

**The Experiences of Male Partners of Women with Breast Cancer: An
Interpretative Phenomenological Analysis**

Thesis submitted in part fulfilment of the degree of

Doctorate in Clinical Psychology

(DClinPsy)

University of Leicester

By

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Declaration

I, Sarah Thomas, can confirm that this thesis and the research reported within it is my original work. It was written and submitted in part fulfilment of the degree of Doctorate in Clinical Psychology (DClinPsy). It has not been submitted for any other degree or academic qualification. I can confirm that I have checked this thesis is complete prior to submission.

Abstract

Breast cancer is the most common cancer diagnosis in the UK, with most cases being diagnosed in females. With advances in treatment, it is being increasingly recognised as a chronic condition, which has an impact not only on the patient, but also on the patient's family. Research suggests that partners often become the primary caregivers for these women, and yet there has been very little research exploring the impact of this diagnosis on partners.

The literature review aimed to explore the information needs of male partners of women with breast cancer. Following a systematic literature search, a total of 13 papers were identified. A synthesis of the findings revealed that men prioritised information about their partner's diagnosis, prognosis and treatment options. They preferred information from the patient or from healthcare professionals, but difficulties with communication were found to be a barrier to accessing information. Recommendations were made for healthcare professionals to aid communication with male partners.

The research report explored the experiences of male partners of women with breast cancer, who had received the diagnosis within the last year. Semi-structured interviews were carried out with five men whose wives were accessing an Oncology Unit.

The transcripts were analysed using Interpretative Phenomenological Analysis (IPA). From the analysis four super-ordinate themes emerged, with a total of 13 sub-themes. The themes were considered in relation to previous research and relevant psychological theories. The discussion led to a number of clinical implications, highlighting the vital role played by healthcare professionals, and the importance of psycho-educational interventions for men.

Finally, the critical appraisal provides the researcher's reflections on the research process and brings to light learning points to be taken forward.

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Finally, I would like to thank my family, friends, and my partner. This thesis marks the end of a long, hard journey for me; one that I would never have been able to make without all of your support and understanding. It is with your on-going encouragement that I have been able to achieve a life-long dream. Thank you all so much.

¹ Regrettably, I shall not be naming this person in order to maintain anonymity of the host site and of the participants.

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Addenda: Transcripts have been presented separately as an addendum³:

Transcript 1: 'John'
Transcript 2: 'Matthew'
Transcript 3: 'Adam'
Transcript 4: 'Ben'
Transcript 5: 'James'

³ Participants' names have been changed to maintain anonymity.

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Part 1

Literature Review

This literature review has been prepared in line with the SciFed Oncology and Cancer Research Journal guidelines.

Guidelines for authors can be found in Appendix A.

Abstract

Background: Male partners of breast cancer patients may cope by seeking information about breast cancer and its consequences. However, it is not clear what men's information needs might be, how they get this information, and what might stop them from fulfilling these needs.

Aims: To answer the following questions:

- What information do men want?
- What are men's preferred sources of information?
- What barriers might prevent men from accessing information?

Method: Search terms were entered onto three electronic databases (PsychInfo, Medline and Scopus). The results were hand searched to remove papers that did not meet the inclusion criteria. A total of 13 papers were identified.

Findings: Men prioritised information about the patient's diagnosis, prognosis and treatment options. They preferred information from the patient or from healthcare professionals. Barriers included difficulties communicating with the patient, and difficulties approaching healthcare professionals.

Conclusion: Healthcare professionals are in a good position to further help men by providing relevant information, being approachable, and encouraging communication between the couple. Further research is needed to ascertain the key points at which men's needs change.

Keywords: Breast cancer, male partners, husbands, information needs, unmet information needs, sources of information.

List of Abbreviations

CASP Critical Appraisal Skills Programme

HCPs Healthcare Professionals

Introduction

Breast cancer is the most common cancer for women worldwide: In 2012 alone, 1,676,000 new cases were diagnosed (Cancer Research UK, 2014). Receiving such a diagnosis can have a significant impact on the patient's wellbeing; for example, women with breast cancer often report poor body image (Arroyo & Lopez, 2011), anxiety and depression (Gallagher *et al.*, 2002), and psychological distress (Montazeri, 2008).

Breast cancer, however, does not only affect patients, but also affects the patient's family. Family systems theory (Minuchin, 1974) emphasises the interrelatedness of family members, and suggests that all members are affected when one person becomes unwell. When one member is diagnosed with cancer, the family may face several challenges in their attempt to maintain a sense of stability: Filling in the lost role of the sick family member; meeting the emotional needs of other family members; and continuing to perform regular family functions whilst attending to extra demands (Lederberg, 1998). Indeed, research suggests that the partners and children of women with breast cancer experience psychological distress above population norms (Segrin & Badger, 2010). The family of cancer patients are being increasingly recognised by policy makers in the British health care system, as they often become informal caregivers. The Calman-Hine report on the re-organisation of cancer services in England and Wales (Department of Health, 1995) states that cancer services should take into account the needs of families and carers, which includes providing information that is relevant, accessible and comprehensible.

Seeking information is a common strategy used in the psychosocial adjustment to an illness such as cancer (Lambert & Loiselle, 2007). Information seeking is relevant not only during treatment, but is also relevant beyond treatment and into survivorship. Research suggests that survivors and their partners often experience uncertainty related to physical changes, relationship challenges and recurrence (Carter, 1993; Dow, 1990). For many of these couples, seeking information is used as a means of coping with this illness-related uncertainty (Miller, 2014). In the Transactional Model of Stress

and Coping (Lazarus & Folkman 1984), information seeking falls under 'problem-focused coping'. In the context of cancer, information seeking may enable individuals to understand the different treatments and their side effects (Blanchard *et al.* 1988; Cassileth *et al.*, 1980). In addition, information may help to reduce uncertainty, and might help patients and their families to learn ways of managing the illness (Helgeson & Cohen 1996).

In the family system, partners are often key attachment figures in supporting the patient (Hazan & Shaver, 1987), and they often become the primary caregiver (Obaidi & Al-Atiyyat, 2013). It is important to differentiate between male and female partners in this area of research, since there are gender differences in the experience of cancer caregiving (Li *et al.*, 2012). Research has also suggested that there are gender differences in the use of coping strategies: With men being more likely to use problem-focused strategies and women being more likely to use emotion-focused strategies (Baker & Berenbaum, 2007; Matud, 2004). Research suggests that differences in cancer information-seeking reflect gender-based differences in coping; for example, women are more likely to seek reassurance and emotional support via information, whereas men are more likely to seek out information on practical issues such as prognosis and treatment (Boudioni *et al.*, 2001). Therefore, the types and sources of information sought are likely to differ based on gender. A recent systematic review of breast cancer incidence in lesbian and bisexual women found no published data in this population (Meads & Moore, 2013). For this reason, this research has focused on the information needs of male partners only.

The information needs of women with breast cancer have been researched extensively (Corney & Swinglehurst, 2013; Gopal *et al.*, 2005; Halkett *et al.*, 2012; Luker *et al.*, 1995; Miyashita *et al.*, 2015; Recio-Saucedo *et al.*, 2016). In contrast, research examining the information needs of partners is relatively sparse. This is quite surprising given the unique role of partners as individuals who both provide care and support, and as people who require care and support themselves. Similarly, recent reviews have explored the information

needs of family members of cancer patients (Adams *et al.*, 2009; McCarthy, 2011), but there is very little research focusing specifically on male partners.

Rees and Bath (2000b) conducted a review of papers published between 1988 and 1998. They found that very few studies had focused specifically on what the information family members needed. Other reviews focusing specifically on spouses have been unable to draw firm conclusions due to the lack of research in this area (Petrie *et al.*, 2001; Schmid-Büchi *et al.*, 2008), highlighting a significant gap in the existing research with regards to spouses' information needs.

1.1 Aims of the Current Review

The existing research evidence and theory suggests that whilst providing information to male partners of women with breast cancer may be helpful, our understanding of partners' information needs is limited. There are many questions that are left unanswered, namely:

- What do partners want information about?
- What are partners' preferred sources of information?
- What barriers might prevent partners from accessing the information that they want?

This study aimed to answer these questions by systematically reviewing published research specifically examining the information needs of the partners of women with breast cancer.

2. Method

The researcher decided to conduct a systematic review to investigate the research aim. Before the main search commenced, a scoping search was carried out on Cochrane and EBSCO to identify relevant reviews that had

already been conducted. It also helped to form the inclusion and exclusion criteria and to identify the key search terms that would be used.

2.1 Systematic Search Strategy

The literature was searched systematically using the following online databases: PsychInfo; Medline; and Scopus. Searches were carried out between 1st September 2016 and 5th November 2016. Databases were chosen to cover relevant subject areas (scientific, psychological and medical). All of the searches had certain limits placed on them. All of the results had to be:

- Written in English
- From a peer-reviewed journal article

Several search terms were identified to locate relevant papers. The following terms were used to focus the literature on breast cancer: 'breast cancer'; 'breast neoplasm'; 'breast tum*r'; and 'breast carcinoma'. These were combined with a second set of search terms, which narrowed searches down to focus on male partners of females with breast cancer: 'partner'; 'husband'; 'spouse'; 'significant other'. Finally, a third set of terms were used to focus on information needs: 'Information'; 'information needs'; 'sources of information'; 'informative'; 'informational'. Some of the databases did not recognise the asterisk; in these cases, all alternative spellings of the term were searched (i.e. both 'breast tumour' and 'breast tumor').

2.2 Inclusion and Exclusion Criteria

A number of inclusion criteria were applied to the search results. Papers had to adhere to the following criteria to be included in the review:

- Written in English.
- Included the male partners of women who have breast cancer.
- Focus must be on the information needs of the participants.

- Qualitative papers must include a measure examining the information needs of participants (such as information topic areas or source of information)
- Qualitative papers must explore the information needs of male partners, or be related to this e.g. information sources, preferred services, experience of receiving information

A number of exclusion criteria were also developed. Criteria for exclusion from the review were as follows:

- Papers analysing the effectiveness of an intervention.
- Papers examining the needs of female partners.
- Papers that focused on medical conditions other than breast cancer.
- Papers that focused on the impact of breast cancer on other family members (such as children). These papers were only considered for inclusion if the results for male partners were separated out or if at least 70% of the participants were male partners.
- Papers that focused on the impact of breast cancer risk and genetic testing.
- Scale development studies.
- Editorials, commentaries or lectures.

2.3 Eligible Papers

The search identified 396 papers after duplicates were removed. The citations and abstracts were imported to 'Refworks', where the titles and abstracts were screened. A total of 220 duplicates were removed after exporting to 'Refworks', and 372 papers being excluded based on the inclusion and exclusion criteria. Most of the papers were excluded because they did not attempt to measure the information needs of male partners (n=160), because they were examining risk factors associated with developing breast cancer (n=57), or because they were medical trials (n=51).

From the initial screening, 24 articles were examined in more detail, reading through the full-text to determine their relevance. Of these 24 papers, 11 met all the inclusion criteria. The final stage of the search strategy involved screening the reference lists of these papers, to identify any further relevant material that might not have been identified in the original search. Two citations were identified as potentially relevant, and their relevance was confirmed when the full-texts were read, and therefore they were included in the research. As a result, a total of 13 research papers were included in the review. A diagram demonstrating the search process can be found in Figure 1.

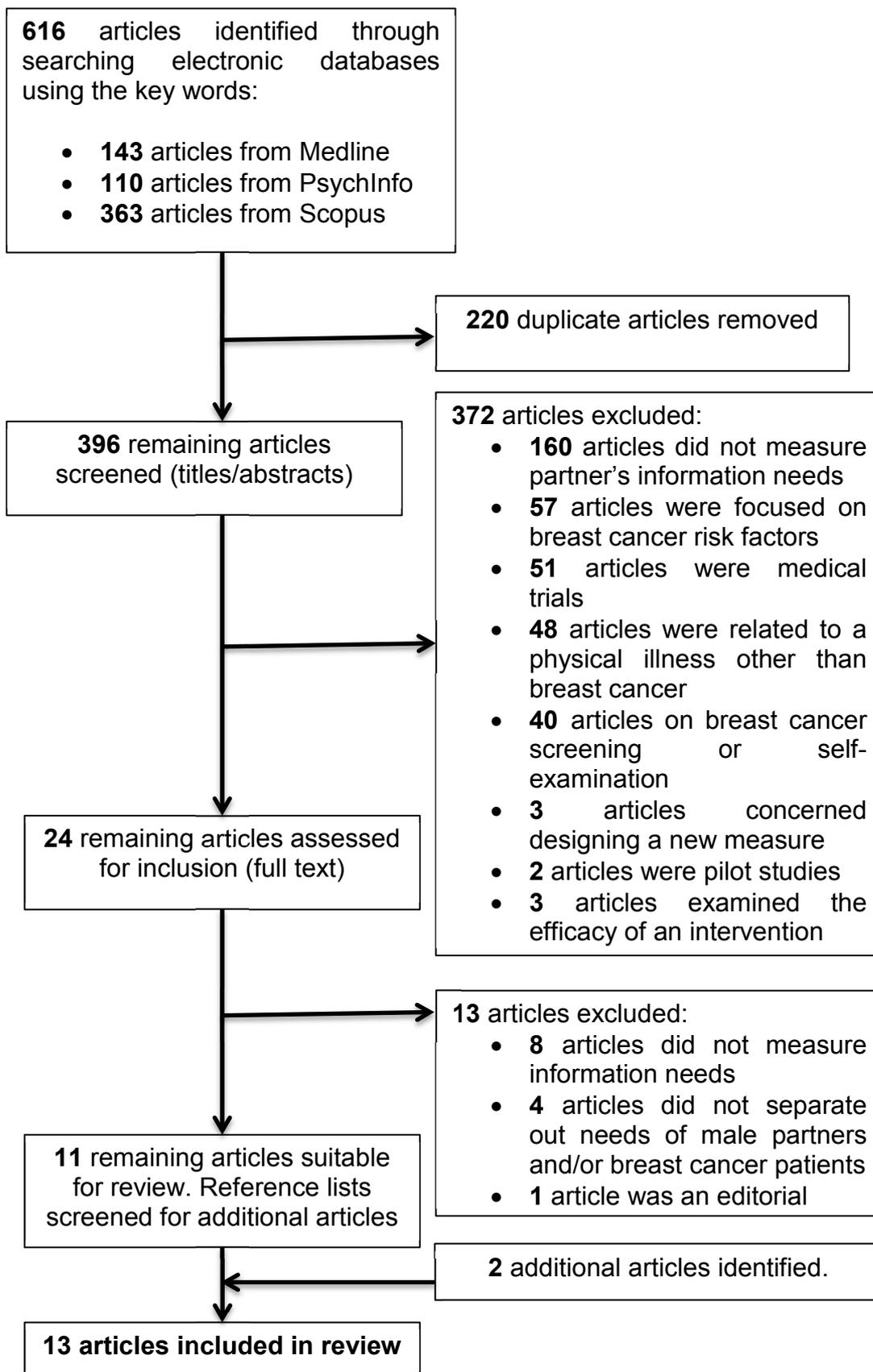


Figure 1: Summary of the Search Process

2.4 Quality Appraisal and Data Extraction

Following the identification of the papers to be included in the review, the researcher quality appraised the papers. The researcher chose to use different tools for the qualitative and quantitative papers, to ensure that the criteria suited the design of the papers. One of the papers (Beaver & Witham, 2007) was quality assessed using both tools because it used a mixed-method design.

