncology* (doi: 10.1002/pon.1272)



INVESTOR IN PEOPLE

MRC Social and Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow, G12 8RZ
Tel: 0141 357 3949 Fax: 0141 337 2389 www.sphsu.mrc.ac.uk

A Research Unit supported by the Medical Research Council and the Chief Scientist Office of the Scottish Government Health Directorates, at the University of Glasgow

Emslie C, Ridge D, Ziebland S, Hunt K. (2007). How do men and women with depression articulate their distress and engage with health professionals? A qualitative interview study. *BMC Family Practice*, 8: 43 doi 1186/1471-2296-8-43.

Emslie C, Ridge D, Ziebland S, Hunt K. (2006). Men's accounts of depression: reconstructing or resisting hegemonic masculinity? *Social Science and Medicine*, 62: 2246-2257"

4. We omitted to include one further form that DIPEX interviewees are requested to sign ('Further use of my DIPEX interview') which makes this clearer and we have now enclosed this as appendix 5.

Yours sincerely,

Caroline Sime
PhD Student
e-mail: caroline-s@sphsu.mrc.ac.uk

Appendix 12 – LBSS Ethics Approval

Faculty Ethics Committee
Email: L.Stevenson@lbss.gla.ac.uk

12 June 2008

Ms Caroline Sime
 4 Lilybank Gardens
 Glasgow
 G12 8RZ

Dear Ms Sime,

SSL/07/23 "Men's experiences of having breast cancer"

Thank you for your application seeking ethical approval for the above project. The committee has considered your application and require the following minor amendments to be made for your own protection, prior to ethical approval being granted:

1. The researcher should provide the contact details of one of her supervisors (or someone else in the university) in case of complaints or need for further clarification. At the moment (on the DIPEX) site the contacts given are the researcher herself and someone from DIPEX.
2. The researcher should be aware that some of the interviewees may have a so called 'hidden' disability and she should carry out her research with this in mind. For example up to 25% of adults in the UK have a learning disability according to latest figures. The researcher has replied 'Not Applicable' to the question on disability in the Application Form. Please complete.
3. Please consider whether the consent form should be more explicit about consent to recording?
4. Regarding the secondary analysis of data, we note that this will involve comparisons with other groups of interviews already undertaken for the DIPEX website. Did the individuals who participated in these interviews give consent for the data to be used in this way?

Please include a cover sheet showing how you have approached the changes set out above.

I would be grateful if your reply to this letter could be sent electronically to L.Stevenson@lbss.gla.ac.uk.

Yours sincerely,

Faculty Ethics Committee

Faculty Ethics Committee
Miss Leeann Stevenson (Secretary)
L.Stevenson@lbs.gla.ac.uk or 0141 3304693

16 June 2008

Ms Caroline Sime
 4 Lilybank Gardens
 Glasgow
 G12 8RZ

Dear Ms Sime,

SSL/07/23 "Men's experiences of having breast cancer"

I am pleased to confirm that your application for ethical approval has been approved by the Faculty Ethics Committee.

As a condition of approval and in line with the committee's need to monitor research, the committee requires that a report be provided to it towards the end of the research, giving brief details of the project to date and any ethical issues which have arisen. You will be contacted in due course in this regard. In addition, any unforeseen events which might affect the ethical conduct of the research, or which might provide grounds for discontinuing the study, must be reported immediately in writing to this ethics committee, from which you have received approval. The committee will examine the circumstances and advise you of its decision, which may include referral of the matter to the central University Ethics Committee or a requirement that the research be terminated.

Please note that this approval is valid for the duration of your project. **Please confirm in writing the end date for approval.** If the project should extend beyond the submission date you entered on your application form it will be necessary for you to contact the committee and seek an extension. As this approval is based upon the information you provided to the committee you will require to seek approval should any changes be made to your project. In particular, please note that if participants in your research involve children or adults with incapacity (as defined in the Adults with Incapacity (Scotland) Act 2000, available via the University Ethics Committee web site) you require to comply with the legislation which governs research involving these groups. If you have not complied with these requirements or you did not anticipate that your research may involve these groups you must exclude them from your study.

Please retain a copy of this letter.

Yours sincerely

Faculty Ethics Committee

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