The STROBE checklist (von Elm *et al.*, 2007) for cross-sectional studies was used to quality assess quantitative papers. The checklist consists of 22 criteria, divided into the main sections of a research paper. The STROBE was originally designed to provide guidance on reporting observational research and not as a quality assessment tool. However, the researcher felt that the STROBE would be relevant to the included studies, which were all cross-sectional in design, and therefore used the tool to inform decisions about the quality of the papers (rather than as a formal assessment tool involving scoring). A copy of the STROBE checklist used can be seen in Appendix C, and a table summarising the quality of the quantitative papers can be found in Appendix D.

The Critical Appraisal Skills Programme (CASP, 2014) Qualitative Checklist was used to assess the qualitative papers. The checklist consists of 10 questions designed to help researchers think about the quality of research in a systematic way. A copy of the CASP checklist used is provided in Appendix E, and a table summarising the quality of the qualitative papers can be found in Appendix F.

A data extraction form was created to abstract the key information from the studies. The form was based on the Cochrane Public Health Group 'Data Extraction and Assessment Template'. This data extraction form was piloted with four papers, which helped the researcher to identify aspects of the form that needed to be amended. The final form was then used with all of the papers to abstract the most relevant information. The data extraction form can be found in Appendix G.

3. Results

In total, 13 papers were included in this review. The results of this review will be initially segregated based on the methodologies (qualitative or quantitative), before the findings are synthesised. Both qualitative and quantitative papers will be discussed in terms of the participants included and the methodologies used. There was one paper that used mixed methods (Beaver & Witham, 2007); the qualitative and quantitative results of this paper will be considered in the respective sections. A table providing a summary of the study characteristics of the qualitative and quantitative papers can be found in Table 1 and Table 2, respectively.

3.1 Study Characteristics of Quantitative Papers

There were six quantitative papers and one mixed-methods paper included in the review. A total of 637 participants were recruited, 512 of which were male partners. Of the papers that included mean age, the overall mean age of these male partners was 55.49 (SD=10.81). Five of the studies reported the male partners' education level: The percentage of participants who had completed higher education (education beyond high school) varied from 17% (Salminen *et al.*, 2004) to 52% (Pauwels, Bourdeaudhuij *et al.*, 2012), with an average of 36% across the five studies. Some of the studies also reported the time since treatment or time since diagnosis. Two of the studies (Kilpatrick *et al.*, 1998; Nikoletti *et al.*, 2003) reported that participants took part in the research very soon after the patient's surgery (10-14 days), whereas other participants took part three weeks to six months after all treatment had ended (Pauwels, Bourdeaudhuij *et al.*, 2012; Pauwels, Hoof *et al.*, 2012). Salminen *et al.* (2004) reported that all of the patients had been diagnosed within the last two years, with the majority (62%) having been diagnosed within the last year. Patients in Beaver and Witham (2007) were an average of 18 months post-diagnosis at the time of participation. Two of the studies reported the patients' treatment: An average of 45% had a lumpectomy and 56% had a mastectomy. Nikoletti *et al.* (2003) reported that 40% of patients had received chemotherapy.

Table 1 Study Characteristics of Included Quantitative Papers

Author (Country)	Number of Participants (Male Partners)	Measures used	Findings		
			Information Needs	Common Sources of Information	Men at Risk of Unmet Needs
*Beaver & Witham, 2007 (UK)	50 (37)	INQ. (MDA)	Likelihood of cure and spread. Treatment options.	Patient. Leaflets. Consultant.	N/A
Kilpatrick <i>et al.</i> , 1998 (Canada)	84 (84)	FIN-PC.	Have questions answered. Assurance of the best care. Probable outcome of illness.	N/A	Lower level of education Retired. Wife has undergone initial surgery
Nikoletti <i>et al.</i> , 2003 (Australia)	141 (98)	FIN-PC; MBSS.	Have questions answered. Assurance of the best care. Probable outcome of illness.	No one. Breast nurse counsellor. Doctor.	Wife receiving private care (vs. public). Wife has stage 2 cancer (vs. stage 1)
Pauwels, Bourdeaudhuij <i>et al.</i> , 2012 (Belgium)	84 (84)	(MDA); CISS; GSE; HADS; IPQ-R; MMQ-M; PSS; RSE; SSL-I & D.	Wife's health. Supporting my wife. Sexuality.	N/A	Emotion- oriented coping. Emotional representations. Perception of illness as chronic
Pauwels, Hoof <i>et al.</i> , 2012 (Belgium)	85 (28)	(MDA); CISS; GSES; HADS; IPQ-R; PSS; RSE; SSL-I & D.	Supporting my partner. Understanding my partner. Life after treatment.	N/A	N/A
Rees & Bath, 2000a (UK)	109 (109)	MBSS; (MDA).	N/A	Patient. Consultant. Nurses.	Longer time since diagnosis. Not visiting HCPs with wife.
Salminen <i>et al.</i> , 2004 (Finland)	168 (72)	(MDA).	Prognosis. Influences on everyday life. Wellbeing.	Treating physician. Patient. Nurse.	Higher level of education.
<p>* This study used a mixed-methods design, and has therefore been included in both tables. INQ: Information Needs Questionnaire; (MDA): Measures Developed by Author/s; FIN-PC: Family Inventory of Needs-Primary Caregivers; MBSS: Miller Behavioural Style Questionnaire; CISS: Coping Inventory for Stressful Situations; GSE: Generalised Self-Efficacy Scale; HADS: Hospital Anxiety and Depression Scale; IPQ-R: The Illness Perception Questionnaire-Revised; MMQ-M: Maudsley Marital Questionnaire-Marital functioning; PSS: Perceived Stress Scale; RSE: Rosenberg Self-Esteem Scale; SSL-I & D: The Social Support List-Interactions and Discrepancies. N/A: This particular finding was not applicable for this study.</p>					

All of the quantitative papers used a survey design, in which questionnaires were either posted out for participants to complete, or were administered by a researcher. All of the studies included some measure of the participant's information needs: Four studies included measures designed by the researchers (Pauwels, Bourdeaudhuij *et al.*, 2012; Pauwels, Hoof *et al.*, 2012; Rees & Bath, 2000a; Salminen *et al.*, 2004), one study used an information needs questionnaire for women with breast cancer that had been amended (Beaver & Witham, 2007) and the remaining two studies used 'The Family Inventory of Needs - Primary Caregivers' (FIN-PC; Kilpatrick, 1995; Nikoletti *et al.*, 2003). Four studies also included questionnaires assessing coping styles: Two studies used the 'Miller Behavioural Style Scale' (Nikoletti *et al.*, 2003; Rees & Bath, 2000a), and two used the 'Coping Inventory for Stressful Situations' (Pauwels, Bourdeaudhuij *et al.*, 2012; Pauwels, Hoof *et al.*, 2012). Pauwels, Bourdeaudhuij *et al.*, (2012) and Pauwels, Hoof *et al.* (2012) measured various other factors, including self-esteem, social support, illness-perception, marital satisfaction, and anxiety and depression.

3.2 Study Characteristics of Qualitative papers

There were six qualitative papers and one mixed-method paper included in the review. A total of 260 participants were recruited, 162 of which were male partners. The total mean age of the participants in the four studies that included this information was 53.28 ($SD=10.22$). Two of the studies reported the male partners' education level: The percentage of participants who had completed higher education (education beyond high school) varied from 82% (Blais *et al.*, 2014) to 85% (Chen *et al.*, 2014). Beaver and Witham (2007) reported that 52% of the participants had educational qualifications, but it is not clear whether this was education beyond high school. Four of the studies also reported the time since diagnosis, the average of which was 21.75 months (standard deviations not reported). Two of the studies (Blais *et al.*, 2014; Marshall & Kiemle, 2005) reported treatment types: An average of 100% of patients had a mastectomy, 64% had received chemotherapy, and 46% had received radiotherapy.

Two of the studies used a focus group to gather data (Blais *et al.*, 2014; Rees *et al.*, 1998), and the remaining five studies used interviews. The researchers used a variety of different approaches in analysing their results: Three papers used thematic analysis (Beaver & Witham, 2007; Blais *et al.*, 2014; Rees *et al.*, 1998), two papers used content analysis (Fitch & Allard, 2007; Lindholm *et al.*, 2007), and the remaining papers used grounded theory (Marshall & Kiemle, 2005) and inductive analysis (Chen *et al.*, 2014).

Table 2 Study Characteristics of Included Qualitative Papers

Author (Country)	Number of Participants (Male Partners)	Data Collection and Analysis	Main Findings
*Beaver & Witham, 2007 (UK)	50 (37)	Survey and interview. Thematic analysis.	Pps. wanted information on the likelihood of cure and spread, treatment and side-effects, and the genetic risk. Information was not wanted on the topic of sexual attractiveness.
Blais <i>et al.</i> , 2014 (Canada)	70 (35)	Focus groups. Thematic analysis.	Communication deemed important, but Pps. were uncertain about sharing feelings with their wife. Most helpful advice was to attend medical appointment and to maintain activities. Some Pps. wanted more information on sexuality.
Chen <i>et al.</i> , 2014 (Canada)	27 (27)	Interviews. Inductive analysis.	Most important topics of information: treatment, the role of the husband and men's emotional and psychological wellbeing. Pps. want an information binder tailored to their needs. They would not attend a support group.
Fitch & Allard, 2007 (Canada)	15 (15)	Interviews. Content analysis.	Information needs changed at each stage of the process. Information was sometimes confusing and contradictory and there wasn't enough information directly for Pps. Professionals could do more to make Pps feel included in their wives' care.
Lindholm <i>et al.</i> , 2007 (Finland)	37 (29)	Interviews. Content analysis.	Pps. witnessing care versus Pps. taking a more active role. Pps. want to participate in the care and be kept informed. Pps. wanted more contact with HCPs.
Marshall & Kiemle, 2005 (UK)	22 (10)	Interviews. Grounded theory.	Not enough information and support from HCPs to be included in the process. Pps. want opportunities to meet other men in a similar situation. Sexual information seen as unimportant and inappropriate.
Rees <i>et al.</i> , 1998 (UK)	39 (9)	Focus groups. Thematic analysis.	Pps. sought information for themselves and for their wives. Some avoided information No information received from HCPs, most received information from their wives. Pps. prefer verbal information over written information.
* This study used a mixed-methods design, and has therefore been included in both tables. Pps.: Participants; HCPs: Healthcare Professionals			

3.3 A Synthesis of Qualitative and Quantitative Findings

Although some of the papers were quite different, many of the findings complemented one another. The papers explored the topics that participants wanted information on, preferred sources of information, barriers to accessing information, and the groups of men who might be more vulnerable to having unmet information needs. The remainder of this section will be organised with subheadings for each of these topics, synthesising the findings from both the quantitative and qualitative papers.

Preferred Topics for Information

The qualitative and quantitative papers both explored the topics that participants wanted information about. Indeed, whilst qualitative findings suggested that a minority of participants avoided information (Rees *et al.*, 1998), the majority thought it was helpful to have the necessary information (Chen *et al.*, 2014; Marshall & Kiemle, 2005), and a lack of information caused them to feel distressed (Fitch & Allard, 2007). Findings from the quantitative papers indicated that participants prioritised information about their partner's psychological and physical care; they most wanted information about the condition (Nikoletti *et al.*, 2003), treatment (Kilpatrick *et al.*, 1998), prognosis (Beaver & Witham, 2007; Salminen *et al.*, 2004), and how to support their partners (Pauwels, Hoof *et al.*, 2012). This mirrored findings in the qualitative papers, in which participants were found to value information about medical aspects of breast cancer and its treatments (Beaver & Witham, 2007; Chen *et al.*, 2014; Lindholm *et al.*, 2007; Marshall & Kiemle, 2005).

There was some information that participants deemed less important, or which seemed to vary from one study to another. Findings from the quantitative papers indicated that information about the participants' own needs (such as information about their own physical and psychological health) was rated as less important (Kilpatrick *et al.*, 1998; Nikoletti *et al.*, 2003; Pauwels, Bourdeaudhuij *et al.*, 2012; Pauwels, Hoof *et al.*, 2012). Some of the qualitative papers revealed variations in participants' needs; for example, sexual information was seen by some as inappropriate (Beaver & Witham, 2007; Blais *et al.*, 2014), but was welcomed by others (Marshall & Kiemle,

2005). Similarly, information about prognosis helped some, but actually heightened anxiety for others (Chen *et al.*, 2014).

Healthcare Professionals as a Source of Information

Another key finding was related to the sources of information for participants. In both the quantitative and qualitative papers, men identified several sources of information, including healthcare professionals (HCPs), their partner, and written sources (such as the Internet and leaflets). Both qualitative and quantitative findings highlighted the importance of gaining information from HCPs. Findings from the quantitative papers suggested that participants rated HCPs as the most important source of information (Salminen *et al.*, 2004), and almost all participants having received information from HCPs (Rees & Bath, 2000a). Furthermore, those who did receive information from HCPs had the lowest percentage of unmet information needs (Nikoletti *et al.*, 2003), and reported feeling satisfied with the information (Beaver & Witham, 2007). Similarly, participants in the qualitative research believed that services providing care were important in alleviating their distress (Marshall & Kiemle, 2005). However, participants did highlight that whilst they received information about diagnosis, prognosis, and treatment (Rees & Bath, 2000a), both qualitative and quantitative papers suggested that men were less likely to receive information about coping from HCPs (Fitch & Allard, 2007; Rees & Bath, 2000a).

The qualitative papers provided a more in-depth understanding of how participants would like to be treated by HCPs. They expressed the desire to be involved in their partner's care through participating in discussions about their care (Fitch & Allard, 2007; Lindholm *et al.*, 2007) and treatment decisions (Marshall & Kiemle, 2005). However, the qualitative papers also revealed several barriers preventing participants from realising these desires. In one study, 62% of participants stated they had never even been in contact with a healthcare professional involved in the patient's care (Lindholm *et al.*, 2007). Similarly, Rees *et al.* (1998) found that the majority of participants reported receiving no information from HCPs. They reported that they often felt like they were 'merely tolerated' by HCPs (Marshall & Kiemle, 2005) or felt they

were 'getting in the way' (Lindholm *et al.*, 2007). As a result, they often felt uncomfortable approaching medical staff (Lindholm *et al.*, 2007; Rees *et al.*, 1998), and felt that HCPs should take the lead by offering information and finding opportunities to talk to them (Marshall & Kiemle, 2005; Rees *et al.*, 1998). Participants preferred for HCPs to communicate with them in an open, honest and clear way (Fitch & Allard, 2007; Lindholm *et al.*, 2007). Participants also reported wanting HCPs to provide precise answers (for example, about the likelihood of cure), but acknowledged the difficulty in providing this (Beaver & Witham, 2007).

Other Sources of Information

Other sources of information were featured in both the qualitative and quantitative paper, including the participants' partners, leaflets, the Internet, and other men in a similar situation. The results were mixed in terms of how helpful these sources were. One of the qualitative papers found that participants' primary source of information was their partner (Rees *et al.*, 1998). Similarly, quantitative papers identified their partners as a source of information for the participants, but there were mixed results in terms of whether they found the information given by partners as sufficient (Beaver & Witham, 2007; Rees & Bath, 2000a) or not (Salminen *et al.*, 2004). In contrast, this was not discussed by any of the participants who participated in the qualitative research. Another social source of information identified by qualitative papers was other men in a similar situation. Participants said that they would like opportunities to meet with other men who were going through similar experiences as a means of gaining information and support (Marshall & Kiemle, 2005), but preferred this not to be in the form of a formal support group, which they said they would be unlikely to attend (Chen *et al.*, 2014).

Findings from the qualitative papers highlighted the usefulness of written information. Participants appreciated written information (Chen *et al.*, 2014) – specifically those including pictures of mastectomies and reconstructions (Marshall & Kiemle, 2005), and those including concrete information (Blais *et al.*, 2014). However, they also reported feeling confused by the differences in opinion, the medical language, and which information applied to them (Fitch &

Allard, 2007). Some participants criticised written information presented as brief messages, because they suggested that there was only one way to adjust to breast cancer (Blais *et al.*, 2014). Whilst they felt that written information could be helpful, they thought that it was secondary to verbal information (Rees *et al.*, 1998). Similarly, quantitative papers explored men's perception of the Internet, and it seemed that they did not value it as a source of information, as they were least likely to obtain information from this source (Beaver & Witham, 2007; Salminen *et al.*, 2004). This was further supported by Pauwels, Hoof *et al.* (2012), who found that less than half of the spouses recruited in their study accessed their informative website.

Groups at Risk of Having Unmet Information Needs

Many of the quantitative studies tried to identify which groups of men might be more at risk of having unmet information needs, but the results were mixed. Kilpatrick *et al.* (1998) indicated that older participants had more unmet needs, and Pauwels, Hoof *et al.* (2012) found that younger participants were more likely to access the informative website (even when accounting for acquaintance with the Internet). Salminen *et al.* (2004) found that those with an academic education expressed a need for more information, and Kilpatrick *et al.* (1998) found that those with less than a high school education were more likely to have unmet informational needs. Pauwels, Bourdeaudhuij *et al.* (2012) found that social support was unrelated to unmet information needs, but Pauwels, Hoof *et al.* (2012) found that those with lower levels of social support were more likely to access their informative website. Other groups found to be at greater risk of having unmet information needs included those living in rural areas (Kilpatrick *et al.*, 1998), families with younger children (Nikoletti *et al.*, 2003), partners who used more emotion-oriented coping (Pauwels, Bourdeaudhuij *et al.*, 2012) and partners who viewed the patient's condition as chronic (Pauwels, Bourdeaudhuij *et al.*, 2012).

4. Discussion

4.1 Summary of Research Findings

The aim of this paper was to review the published research on the information needs of male partners of women who had breast cancer. There were three specific aims developed, which reflected on the gaps in existing literature:

- What do male partners want information about?
- What are men's preferred sources of information?
- What barriers might prevent men from accessing the information that they want?

The literature search identified 13 papers that met the inclusion criteria. Six of these papers were qualitative, six were quantitative, and one used a mixed-methods design. The findings will now be discussed in more detail, using the aims of the research as a framework to structure the discussion.

What do Male Partners want Information About?

Across the studies, men identified similar topics that they wanted information about. Men prioritised information about the patient's diagnosis, prognosis and treatment options.

These findings were similar to previous reviews: McCarthy (2011) found that of the 34 studies examining the information needs of family members of cancer patients, 28 studies identified prognosis as a major information need, and 27 identified treatment as a major information need. Similarly, Adams *et al.* (2009) found that treatment-related information and diagnosis/prognosis-related information were the most frequently mentioned information needs among family members of cancer patients across 32 research papers.

The findings indicated that men's information needs might change at each stage of the process. For example, information about prognosis helped at the time of diagnosis, but actually heightened anxiety at the time of potential recurrence (Chen *et al.*, 2014). Sexual information was seen by some as

inappropriate during treatment (Beaver & Witham, 2007; Blais *et al.*, 2014), but was more likely to be welcomed at a later stage (such as after treatment) (Marshall & Kiemle, 2005).

It has been acknowledged that the needs of cancer patients and their family members change throughout the illness (Chen, 2014); for example, early in the course of the illness, the need for medical information is high, whereas the need for symptom management may be more important as the disease progresses (Fitch, 2008). Whilst sexuality is often an information need which is almost exclusive to the partners of cancer patients (Adams *et al.* 2009), reviews have revealed inconsistencies in the need for information on sexuality (McCarthy, 2011). It may be that some issues, such as sexuality, are far from male partners' priorities at some points in the cancer journey. Beaver and Whitman (2007) concluded: 'It was more important to be rid of the cancer, regardless of the treatment and side effects involved'. (p.22.)

It is also important to acknowledge that whilst information seeking is typically viewed as a problem-focused coping strategy, it has been shown to have emotion-focused coping functions, such as providing reassurance and reducing negative emotions linked to uncertainty (van der Molen, 1999). Indeed, some researchers have suggested that perhaps information seeking in men represents a more gender-appropriate way of requesting emotional support, especially in those who may be attempting to maintain a brave façade (Boudioni *et al.*, 2001).

What are Male Partners' Preferred Sources of Information?

Many of the studies identified the patient as the partner's main source of information, but results were mixed in terms of how satisfied participants were with information gained from patients (Beaver & Witham, 2007; Salminen *et al.*, 2004). Another important source of information was HCPs, which seemed to be valued highly by the participants. There were mixed findings in terms of how satisfied men were about the information they had received from HCPs. This is not dissimilar to the findings in a previous review, which found mixed findings in terms of the experiences of family members seeking information

from HCPs. It was reported that many family members feel ignored by HCPs, and participants thought that HCPs provided ambiguous and conflicting information (McCarthy, 2011).

Male partners also discussed alternative sources of information, including written information, Internet sources, and support systems. Men appreciated written information (Chen *et al.*, 2014) but felt that this was secondary to verbal information (Rees *et al.*, 1998). This is similar to other research that suggests that hospital booklets can effectively supplement the verbal messages provided by HCPs (Iconomou *et al.*, 2001), but it is not clear how effective leaflets alone are.

Some men used the Internet as a source of information, but many felt dissatisfied with the information gained from this source. However, it is possible that information will increasingly be sought from the Internet as new generations of Internet-literate individuals emerge. More recent research has found that the Internet was the most frequently reported source of information among cancer patients (Shea-Budgell *et al.*, 2014).

Finally, male partners wanted opportunities to meet with other men who were going through similar experiences, but preferred this not to be in the form of a support group. This is in line with previous research, which has found that cancer support group participants are predominantly female (Grande *et al.*, 2006). It is not clear why this is the case, but it may be helpful to find out why men might find it difficult to attend a support group, which would provide another source of information, as well as social support.

What Barriers Might Prevent Men from Accessing the Information that they Want?

As discussed previously, many participants reported that the patient was their primary source of information, but some felt that information from their partner was insufficient. There could be a number of reasons why men might not feel information from the patient is sufficient. Protective buffering is a recognised process that can occur between cancer patients and their partners, which can

lead to communication difficulties and psychological distress (Manne *et al.*, 2007). In the context of the cancer literature, protective buffering is defined by Hagedoorn *et al.* (2000) as: 'hiding one's concerns, denying one's worries, concealing discouraging information, preventing the patient from thinking about the cancer, and yielding in order to avoid disagreement' (p. 275). Indeed, Blais *et al.* (2014) found that several spouses expressed reserve about sharing their own feelings with their wife, perhaps because they wanted to protect her from their fears. However, this might prevent male partners from seeking the information they want from their wife, particularly with more sensitive topic areas (such as prognosis and sexuality). Similarly, patients may attempt to protect their partner by only sharing specific information, or avoiding the sharing of information altogether (Rees & Bath, 2000a).

With regards to receiving information from HCPs, some partners felt unsupported (Lindholm *et al.*, 2007; Marshall & Kiemle, 2005) and uncomfortable approaching medical staff (Lindholm *et al.*, 2007; Rees *et al.*, 1998). This might make it difficult for partners to use HCPs as a source of information. Many partners gained information from HCPs by attending appointments with the patient (Beaver & Witham, 2007). This is similar to findings in a previous review, which found that the main way that family members sought information from HCPs was by accompanying patients to medical appointments (McCarthy, 2011). However, they also found that some family members did not know how to get information from HCPs, and some family members experienced difficulties trying to access HCPs (McCarthy, 2011).

4.2 Limitations of Reviewed Papers

Overall, the methodological quality of the included papers was 'medium'. Some of the papers were generally rated as having good quality (e.g. Blais *et al.*, 2014), whereas others were of poor quality (e.g. Salminen *et al.*, 2004). One of the main criticisms was that many of the papers did not report basic demographic and relevant medical information. Some of the studies failed to provide mean ages, and many of the papers did not provide information on the stage of the cancer, the time since diagnosis, and whether treatment had

ended. As has already been discussed, the information needs of cancer patients and their family members varies across the various stages of the cancer journey (Chen, 2014); the information needs of a man whose partner has been recently diagnosed are not the same as a man whose partner has completed treatment (Fitch, 2008). This may have contributed to some of the mixed findings (such as information needs related to sexuality), which makes it difficult to draw conclusions.

Many of the papers included other family members as participants, or included the patient. Whilst most papers differentiated between the findings related to male partners and other participants, some did not. This seems counter-productive, since male partners are likely to have information needs that are very specific to them (Adams *et al.*, 2009). By not differentiating the findings related to men, it makes it difficult to identify needs that are specific to male partners.

Finally, many of the studies failed to take into account potential sources of bias. This was particularly noticeable in the qualitative studies, where there was very little evidence that researchers had critically examined their own role in the research process and their potential biases. Reflexivity is important in qualitative research in order to improve the validity of the research findings (Willig, 2008). As a result, it is difficult to be able to gage the quality of many of the qualitative papers.

4.3 Limitations of Present Review

The researcher developed several different search terms and applied a number of inclusion criteria to the results to ensure they were relevant to the review. A total of 13 papers were identified for inclusion, which is a relatively small number of papers. However, this was not unexpected, since this is a relatively specific research area. Had the researcher chosen to include any cancer rather than focusing on breast cancer, it is likely that a much larger number of papers would have been identified. However, there is reason to think that women with breast cancer and their partners might have some unique information needs (e.g. information about mastectomies; Marshall &

Kiemle, 2005). However, a larger number of papers may have allowed the researcher to remove papers deemed to be low quality after the quality appraisal process. Including high-quality papers only would have allowed the researcher to make firmer conclusions.

In order to focus the searches specifically on male partners, a set of terms were developed including 'partner', 'husband', 'spouse' and 'significant other'. However, some of the papers selected used different terms, such as 'informal carers' and 'family members'. This was particularly the case for studies that included male partners as well as other family members. Had these additional search terms been used, further papers might have been identified that were relevant to the current review. However, the researcher did develop a thorough research strategy, involving searching three different databases, hand-searching the results for relevance, and the examination of reference lists for further relevant research. This should allow confidence in the review; that all relevant research was included and that the conclusions arising from the synthesis were a reflection of all the available evidence.

Another potential criticism concerns the Researcher's choice to include both qualitative and quantitative papers in the review. Reviews including both qualitative and quantitative research can be difficult to synthesise, and therefore it can be difficult to make firm conclusions. However, the researcher thought that this type of review would be suitable given the multiple aims. Furthermore, it has been argued that including evidence from different types of research maximizes the robustness of findings, so that the researcher is more able to use their findings to inform policy and practice (The Joanna Briggs Institute, 2014).

4.4 Implications for Health Care

The findings of this review could be used to make a number of recommendations for services and HCPs supporting breast cancer patients and their partners:

- Male partners primarily want medical information about the diagnosis, prognosis and treatment options, including potential side-effects of

treatments. Their needs for information vary as they progress through the various stages of the cancer journey. It is helpful to check with men at each stage (e.g. diagnosis, treatment commencement, treatment completion) to enquire about their information needs. It may be helpful at key points to ask men to complete an information needs questionnaire – such as The Family Inventory of Needs-Husbands (Kilpatrick, 1995) – to help them to identify the types of information that male partners need.

- Many men find it helpful to speak to HCPs, but may find it difficult to approach them to seek out information. Therefore, it would be helpful if HCPs could provide opportunities to speak to male partners, to encourage their attendance at appointments, and to provide their contact details if men are not able to attend appointments. In addition, many men seek information from their partner, so it is helpful to encourage open and honest communication between the couple, but also not to pathologise not sharing information.
- When providing information, it is important that HCPs understand the role that this might play in providing emotional support to male partners. HCPs should try to impart information in a way that is sensitive to men and what they are going through, and this could help men to feel more supported.
- HCPs should try to have discussions not only with the patient, but also with her partner. A friendly, open and collaborative manner might help men to feel more involved in their partner's care, and help them to feel more able to seek information from HCPs if they need to.
- Male partners may benefit from written information (such as leaflets), but it is important that this does not replace verbal information. It may be helpful to highlight the information that is relevant to them, and to be available to answer questions.
- Male partners may benefit from services providing opportunities for men to contact others who have had a similar experience. Whilst men may not attend a more formal support group, they may be more inclined to attend less formal forums.

4.5 Recommendations for Future Research

Similar to previous research, this review revealed that whilst the priority for information needs is related to diagnosis, prognosis and treatment, there were many other needs that were deemed relevant to male partners, but which may vary depending on where the couple are in their cancer journey. It seems important to have a better understanding of how male partners' information needs to change, and the key stages at which they change. This might help HCPs to identify when male partners might have unmet information needs, and take action to provide opportunities to have these needs met. A longitudinal piece of research assessing men's information needs at various time points might provide insights into these changes.

The results suggest that male partners would appreciate having opportunities to speak to other men who have had a similar experience, but that they would be unlikely to attend a formal support group. It may be helpful for researchers to think about men's preferences in terms of an intervention that would allow them to have contact with other men going through similar experiences, which is likely to provide them not only with information, but may also be a valuable source of support.

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Part 2

Research Report

Abstract

Breast cancer has become the most common cancer diagnosed in the UK, but is increasingly being recognised as a chronic condition due to advances in treatment. As a result, researchers have become increasingly interested in women's quality of life, and the impact that their diagnosis has on the family. Surprisingly, relatively little research has explored the experiences of male partners of women with breast cancer, who often become the primary care giver. The research that does exist is often conducted one to two years post diagnosis, leaving a gap in our understanding. This research therefore aimed to explore the lived experiences of male partners of women with breast cancer who had received their diagnosis within the last year.

Semi-structured interviews were carried out with five male partners, and the transcripts were analysed using Interpretative Phenomenological Analysis (IPA). Four super-ordinate themes were identified: Treatment as '*a necessary evil*'; His role as protector; The ebb and flow of hope; and Maintaining hope in the face of uncertainty. A total of 13 sub-themes were identified, which helped to explore similarities and idiosyncrasies within the super-ordinate themes.

Many of the themes generated shared similarities to themes in previous research (such as taking on a protective role, attempts to remain positive, and perceptions of support). Uniquely, respondents in the current research framed many of their challenges as 'sacrifices to prioritise treatment', which may reflect the time since diagnosis. The respondents' coping strategies are discussed alongside models of coping and family systems theory.

Clinical implications are discussed, including increasing the awareness of healthcare professionals of their vital role in reassuring and supporting male partners, and the importance of interventions aimed at dyadic coping. Further areas of research interest are also discussed.

1. Introduction

1.1 Cancer as a Chronic Illness

Chronic illness is a challenge faced by many people in their lifetime: One in three British adults report living with a chronic illness or disability (Office for National Statistics, 2011). Chronic illness has a significant impact on individuals, their families, and healthcare systems, with approximately 70% of health care budgets in England being spent on by patients with long-term conditions (DoH, 2012). By far the fastest-growing chronic illness in the UK is cancer (DoH, 2012), with estimates suggesting that one in two people will be diagnosed in their lifetime (Ahmad *et al.*, 2015).

Cancer was once considered a terminal diagnosis, but due to treatment advances is being increasingly recognised as a chronic illness. It is estimated that half of the people diagnosed with cancer in England and Wales survive the disease for ten years or more (Cancer Research UK, 2010). The advances in treatment and associated improvement in survival rates is reflected in the research literature, where there seems to have been a paradigm shift: The psychosocial impact of cancer has only started to be explored in the last 30 years. In the 1800s, it was difficult to make a definite diagnosis, and mortality rates were high. There was a lot of shame associated with cancer (as people thought it was an infectious disease), and many people's deaths were recorded as 'natural causes' (Hagedoorn *et al.*, 2008). From the 1940s to the 1970s, there were developments in treatment (such as the use of chemotherapies and the first cases of remission), and research focused more on prevention and treatment (Veitch *et al.*, 2002). Researchers have become increasingly interested in the quality of cancer patients' lives, and not just the quantity.

1.2 The Unique Impact of Breast Cancer

Breast cancer is the most common cancer diagnosis in the UK (DoH, 2012). In 2012 alone, 1,676,000 new cases of breast cancer were diagnosed worldwide (Cancer Research UK, 2014). Out of the more common cancers diagnosed in women (breast, lung and bowel cancers), breast cancer has the highest

survival rates, with 78% of women surviving 10 years or more (Cancer Research UK, 2014).

Cancer in the breast has been perceived by some as particularly traumatic due to the patient (and potentially her partner) experiencing a change in the patient's identity and body image (Andersen & Golden-Kreutz, 2000). Almost three-out-of-four women diagnosed with breast cancer in England will receive a major surgical resection, and many will experience hair loss as a result of chemotherapy (Cancer Research UK, 2015). Some women report experiencing these side-effects as an assault on their femininity (Arroyo & Lopez, 2011; Butler *et al.*, 1998; Ussher *et al.*, 2012).

Why does breast cancer have such an impact on women's identities? Boyd (2001) suggested that this might link to the meaning that the female breast has in our society and culture. Historically, the female breast has been portrayed as an object of sexual desire and fertility. The amputation of breasts in the middle ages signified a severe punishment, rendering the woman both undesirable to men and dysfunctional as a mother. In modern society, the female breast still symbolises femininity, motherhood and sexuality (although this has been increasingly challenged in the post-feminist era). These competing narratives are influenced by modern literature and the media (including fashion, magazines, and movies; Boyd, 2001). This social context has an impact on the experiences of women diagnosed with breast cancer, influencing their treatment decisions and how they cope with the disease (Thorne & Murray, 2000).

Due to the unique way in which the female breast is socially constructed, it is likely that women and their families experience breast cancer differently to other commonly diagnosed cancers. Not only does breast cancer present a threat to the patient's life, but it may also represent a threat to her identity as a woman and as a sexual being. This, of course, is likely to have a secondary impact on any intimate relationship she has with another person, such as a husband.

1.3 The Psychosocial Impact of Breast Cancer on the Patient and her Family

Women with breast cancer often experience a number of psychosocial concerns, including relationship difficulties (Holmberg et al., 2001), existential concerns (Ganz, 2008), body image disruption (Arroyo & Lopez, 2011; Begovic-Juhant, 2012) and sexual dysfunction (Fobair *et al.*, 2006). Whilst most women adjust well to the diagnosis and treatment (Frost *et al.*, 2000; Ganz *et al.*, 2002), inadequate social support has been identified as a factor that puts women at risk of higher levels of distress (Institute of Medicine and National Research Council, 2004). Family members have been recognised as an important source of social support for the patient, but they are being increasingly recognised as individuals in need of support themselves (Grunfeld *et al.*, 2004; Northouse *et al.*, 2002; Veach *et al.*, 2002).

Cancer presents a major crisis to the family (Glajchen, 2004), with some referring to it as a 'we-disease' in acknowledgement of the relational impact (Kayser *et al.*, 2007). This impact on family members has also been recognised in the NHS Cancer Plan, which states that 'diagnosis and treatment of cancer can have a devastating impact on the quality of patients' lives and that of their families and carers' (p.62) and that 'families commonly experience psychological problems' (p.64) (DoH, 2000).

Family members often have the added burden of caring for the patient: 69% of cancer carers in the UK are family members (Macmillan Cancer Support, 2016). Family caregivers are confronted with primary stressors associated with the cancer and its treatment, such as witnessing emotionally challenging symptoms in the patient (e.g. pain, agitation and depression; Weitzner *et al.*, 2000). They also have to accommodate for associated caregiving demands, such as assisting the patient with daily living activities (Oberst & James, 1985; Weitzner *et al.*, 2000), monitoring treatment (Given et al. 2001), and providing emotional support (Zahlis & Shands, 1991). Family caregivers can also experience stress from the impact that primary stressors have on other areas of their lives, such as role changes (Weitzner *et al.*, 2000), relationship changes (Gaugler *et al.*,

2008), feelings of isolation (Cameron *et al.*, 2002) and sleep disturbance (Carter, 2003). Of all family members, partners are most likely to take up the role of 'carer' (Kurtz *et al.*, 1995; Soothill *et al.*, 2001). More and more men are becoming caregivers in Britain (Hoff, 2015).

The needs of cancer carers is becoming an increasingly pressing issue in the UK: Compared to five years ago, there are more people caring for someone with cancer, they are providing more time caring than before, and they are having to complete more hands-on and complex care tasks (Macmillan Cancer Support, 2016). These statistics reveal the mounting pressure on cancer carers, and yet carers are no more likely to get the help and support that they need than they were five years ago (Macmillan Cancer Support, 2016). The statistics supporting these claims are shown in Table 3.

Table 3 Statistics about Cancer Carers in the UK
(Macmillan Cancer Support, 2016)

Category	2011	2016	Percentage change
Number of people caring for someone with cancer	1.1 million	1.5 million	+36%
Number of people providing more than 50 hours of care per week	110,000	230,000	+109%
Percentage of carers helping with healthcare tasks (such as giving medication and changing dressings)	28%	38%	+36%
Percentage of carers helping with intimate personal care (such as washing, dressing, and using the toilet)	23%	34%	+47%
Percentage of cancer carers who report not getting any support	55%	55%	0%

1.4 Male Partners of Women with Breast Cancer

The experience of a family caregiver is complex and dynamic, and is therefore influenced by a number of factors. Research has suggested that spouses experience higher caregiver burden compared with other family members (Hong & Kim, 2008; Pinguart & Sorensen, 2011), which could be because spouses are usually the most important attachment figure for the patient (Hazan & Shaver, 1987). In addition, spouses are most likely to live with the patient, and therefore tend to provide more hours of care. Indeed, a recent report suggested that when compared to friends and other family members, spousal caregivers provide care longer-term, for a greater number of hours per week, and are least likely to receive support (Macmillan Cancer Support & Ipsos MORI, 2011).

Partners are likely to experience similar stressors to other family members, such as difficulties adapting to their caregiver role (Northouse *et al.*, 2000), fatigue (Lopez *et al.*, 2012) and having to change their lifestyle (Lopez *et al.*, 2012). However, partners will also experience additional stressors that other family members would not face, such as changes in intimacy and sex (Gilbert *et al.*, 2010), the potential loss of their life partner (Maughan *et al.*, 2002; Thomas *et al.*, 2002) and concerns about becoming a single parent (Zahlis & Shands, 1991).

It is important to differentiate between the experience of male and female caregivers in this research, since gender is a factor that is thought to significantly influence the caregiving experience. For example, a recent literature review found that when compared to females, male spousal caregivers felt unprepared for the caregiving role, found it more difficult to express their emotional reaction to caregiving, and were more likely to be affected by fatigue due to their caregiving role (Li *et al.*, 2012). Indeed, the majority of spouses of patients with breast cancer are male, since over 99% of breast cancer diagnoses are made in women (Breast Cancer Care, 2015), and the vast majority of women in the UK identify themselves as heterosexual (ONS, 2016). Therefore, whilst the experiences of female spouses is of interest

(particularly because there little known about this population; Meads & Moore, 2013), this research with focus solely on the experiences of male partners of women with breast cancer given this evidence that experiences are likely to vary as a function of both carer and patient gender

Caregiving can have a significant impact on spouses, who can experience anxiety and depression (Alacacioglu *et al.*, 2014; Askari *et al.*, 2012; Woloski-Wruble & Kadmon, 2002), high levels of stress (Fitzell & Pakenham, 2010), and a low quality of life (Wagner *et al.*, 2006). There are a number of qualitative research papers exploring the experiences of male partners of women with breast cancer. However, most of these involve spouses of women who have been diagnosed one to two years ago (Samms *et al.*, 1999; Sandham & Harcourt, 2007; Skerrett, 1998; Zahlis & Shands, 1991). In addition, many of the existing literature includes a wide range of 'time since diagnosis' within the same sample (Duggleby *et al.*, 2012; Hilton *et al.*, 2000; Holmberg *et al.*, 2001); for example, Levy (2011) included participants who were a few days post-diagnosis as well as participants who were five years post-diagnosis. Having such a wide range is problematic because men will have different experiences depending on where they are in their cancer journey. Research has also focused upon very specific areas of the breast cancer experience, for example the experience of breast reconstruction (Marshall & Kiemle, 2005; Nano *et al.*, 2005; Sandham & Harcourt, 2007) and sexual issues after breast cancer (Nasiri *et al.*, 2012).

The limitations of the existing literature have been acknowledged in a recent review, which recommended that new studies are developed with the aim of producing a deeper understanding of the experiences of male partners (Neris & Anjos, 2014). In particular, there seems to be limited understanding of the experiences of men in the first year after diagnosis, when spouses are likely to experience the highest levels of distress (Hinnen *et al.*, 2008; Northouse, 1989).

There appears to be only a few studies that have examined the early

experiences of male partners. Zahlis and Lewis (2010) aimed to describe more fully the experiences of American spouses in the first six months after diagnosis. Similarly, Lethborg *et al.* (2003) interviewed eight 'significant others' in Australia an average of nine months after the diagnosis. However, it is not clear how applicable these results might be to men living in the UK, where the prognosis, treatment options and the healthcare system are all very different to those in the USA and Australia.

In addition, gender role expectations are likely to differ between the UK, Australia and the USA. Some of the variance observed between male and female caregivers (Li *et al.*, 2013; O'Grady, 2005; Ussher & Sandoval, 2008) has been associated with differences in gender role expectations. Similarly, different countries are likely to have distinctive gender role expectations for men (Connell, 2005), because these ideals are socially constructed. Since the experiences of a male caregiver may directly challenge (Gilligan, 1982; Wagner *et al.* 2011) or comply with (Levy, 2011; Lopez *et al.*, 2012; Molassiotis *et al.*, 2011) socially constructed masculine ideals, it is important to gain an understanding of British male partners' experiences that is sensitive to their socio-cultural milieu.

Whilst the research discussed provides some understanding of the experiences of men whose partners have been diagnosed with breast cancer, there has been no research exploring the experiences of British men's experiences in the first year after diagnosis.

1.5 Aims and objectives

The aim of the current research is to explore men's experiences in the first year after their partner has been diagnosed with breast cancer. Within this aim, the researcher developed a number of primary questions that are of interest:

1. How do men perceive physical changes in their wife as a result of treatment?
2. How do men understand 'coping' in the context of their wife's breast cancer?

2 Method

2.1 Design

Since there is a lack of research exploring this area, the researcher chose to take a qualitative approach. An Interpretative Phenomenological Analysis (IPA) approach was thought to be the most appropriate in attempting to understand the lived experiences of respondents, and the meanings that they associate with these experiences (Smith *et al.*, 2009). Semi-structured face-to-face interviews were used to aid the collection of rich verbatim data (Smith, 1995).

2.2 Position of the Researcher

The researcher's epistemological position (a critical realist approach) helped to guide the research process. A statement of the researcher's epistemological position can be found in Appendix H.

2.3 Respondents and Recruitment

The sample size was chosen to reflect the methodology. IPA aims to obtain enough data to give a detailed account of individual experience (Smith & Osborn, 2009), but not so much data that the researcher is unable to make a detailed interpretative account (Smith & Osborn, 2009). A sample consisting of five to six participants would be an appropriate sample size; allowing the researcher to access rich data that can be interpreted in depth.

2.4 Inclusion and Exclusion Criteria

Purposive sampling helped to identify men whose wives had been diagnosed with breast cancer. The following inclusion and exclusion criteria were applied in an attempt to gain a reasonably homogenous sample. The criteria were developed to reflect obvious social and theoretical factors that could introduce too much heterogeneity:

- Respondents must have a female partner who has been diagnosed with breast cancer. Participants with male partners will not be included.
- The diagnosis must have been received within the last year – This is to reflect a gap in the literature; most of the research has included spouses of women who were diagnosed one to two years ago.
- Respondents must be male - the experience of caregiving is different for men and women (Hagedoorn *et al.*, 2008; Li *et al.*, 2013; Sharma *et al.*, 2016).
- The couple must be cohabiting –Couples who are living together are likely to share certain household and financial responsibilities, and the male partner’s role within the home may change whilst his partner is receiving treatment.
- Respondents must be competent with spoken English – whilst non-English speaking interviews could have been translated, it is possible that some of the meaning could have been lost through the translation process.

2.5 Final Sample

The final sample consisted of five respondents, whose ages ranged from 39 to 70 years. Three of the respondents were employed, and four of the respondents had children (although for most, their children were adults and had left home). All of the respondents’ wives were either undergoing chemotherapy at the time of the interview, or had just completed chemotherapy. Three of the respondents’ wives had undergone surgery. The time-since-diagnosis ranged from four months to eight months, with the average time-since-diagnosis being six months. Limited demographic information is presented in order to maintain anonymity.

2.6 Materials

The research materials used included a Participant Information Sheet (PIS; Appendix I), consent form (Appendix J), research summary and expression of interest form (Appendix K), and the semi-structured interview guide (Appendix L).

The interview schedule was developed with the research questions in mind. The researcher developed the interview schedule by reviewing existing literature and gaining insights from the nurses involved in recruitment. The researcher consulted textbooks on IPA (such as Smith & Osborn, 2009), to make sure that the questions were relevant and open, but not leading. The schedule was designed to provide optimal conditions for building rapport between the interviewer and the participant.

2.7 Procedures

Ethical considerations

The initial research protocol was peer reviewed by academic staff at the University of Leicester, and was also reviewed by the service-user reference group. This feedback was used to further develop the protocol and relevant documents, which were uploaded onto the Integrated Research Application System (IRAS). A proportionate review by the sub-committee of the Local Research Ethics Committee (LREC) was recommended. Following some changes requested by the LREC, ethical approval was given. The correspondence to and from the LREC can be found in Appendix M. Approval was also sought and granted from the relevant Research and Development department.

Since the interview was of a sensitive nature, the PIS informed participants that they may find it upsetting to talk about their experiences. Whilst some of the participants did seem to become emotional during the interview, all of them continued with the interview, and none wanted contact details for Macmillan Cancer Support.

Recruitment

Respondents were recruited from an NHS Oncology unit in a Midlands hospital that their partners were receiving treatment from. As per the request from the LREC, all of the recruitment occurred via the chemotherapy nurses. Nurses

approached potential participants or their partners either at the pre-chemotherapy assessment, or during one of their other scheduled appointments. Alternatively, the researcher approached potential participants if they had given verbal consent to one of the nurses (who were a part of their usual care team).

Individuals who showed interest in taking part were given a research summary sheet and were asked to complete the 'expression of interest' form. This was then given one of the nurses, who secured the form in an envelope to hand directly to the researcher or to post to her address.

The researcher called the potential participants; to ensure that they met the inclusion and exclusion criteria, to discuss the research further, and to answer any questions. The researcher sent a participant information sheet to those interested in participating, and arranged a date for the interview. The researcher allowed enough time for the respondent to receive the participant information sheet and have at least 24 hours to read through it before the agreed date for interview.

Table 4 Participant Characteristics

	Age range	Married?	Number of Children (number of children living at home)	Treatment Stage
John	50-55	Yes	2 (0)	6 cycles of chemo and mastectomy
Matthew	70-75	Yes	1 (0)	3 cycles of chemo and lumpectomy
Adam	35-40	Yes	2 (2)	1 cycle of chemo
Ben	45-50	Yes	0 (0)	3 cycles of chemo and lumpectomy
James	55-60	Yes	1 (0)	6 cycles of chemo and lumpectomy

Conducting the interviews

Three participants chose to be interviewed at the hospital, and the remaining two participants asked to be interviewed at home. The researcher complied with the Unit's lone working policy, and developed a protocol with her research supervisor to maintain her safety whilst conducting interviews in respondents' homes.

The researcher confirmed that participants had received and read the PIS. The researcher read through the PIS with the participant again, highlighting the key points and answered any remaining questions, before completing the consent form. The researcher then started the recording device and continued with the interview.

The semi-structured interviews were guided by a set of interview questions and prompts. Preparing a schedule allowed the researcher to have a loose agenda, whilst still being able to follow up topics brought to light by the participant. The interviews ranged in length from 48 minutes to 60 minutes. Once the interview was completed, the researcher verbally debriefed the participant, and offered to provide participants with details of the Macmillan Cancer Support.

2.8 Analysis

The researcher transcribed the audio recordings of the interviews. The transcripts were not edited for grammatical correctness: Verbatim transcripts allowed for the analysis of more subtle linguistic features.. The participants' names and other potentially identifying details were changed in order to maintain anonymity. Analysis was completed in six stages: Reading and immersion in the data; initial notes; noting of emerging themes; mapping connections between emerging themes; moving on to the next transcript; and noticing patterns across transcripts (Smith *et al.*, 2009). A more detailed account of the process of analysis can be found in Appendix N. An example of the researcher's coding is presented in Appendix O.

A full chronology of the research process can be found in Appendix P.

3. Results

Four super-ordinate themes emerged from the data following analysis, capturing the significant aspects of the respondents' experiences. A total of 13 sub-themes highlighted both similarities and idiosyncrasies across the respondents' experiences. The occurrence of sub-themes across all the men's transcripts can be found in Appendix Q.

In order to allow the reader to follow the researcher's interpretative narrative, the super-ordinate themes have been used to structure this section. However, many of the themes either overlapped or interacted with one another. These relationships have been discussed in the text, and a diagrammatic representation of these relationships is provided in Figure 1.

The titles for the themes were chosen to represent the underlying experiences and the associated meanings. Respondents viewed **'treatment as a necessary evil'**: Whilst they attempted to prioritise their wives' treatment, the sacrifices made seemed to lead to feelings of ambivalence. **'His role as protector'** describes the men's experience of their own perceived role; to protect others, which sometimes involved keeping family away and hiding their own fears. Men described experiencing **'the ebb and flow of hope'**, which was influenced by the behaviours of healthcare staff, the timing of treatment, and social support. Despite facing many obstacles (such as uncertainty about the future and difficulties in getting back to normal), many respondents spoke of **'maintaining hope in the face of uncertainty'**, by relying on familiar coping strategies and by 'pulling the good out of the bad'. The sub-themes are discussed in more detail on the following pages under the super-ordinate theme that they are related to.

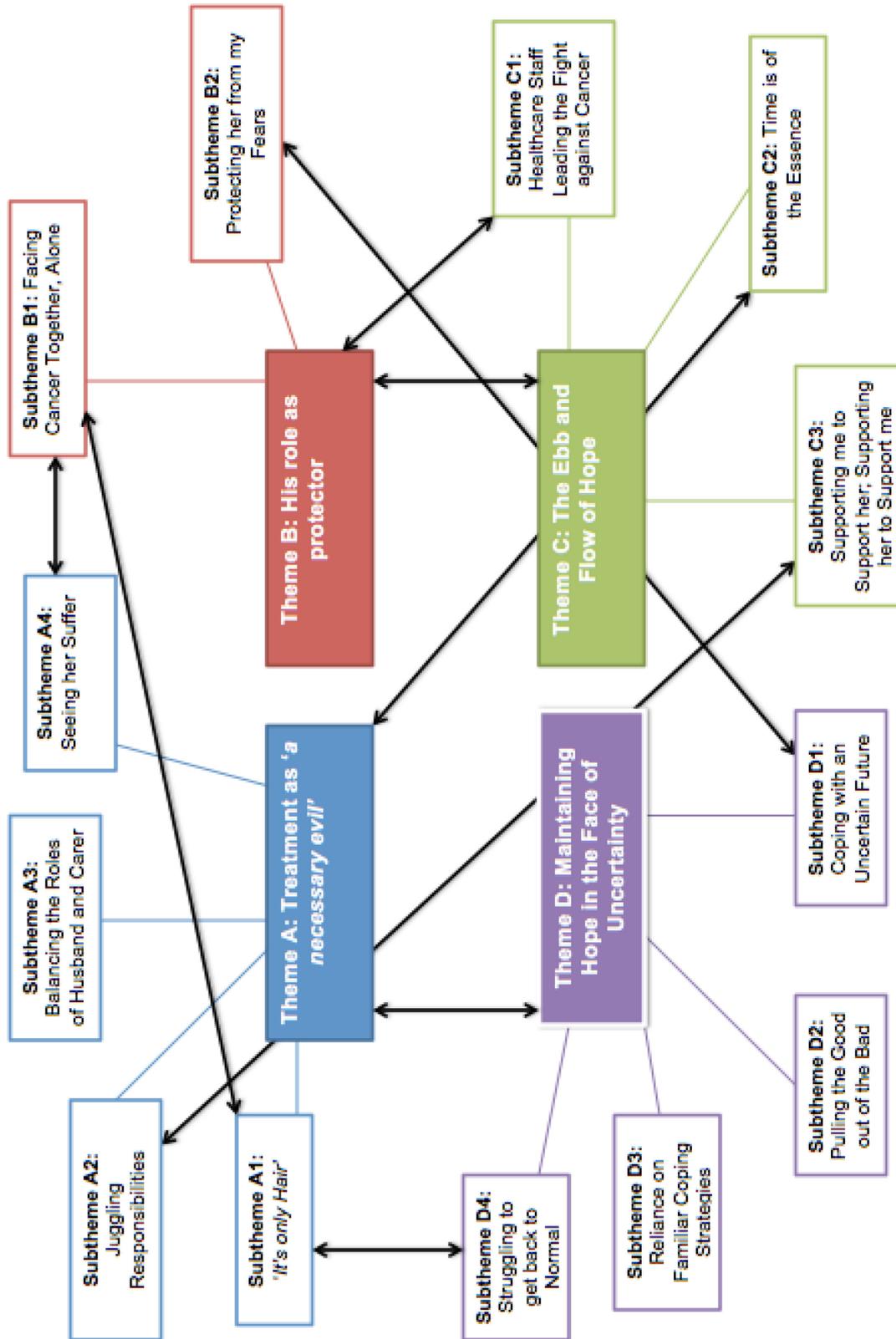


Figure 2

Diagrammatic Representation of Themes

3.1 Theme A: Treatment as 'a necessary evil'

This theme encapsulated respondents' ambivalence towards treatment and contains a quote from James. Whilst respondents spoke about various sacrifices that needed to be made, the overwhelming message was, '*I want her to live and be healthy, and that's the massive priority*' (John). Respondents also sacrificed time with their families, demonstrating the link with sub-theme B1, 'Fighting cancer together, alone'.

Sub-theme A1: 'It's only Hair'

All of the men spoke about changes in their wives' appearance, including hair loss (Ben, John, Matthew, Adam, James), changes in the appearance of her breasts (John, Ben) and aging (John, Matthew). Whilst many of the men were able to empathise with their wife's anguish, they viewed the changes as a small price to pay for her life:

My views were, (...) it's only hair. (...) I said, 'it's only materialistic. At the end of the day, it's hair. It'll grow back', and that's it. I mean the same as any part of her; her hair, her eyebrows, if she loses her breasts, it's not a big thing (...), as long as she's here with us at the end of the day, after all the treatment, then I'm happy.

Adam

Adam was previously discussing his wife's difficulty in coming to terms with her hair loss. Adam sees her hair loss (and indeed, any other physical changes) as unimportant, which is emphasised in the phrases that he uses, such as '*it's only hair*' and '*it's not a big thing*'. His use of the word 'materialistic' suggests that he sees her hair as a tangible possession - the loss of which is meaningless when compared to the potential loss of the less tangible – her life. He also says, '*it'll grow back*'; the loss of her hair is temporary, whereas the loss of her life would be permanent. This really puts the sacrifices into perspective. His final statement clarifies his position; if she is still alive by the end of treatment, no matter what sacrifices have to be made, '*then I'm happy*'.

Adam's stance is echoed in many of the other interviews. For example, whilst talking about his wife's mastectomy, John emphasises that his priority is his wife's health:

Physically (...) that never bothered me. The overriding factor in everything is you want this disease out of your body.

John

Sub-theme A2: Juggling Responsibilities

The respondents spoke about adopting extra responsibilities. For some, this included responsibilities that felt very unfamiliar:

I've got to come home, get her some lunch, walk the dog (...) go back out again, get home at a reasonable time... do the washing... (...) I didn't stretch to the ironing. I did try the ironing, but... (Participant laughs)... In 32 years of marriage I've never ironed (...) There was a lot of stuff that I was doing that I wasn't used to doing - they were jobs that Jane did.

John

John speaks about both familiar and unfamiliar responsibilities. The stress and exhaustion associated with managing these multiple demands is evident in the way that he lists the responsibilities. This was echoed in other interviews: Ben said that he would often be '*finally just sitting down in a chair at ten o'clock at night*', which he said, '*was a bit full-on for a while*'. John and his wife seemed to have fixed responsibilities, which meant that he was confronted with '*a lot of stuff that (...) I wasn't used to doing*'. Other respondents with more flexible roles at home (such as Adam and Matthew) seemed to have fewer difficulties with unfamiliar tasks, but still struggled with the extra demands placed on them.

Whilst two of the respondents were not working at the time of the interview (Matthew and James), the other respondents spoke about their difficulty in balancing their responsibilities at work and at home:

I am aware that she is at home on her own (...) Particularly when she's feeling bad, she doesn't want to see anyone, but then she's stuck in the house on her own and going stir-crazy, so... I'm quite conscious of trying to get home at a reasonable hour (...), which is tricky at the minute because I'm responsible for the unit (...) and because I work late (...). It does just mean I've got to be better at planning and trying to bring it forward.

Ben

Ben's comment that '*she is at home on her own*' suggests that he worries about his wife whilst he is at work. His comment, '*she doesn't want to see anyone*', demonstrates his awareness that there are times when his wife feels too unwell to see anyone. This places a heavy burden on Ben, especially as he is also trying to meet his responsibilities at work. Indeed, this dilemma is evident in his concern about her '*going stir-crazy*', and him being '*conscious of trying to get home*', but at the same time, Ben speaks about his awareness that '*I'm responsible for the unit*'. However, the last few lines reveals his wife as his priority - ultimately, he had to fit work around his wife's needs by '*planning and trying to bring it forward*'.

Sub-theme A3: Balancing the Roles of Husband and Carer

Many men positioned themselves as both a husband and a carer. The balance between these two roles seemed to cause difficulties in the relationship as the couple attempted to adjust:

I try to get her to eat foods. (...) She loses her temper eventually because I keep saying, 'Can I get you some of this? Can I blend you some food?'. The children have pouches where they can take vitamin food, and we've tried them. (...) I know that she needs vitamin C, she needs fresh fruits...

Matthew

In the above passage, Matthew positions his wife as child-like, making both direct (*'the children have pouches...we've tried them'*) and indirect (*'blend you some food'*) references. Indeed, many of the men made references to either children or the elderly when speaking about their wives (*'she'd got the body of a 70-75 year old'*, John), which may reflect changes in the dynamics of their relationship from husband to carer. Matthew spoke generally about his concern at his wife's lack of appetite, and his caring behaviours to try to address it. However, it seems that his wife found the change in dynamics difficult, causing her to lose her temper. This is something that was spoken about by the other men; trying to strike the balance between husband and carer, and their wives becoming irritated when they got it wrong (James, Ben, Matthew).

Respondents also mentioned changes in intimacy; for example, spending less time together as a couple (James) and sleeping in separate beds (Matthew). Ben spoke about changes in the meaning associated with 'hugs', and his difficulty adjusting to this:

She hates people feeling sorry for her and that sort of thing, and it's almost like, can't hug her. 'Well you're only hugging me because you feel sorry for me', it's 'No, I'm hugging you because you're my wife and I want to give you a hug'

Ben

Ben seems frustrated at his wife's interpretation of his physical contact - as

'feeling sorry for her', which positions him in the carer role. The consequence for Ben is that his attempts to seek physical closeness as a husband are misinterpreted and ultimately rejected. He seems frustrated at the loss of intimacy ('can't hug her'), and tries to reassert his role as her husband in his emphasis on the word 'wife'.

Sub-theme A4: Seeing her Suffer

The respondents' sense of helplessness when seeing their wives suffer was obvious in the interviews:

At times, she's become more vulnerable (...), so that's the worst thing (...) it's... seeing her. (...) Although I can support her, it's frustrating not being able to do something and make it better. So that's probably the hardest thing; not being able to make it better.

James

James' sense of passivity is emphasised in his statement about 'seeing her'. This was mirrored by others, such as John and Ben. James feels frustrated at not being able to 'make it better', and implies that supporting her is not enough. He emphasises the word 'do', wishing that he could offer some practical support. Indeed, many men spoke about their preference in focusing on practical tasks to make their wife's life easier, such as buying a new bed (Matthew), buying antiseptic wipes (Ben) and taking responsibility for maintaining the house (John). James states that it is not the physical changes that worry him, but his wife's vulnerability, and his inability to protect her from this. This stance was mirrored by the other respondents. In the below passage, James points out that it is not the hair loss that will bother him, but having to be a helpless witness to his wife's distress:

It's going to be hard to watch her going through that. It'll be harder to watch her going through that than it will be to watch her lose her hair.

Ben

3.2 Theme B: His Role as Protector

The respondents' experience of protecting their wives and their families was encapsulated within this theme. Their drive to protect others from both external and internal sources of stress contributed to the respondents' sense of isolation, but also contributed to a heightened sense of togetherness with their wives.

Sub-theme B1: Fighting Cancer Together, Alone

The respondents spoke about the significant impact that cancer had on their families, '*it's really a nasty experience for the whole family*' (Matthew). John, Adam and Ben spoke about keeping family away, in order to protect their wife from illness when her immune system was low. However, many of the men found this difficult, as it contributed to a sense of isolation, and missing family milestones:

As hard as it was, we made family stay away (...). Jane feels she's lost months of seeing her (grandchild) grow up.

John

The whole family have colds and there's a family meal for someone's birthday (...). I can't put us in a situation where Grace is likely to get anything like that

James

The respondents also spoke about protecting their wives by trying to coach family on sensitive topics that might upset their partners:

It's just keeping things on an even keel, trying to keep her away from any upsets. (...) So if I can, I just get in and just say, 'Look, just steer off that subject if you can' (...) – even with her Mum and Dad as well.

Ben

Adam spoke about 'keeping things on an even keel' and advising family to 'steer off that subject'. He used the metaphor of sailing to describe his experience; whereby he was the sailor navigating the ship (his wife) through the sea (the cancer journey). The metaphor emphasised the unpredictability of the journey that he was on – Both sailing and having cancer involve being at the mercy of nature. However, like a sailor focusing on keeping the keel even, Adam chose to focus on what he could control, which was protecting his wife from 'any upsets'. His final comment, 'even with her Mum and Dad', was intended as indicating that no one was exempt from his attempts to protect his wife.

As well as protecting their wives, respondents also spoke about protecting their families by withholding information:

If she was having a bad day in bed, I'd lay on the bed for 10 minutes with her. It's... It's a lonely battle. There's just me and her, and Jane is very protective of the children, so she was very reluctant to give them too much information about how she felt; how down she was, how frightened she probably was. So maybe I saw everything. I probably got... I got all of it. When she was at her lowest and when she was most frightened and everything. I, I knew. (...) She hated coming to chemo... but we got through it.

John

The above passage is quite evocative, particularly John's use of the phrase 'lonely battle'; this emphasises the constant (but private) nature of their fight. John's description of laying with his wife provides the reader with a visual image of solitude, but also togetherness. John's response to his wife's '*bad day*' is simply to be with her, which is something that many of the other men spoke about; when asked how he supported his wife, James said, '*It's just a matter of being there*'. John said that his wife was protective of the children, but John himself suggested throughout the interview that he was also protective of them. It was this urge to protect that seemed to have led to John and his wife being '*very reluctant to give them too much information*', by hiding his wife's emotional distress. With his use of the phrases, '*I saw everything*', '*I got it all*', and '*I, I knew*', John situates himself in a position of privilege and isolation (being the only one who really knew how his wife felt). These phrases also demonstrated the relationship with sub-theme A4, 'Seeing her suffer'. His concluding comment, '*but we got through it*' emphasises John's sense of their resilience as a couple. John begins this passage by using singular pronouns ('*I saw everything*' – denoting aloneness), but by the end, has switched to using a plural pronoun ('*we got through it*' – denoting togetherness), which embodies the sub-theme, 'fighting cancer together, alone'.

Sub-theme B2: Protecting her From my Fears

Many of the men spoke about hiding their own fears about their wives mortality in an attempt to protect her and to provide her with the support that they thought she needed.

When she was diagnosed - this is my own thoughts, this is me

in my head, I've never said this to Jane, but - she could die, you know? You could lose her. I'm [mid 50s] and you think (sigh), what happens next? And many people do lose their wives and partners, there's thousands every week. We had some friend over the road from us, he lost his wife, she was 36 - breast cancer. (...) That came back to me when Jane got diagnosed - his wife - and I could be next. You don't really want to be thinking about being on your own at [mid 50s] years of age

John

The above passage was quite poignant, particularly because John had presented such a 'tough' persona throughout his interview ('*nothing phases me*', '*I can deal with a lot of things*'). John's repetition in the first few lines emphasises the importance of keeping his fears from his wife. His difficulty in talking about this was apparent from his sigh. John asked '*what happens next?*'; the possibility of his wife's death had led him to question his identity without her. This was something that Adam also spoke about: '*We've been together for 27 years (...). We've never known this life without each other*' (Adam). John's comments that, '*thousands*' of men lose their wives make his wife's death a very real possibility, and his neighbour represents what his life could be like if his wife does die.

The dichotomy between hidden fears and visible hope was something that many of the men spoke about. The struggle to maintain hope when there was a constant fear of losing their wives, was summarised well by Adam, who said that '*You can only say, 'You're going to be alright' so many times. (...) Because deep down, I didn't know*'.

Ben also spoke about hiding his emotions, in an attempt to support his wife in her preferred way:

It's just a case of talking things through logically; She finds that helpful (...). I'll do that, then I'll sort of... go away, on my own and... (participant sighs) get upset sometimes, get frustrated.. But I just try not to do that anywhere where I'm around her, because she wants to stay calm

Ben

Ben previously indicated that he finds it helpful to talk about his difficulties, but here, he demonstrated that he prioritised his wife's preference for 'calm' and 'talking things through logically', over his own need to talk about feelings and fears. Instead, Ben hid his emotions, only letting them out when he is 'on my own'. Other passages in Ben's interview revealed that he also coped by seeking out support elsewhere – Such as talking to friends or work colleagues about difficulties that he was having.

3.3 Theme C: The Ebb and Flow of Hope

This theme attempts to describe respondents' experiences of fluctuations in hope. Some factors (such as support from others) instilled hope, whereas other factors (such as treatment delays) took hope away. This theme was strongly connected to the super-ordinate theme 'His role as protector', since most of the factors that respondents said helped them, seemed to support them in their role as 'protector'.

Sub-theme C1: Healthcare Staff Leading the Fight against Cancer

The men spoke a lot about their reliance on healthcare staff. For many, this helped them to maintain hope. However, when the men felt let down by staff, they felt frustrated and anxious.

[Wife] said to him, 'I just want to know if I'm going to be here this time next year', and he says, 'Why would you even say that? Of course you're going to be'. That put both of us at ease because we didn't know the severity of the cancer at the time. He was like, 'We're going to throw everything at it' (...). So, it helped Laura massively, she perked up straight away. She goes, 'Right, I'm going to do this, we're going to fight it'.

Adam

Here, Adam speaks about meeting one of the doctors. His comment that *'we didn't know the severity'*, and his wife's question indicates their uncertainty prior to the meeting, which may have led them to assume the worst. This was echoed in other interviews; for example, when asked about his initial thoughts following diagnosis, James said, *'automatic assumption... cancer... death'*. The use of the word 'throw' brings to mind a physical fight, which is later mirrored by his wife (*'we're going to fight it'*). Adam viewed the doctor not only as someone who could *'put both of us at ease'*, but also as an ally, leading them into battle (*'we're going to throw everything at it'*).

The reliance on healthcare professionals was echoed in other interviews (*'We have trusted the health people when they say that it has been corrected'*, Matthew). This emphasises the key role played by healthcare staff: The men were relying on them to treat their wives, but also to instil hope. However, there were some instances when healthcare staff took hope away:

We were told that we'd have a meeting with him half-way to see how the treatment is going. And after the third... not happened,

still not happened. So we've got a meeting with him umm in two week's time, (...). So that's very frustrating. We were told that this would happen, that would happen, that would happen... that's not happened, that's not happened, that's not happened.

James

James' frustration with the delay in meeting the doctor was clear from his repetition of the phrase '*not happened*'. James' contrast between what '*we were told*' and what '*happened*' implies his perception of unreliability. Given the necessary reliance on staff to treat his wife, it is easy to understand James' frustration. Unreliable staff is equal to unreliable treatment, which was presumably a great source of anxiety. Indeed, James and Adam both spoke about instances where they felt let down by staff, which seemed to enhance their experience of the super-ordinate theme 'His role as protector'; they took actions to 'chase up' treatment, to protect their wives from the possibility that treatment might stop.

If she didn't make that complaint, then things wouldn't have happened as quickly as they did.

Adam

We had to change it (the appointment) from a quarter-past nine to a quarter past ten because otherwise we'd have never had it.

James

Sub-theme C2: Time is of the Essence

This sub-theme is best demonstrated in the interviews of the men who experienced treatment delays (James and Adam). Other respondents hinted at the importance of treatment running smoothly. Adam reported that, after the initial shock, his thoughts turned immediately to treatment ('*Right ok well that's it,*

official it is; [...] What's the treatment going to be?'), which suggests a sense of urgency. Also, men who reported positive experiences spoke about treatment reliability, 'the bookings, everything went clockwork (...) absolutely first-class' (John). This sub-theme overlaps with 'Treatment as 'a necessary evil'', in which men were concerned with prioritising treatment.

Unfortunately, James seemed to experience a lot of frustration and anxiety as a result of his perception that treatment was not being delivered quickly enough:

The start of the process from the initial diagnosis seems to take a hell of a long time (...) [Wife] wanted it basically saying: Diagnosis, therefore we are starting treatment next week - rather than a month. I forget how long it was but it seemed like a month before she got to that point and that was a, 'This cancer is growing inside of me, and it's getting bigger and bigger and bigger... you're not doing anything'. It's waiting and waiting and waiting. So probably that, the initial... speed. If that would have been quicker, that would have helped.

James

James' sense of frustration in waiting is evident from his repetition in this passage, which is mirrored in his interview as a whole. His sense of urgency is evident in his comment about expecting treatment the week after diagnosis. A relatively short amount of time (a month) is perceived by James as '*a hell of a long time*'. When the reader looks further down the passage, it becomes clear that James associates waiting with giving the cancer opportunities to grow. The passage highlights James' reliance on professionals to treat his wife, and his sense of helplessness and frustration at the thought of the cancer growing, and professionals' lack of urgency in responding, '*you're not doing anything*'.

Adam also spoke about his experience of waiting as a very distressing one. When asked if he thought anything could have been differently to help him to

cope better, Adam responded with the following:

If things moved a bit quicker. I always found that everything was moving too, far too slow. Like waiting for the results from the hospital was really frustrating because, we obviously honestly thought that it could be moving elsewhere. It could get into her bones and brain, and then it's game over really, isn't it? And that was the most frustrating time for us.

Adam

This passage is very similar to what James said, in that Adam also emphasizes his difficulty in the speed of the process from diagnosis to treatment. James also perceived waiting before treatment as giving the cancer the opportunity to spread. The phrase 'game over' gives the reader clues about Adam's ultimate fear – that the cancer would spread, and would become terminal.

Sub-theme C3: Supporting me to Support her; Supporting her to Support me

This sub-theme reflects the knock-on effect that respondents' wives' wellbeing had on them (supporting her to support me). It also reflects the value that men placed in the support that they personally received – because it helped them to further support their wives (Supporting me to support her).

My wife is very spiritual (...). I'm not spiritual or religious at all, I think I don't have 0.3 on the Richter scale, so... I can't say that faith is a comfort (...). But my wife's very spiritual(...). So I think she gets a lot of comfort from that and... I just let her do that because obviously, if she gets comfort, then it's comfort for me.

Matthew

Matthew talked about the 'comfort' that his wife got from spirituality. In contrast,

he explained that he was not spiritual *'at all'*. His comment about not having *'0.3 on the Richter scale'* suggests that whilst spirituality *'moves'* his wife significantly, it does not *'move'* him at all – not even on an unconscious level. However, the last few lines of the passage revealed that Matthew gains indirect benefit from seeing his wife being comforted. This demonstrated the relationship between the men's wellbeing, and their perceptions of their wives' wellbeing (even if the men themselves gained no direct benefit from the source of support). This was also evident in the other interviews, for example, when asked what he thought had contributed to him feeling better, John responded, *'Purely because she feels better. Purely that'*.

The respondents spoke about their appreciation of things that enabled them to further support their wives, such as support from family and friends, which was often framed as contributing to their efforts to support their wife:

I'm an absolute rubbish cook. Whenever I've tried in the past, it's ended in disaster (...).I did have to step up and ... do the cooking (...).I did also get... parcels sent from family members. My brother was really good to me, he'd send like stews and casseroles and things where I'd only got to heat it up and throw some potatoes in the oven

Ben

Ben admits that he is *'an absolute rubbish cook'*, and as evidence for this, speaks about his failed attempts in the past. He explained previously that his wife used to do all the cooking. However, his wife's illness had forced him to *'step up'* – presumably by taking on new responsibilities as her carer, which includes cooking. Other respondents also spoke about their difficulties adjusting to this role, especially if it involved taking on unfamiliar responsibilities, *'I did try the ironing, but... (Participant laughs)... In 32 years of marriage I've never ironed'* (John). Support from others was appreciated most when it was perceived as *'supporting me to support her'*. For example, Ben repeatedly spoke about

family and friends buying him food or sending him meals, which perhaps made it easier for him to support his wife (*'I'd only got to heat it up and throw some potatoes in the oven'*). This demonstrates well how this sub-theme overlapped with sub-theme A2, 'Juggling responsibilities'.

John, Adam and Ben were all employed. They were very appreciative of allowances made at work, which they said enabled them to further support their wives. James and Matthew were not working at the time of the interview, but both recognised that employment could have made it difficult for them to support their wives, *'I think if I had been working, I'd have found it... quite difficult'* (James).

3.4 Theme D: Maintaining Hope in the Face of Uncertainty

This theme captures the men's experiences of attempting to maintain hope and positivity, despite the many challenges faced by their wives' diagnoses. For some men, knowing that their wives were receiving treatment helped them to cope, which demonstrates the link with the super-ordinate theme 'Treatment as *'a necessary evil'*'.

Sub-theme D1: Coping with an Uncertain Future

Respondents spoke about their uncertainty about the future, including the impact of future treatments (Ben), recurrence (John) and genetic risks to younger generations (Adam):

I'm saying, 'We've kicked it' (...). But always in the back of your mind is... Will it come back? Will the kids get it? Will it miss their generation? Will one of the grandchildren get it eventually? Do you know what I mean? I might be long gone by then, but you still worry for your family.

John

There are number of questions in this passage, which reflects John's unanswered questions about the future, despite his wife coming towards the end of her treatment. John recognised that he may have to live with these unanswered questions in his comment about being '*long gone by then*'. Despite this, he maintained a stance of hope in his statement that '*We've kicked it*'. At the same time, the uncertainty about the future was a constant worry lingering in the background. Many of the men spoke of their struggle between the dichotomous states of hope (the state men presented to the outside world) and uncertainty and fear (which was always there, but was hidden). In the above passage, John also demonstrated how his uncertainty about the future was linked to his desire to keep his fears about the future hidden (sub-theme B2, 'Protecting her from my fears').

When asked about what helped them to cope, John, Adam and James spoke about focusing on the present, which may be an attempt to avoid their turmoil associated with uncertainty about the future.

We both tend to compartmentalise it. So it's the pre-chemo (...), then the chemo. So we've not been thinking out anything after that. Now that's finished and it's the next thing - which is surgery. Not really thinking about the radiotherapy until probably after that.

James

It seemed James had coped by breaking treatment down into separate sections, which he focused on completing one at a time. James' wife had completed chemotherapy when he was interviewed. Like many of the other men, James described his frustration at the unpredictability of treatment and side effects (such as his wife unexpectedly having a blood clot). Therefore, James' 'compartmentalising' strategy may be a coping response to a disease where there is a high level of uncertainty.

Sub-theme D2: Pulling the Good out of the Bad

The respondents' stance was overwhelmingly positive and appreciative. For some, this meant recognising this period of their lives as an opportunity for personal growth:

For me this has been a massive wake up call; We've had a good life, we've got beautiful children and grandchildren... but I think it will re-focus us to go out there, do what we want to do.

John

John described the experience as one that had made him not only appreciate the life that he has had so far, but also to take action to make the most of the remainder of his life. His use of the phrase 're-focus' suggested that the experience had caused John to see things differently.

Other men expressed their gratitude by being appreciative:

We are really lucky (...). A girl was saying she's having chemo and she's struggling – she's got two kids, she's got no family, she hasn't got a partner, and Laura was like, 'How does she carry on? How does she do that?'

Adam

Adam spoke a lot in his interview about the support he had received from his family. In the above passage, he expressed his appreciation for this by comparing himself to others worse-off ('she's got no family, she hasn't got a partner'). This is something that many of the other men did, for example, James said, 'if you are in your forties, (...) you had teenage children, that must be absolutely terrible! (...) For us, luckily, it's pretty calm.' Although the respondents varied in terms of age, time since diagnosis, and treatment plan, they all expressed gratitude, whether it was for their financial security (John), being able

to attend all their wives appointments (Matthew) or their own resilience (James). The men also spoke very appreciatively about the support they received from others, whether it was family, friends, professionals or employers.

Sub-theme D3: Reliance on Familiar Coping Strategies

The men spoke about a variety of different coping strategies. It became clear that all of the men were choosing to rely on familiar ways of coping:

I think it's better to talk than bottle up things. (...) My Dad had depression and I always think, 'If you bottle things up, it builds up and then you just explode'. (...) So I've always spoken about things quite openly. I think that helps, definitely.

Adam

Throughout his interview, Adam suggested that he found it helpful to talk to others. This influenced not only the support that he sought out, but also the support that others seemed to offer him. The above passage frames Adam's coping style as one that is based on a long-held family narrative (that '*talking helps*'). The men spoke of their beliefs about coping, and how their response to cancer was merely a continuation of previously used coping strategies.

You go away, research, and then do what you think is best for you (...), but that's the kind of people we are anyway. So if there's something we don't understand, then we go and find out about it.

James

In contrast to Adam, James spoke a lot about the importance of knowledge and being well-informed, which guided his behaviour (e.g. attending all appointments, doing research). However, like Adam, this was a coping strategy that James relied on previous to the diagnosis, and that he had continued to use.

Other 'tried-and-tested' strategies men used to cope included focusing on the positive (James), talking about it to friends (Ben), and 'pulling together' with their wives (John).

Sub-theme D4: Struggling to Get Back to Normal

Many respondents attempted to gain a sense of normality in their lives, but this was made very difficult, as they said that they often felt like their lives revolved around chemotherapy:

The chemotherapy is a cycle. When you first get it, you get these tablets to boost you up, and then after the first three days of tablets you drift into this big deep well, (...) like now she is starting to come out of it because it's nearly a week since she's had it. So probably tomorrow, we might go out or even lunchtime today.

Matthew

Matthew's use of contrasting phrases ('boost you up' vs. 'big deep well') highlights the extreme nature of his wife's states, which would presumably be very difficult to live a 'normal life' around. However, the passage demonstrates how he uses the chemotherapy cycle to predict his wife's state, which allows him to make plans, ('we might go out'). Whilst many of the respondents valued this predictability, they also found it confining, as their plans would often have to fit around the cycle. Ben spoke about his wife's plans which '*just happened to work*

out with her chemo cycles', but these plans had to be cancelled, as she missed the window of opportunity when her chemotherapy was arranged for a week later. James spoke about not being able to go on holiday with his wife, because it wouldn't fit into the 'window of opportunity' in which his wife would feel better. The struggle between putting treatment first and trying to live a normal life is demonstrated well in the passage below:

Cancer is the main thing. Everything revolves around cancer... You have things that you have to do because of going to the hospital (...). We try and put those to one side and if it interferes, then it interferes, but otherwise trying to do the things that you normally do.

James

Not only did the men speak about working around their wives' side-effects, but James points out here that the treatment regime can be very demanding. His comment about putting '*those to one side*' suggests that he tries not to let the treatment take over their lives. At the same time, he also seemed to have an attitude of acceptance if treatment did interfere with their plans. Later in the interview, James contradicts himself by saying that their lives *do not* revolve around cancer, which emphasises the struggle between prioritising treatment (link to Theme A, 'Treatment as '*a necessary evil*') and yet trying to carry on with life as normally as possible.

4. Discussion

This research aimed to explore the experiences of men whose wives had received a breast cancer diagnosis, with particular interest in their perceptions of their wives' physical changes, and meanings associated with 'coping'. Four super-ordinate themes emerged following analysis, which encapsulated the researcher's interpretations of the men's experiences: Treatment as '*a necessary evil*'; his role as protector; the ebb and flow of hope; and maintaining hope in the face of uncertainty.

4.1 Summary of research findings

For ease of reading, the discussion of the findings in relation to previous research and relevant theory will be organised by the titles of the super-ordinate themes.

Theme A: Treatment as '*a necessary evil*'

The respondents recognised the need to make sacrifices in order to prioritise treatment, but they seemed to struggle with the various responsibilities, their role as carer, and seeing their wife suffer. This theme helped to address the first aim about the meanings associated with physical changes, which were framed as 'sacrifices'. The changes also seemed to represent a physical manifestation of their wife's suffering.

The focus on their wives illnesses and care was echoed in previous research (Hilton *et al.*, 2000). Previous research has also found that male partners experience changes in their lifestyles (Zahlis & Lewis, 2010), their relationships (Sandham & Harcourt, 2007), and their wives' bodies (Rowland & Metcalfe, 2014). However, the narrative around these changes was different in the current research, where respondents framed them as 'sacrifices to prioritise treatment'. This may reflect differences in the time-since-diagnosis. The current research focused on men whose wives had been diagnosed in the last year, when they may be more likely to prioritise their wife's survival over other concerns (Marshall & Kiemle, 2005).

Theme B: His Role as Protector

The respondents felt urged to protect others. At times, this contributed to their sense of togetherness with their wives, but also contributed to a sense of isolation. This is similar to previous research, where men have described cancer as bringing them closer to their wives (Zahlis & Shands, 2010), but they also described feeling alone with their own feelings and worries (Hilton *et al.*, 2000; Skerrett, 1998; Zahlis & Shands, 2010).

Similar to the current research, previous research has described male partners as a 'protective guardian' (Sabo *et al.*, 2008), or a 'strong saviour' (Levy, 2011). Previous research has also found that men choose to hide their feelings to protect others (Hilton *et al.*, 2000; Holmberg *et al.*, 2001; Marshall & Kiemle, 2005). This is a recognised coping strategy known as 'protective buffering' (Hagedoorn *et al.*, 2000). Quantitative research has shown that male partners of breast cancer often use protective buffering (Hinnen *et al.*, 2007; Manne *et al.*, 2007). However, the helpfulness of this strategy is questionable: A recent systematic review looking at couples coping with cancer found that protective buffering can lower relationship functioning (Traa *et al.*, 2014).

Men's experiences of 'hiding my fears' and 'protecting others', need to be considered within the socio-cultural context, especially since they seem to comply with Western ideals of masculinity. These ideals stipulate that men should inhibit certain emotions (especially fear and sadness; Brody & Hall, 2008), and they should protect the weak and vulnerable (Connell, 2005). Many men may feel even more drawn into adopting a 'protector' role in light of their partner's illness (Levy, 2011). This, in turn, might influence the coping strategies that they adopt. Research suggests that male caregivers are more likely to use avoidant coping strategies (Badr, 2004; Lopez *et al.*, 2012; Ussher & Sandoval, 2008). Whilst this approach may be adaptive in the short-term by enabling men to feel competent as caregivers whilst avoiding being positioned as 'unmanly' or 'feminine', it may result in men's emotional needs being left unacknowledged and unmet.

Theme C: The Ebb and Flow of Hope

Respondents spoke about various factors that either elicited or took away hope. In particular, they relied on healthcare professionals for reassurance, advice and support, similar to previous research (Hilton *et al.*, 2000; Hoga *et al.*, 2008). Respondents also spoke about their dissatisfaction with waiting for treatment, the seriousness of which was spoken about by men in other research (Hilton *et al.*, 2000). The respondents in this research feared that waiting would allow time for their wives' cancer to spread. Other research also identified 'fear of cancer and it's spread' as a major concern of caregivers of cancer patients (Northouse & Peters-Golden, 1993).

Similar to sub-theme C3, 'Supporting me to support her; supporting her to support me', previous research has found that men perceive support from others as helping them to maintain their caregiving role (Hilton *et al.*, 2000; Lethborg *et al.*, 2003). Respondents also spoke about their wives' wellbeing having an impact on their own wellbeing. Perhaps this isn't surprising, since researchers have increasingly recognised coping as an interdependent process between couples, rather than two separate individual coping processes (Coyne & Smith, 1991; Pistrang & Barker, 1995).

Bodenman suggested that couples coped as a dyad when faced with stress (1995). The coping of the couple is interdependent: Both provide and receive support from each other and engage in joint processes, such as emotion regulation and problem-solving (Bodenmann, 1995; 2005). Therefore, the coping of one of the partners in the dyad is influenced by the quality and effectiveness of their coping as a unit (Bodenman *et al.*, 2011). There is empirical evidence for this theory, with researchers finding correlations between the distress experienced by cancer patients and their carers (Hagedoorn *et al.*, 2008; Hodges *et al.*, 2005). In addition, research has found that couple-based interventions can enhance adjustment to cancer when compared to individual interventions (Scott *et al.*, 2004).

Theme D: Maintaining Hope in the Face of Uncertainty

The final theme captured men's experiences of trying to maintain hope, despite uncertainty about the future. This theme helped to answer the second research question, 'how do men understand 'coping' in the context of their wife's breast cancer?'. When asked directly, many respondents spoke about the importance of showing gratitude, appreciation and hoping for a positive outcome, which is similar to previous research (Duggleby *et al.*, 2012; Lethborg *et al.*, 2003; Zahlis & Shands, 2010). The respondents spoke about their reliance on familiar coping strategies, and their struggle to 'get back to normal'. Many of these themes have emerged in other research; for example, men in previous research have spoken about their focus on 'getting back to normal' (Lethborg *et al.*, 2003), and their difficulty in achieving this given the uncertainty that they experience (Harrow *et al.*, 2008).

Both the adoption of familiar coping strategies and attempts to 'get back to normal' could be conceptualised as attempts to maintain familiar values, rules and relationships. In family systems theory, homeostasis refers to the family's efforts to resist change and maintain stability (Minuchin, 1974). Destabilising events (such as a family member being diagnosed with cancer) can lead to deviation that is too sudden. This results in disequilibrium, which may be met by the system with increased rigidity and efforts to retain the familiar family norms (Goldenberg & Goldenberg, 2007). However, this can be problematic if the familiar coping strategies are ineffective, leading to a prolonged period of disequilibrium and crisis (Roberts, 2000). Research suggests that family members of cancer patients are less likely to experience distress if the family system is able to maintain a balance between rigidity and adaptability (Schulz *et al.*, 1996).

4.2 Clinical implications

Respondents prioritised their wives' treatment, which may explain their sense of urgency, and frustration when treatment was delayed. The perception of waiting as a threat is a justified concern (Elit, 2015). In the UK, healthcare targets suggest that cancer patients should receive treatment within 62 days of an urgent GP referral (Independent Cancer Taskforce, 2015). However, more

than 25,000 people in the UK waited longer than this to start treatment in 2016 (Macmillan Cancer Support, 2017). Healthcare professionals are in an ideal position to provide advice, support, and reassurance. For example, cancer patients and their partners might find it helpful if healthcare professionals prepared them for a wait between diagnosis and treatment, and provided them with information about the small likelihood of the cancer spreading in this time. Respondents found it helpful when the waiting time was explained to them. Whilst healthcare professionals may feel tempted to focus primarily on the needs of the patient, the dyadic nature of coping in couples suggests that it is just as important to support male partners.

In an attempt to protect their wives, it seems that many men might rigidly hold on to more familiar coping strategies, which could lead to distress and crisis (Roberts, 2000; Schulz *et al.*, 1996). Therefore, it seems important to provide partners with psycho-education and alternative coping strategies, in order to help them to better cope and adjust. A group intervention for couples seems an ideal place to deliver this information whilst encouraging more open communication. Indeed, a systematic review evaluating the efficacy of psychological interventions for couples coping with breast cancer (Brandão *et al.*, 2014) found that men experienced improvements in sexual functioning (Christensen, 1983; Zimmermann & Heinrichs, 2011), psychological wellbeing (Baucom *et al.*, 2009), coping and communication (Heinrichs *et al.*, 2012), and relationship functioning (Baucom *et al.*, 2009).

4.3 Strengths and Limitations

The use of IPA as a methodology has added a rich understanding to the literature about the experiences of male partners in the first year after diagnosis. The semi-structured interview allowed respondents the freedom to discuss other topics that might not have come to light otherwise.

The researcher used a critical realist approach throughout, and therefore the findings are based on the researcher's subjective interpretations of the data. However, the researcher attempted to achieve transparency and coherence, by

remaining reflexive, providing a transparent account of the collection and interpretation of the data, and by making a clear connection between the research question, theoretical framework, and chosen methods. This further strengthens the current findings by allowing the reader to follow the various stages of the research process (Yardley, 2008).

Another strength of the current research is that it did not rely too heavily on retrospective recall, which was one of the criticisms of previous research (Zahlis & Lewis, 2010). In the current research, all of the respondents had received the diagnosis within the last year, and were either currently going through chemotherapy, or had just finished.

The interviewer in this research was a young female, and it is possible that this could have influenced the respondents. Some respondents had noticeable difficulties in talking about intimacy, or they avoided the topic altogether. Given the recognised changes in sex and intimacy in previous research (Beaver & Witham, 2007; Gilbert *et al.*, 2010; Marshall & Kiemle, 2005; Nasiri *et al.*, 2012), this seems like a significant omission. There is evidence to suggest that male respondents are influenced by a female interviewer, particularly if the questions concern sexual behaviour (Catania *et al.*, 1996; Fuchs, 2009; Wilson *et al.*, 2002). Perhaps the participants would have felt more comfortable disclosing this information to a male interviewer, but this was beyond the scope of the current research. Alternatively, respondents may have felt that changes in their sexual relationship were not an important part of their experience (Beaver & Witham, 2007; Blais *et al.*, 2014).

4.4 Recommendations for Future Research

The current research has added to our existing knowledge of the experiences of men in the first year after diagnosis. Other research has focused on the experiences of men further along in their breast cancer journey, typically one to two years after diagnosis. A key difference between the current research and previous research was that respondents in the current research framed

changes as 'sacrifices to prioritise treatment'. However, it seems that at some point, men recognise these changes as things that are sources of stress for themselves (and not just necessary sacrifices). It would be interesting to find out more about how men 'transition' between these two stages.

The transition period from 'cancer patient' to 'cancer survivor' has been well established as a time of difficulty for breast cancer patients (Knobf, 2015). However, the experiences of male partners in this transition period is unclear. Men whose wives have just finished treatment describe being 'in limbo' which epitomised their difficulty with their wives' transition to survivorship (Harrow *et al.*, 2008). A longitudinal study would help to explore the experiences of men over the time period - from 'cancer patient' to 'cancer survivor', and the transition period in between. Perhaps this would also help to identify when men's priorities are less focused on their wife, which would allow interventions to be targeted at men who are perhaps more open to thinking about their own concerns and how to cope with them.

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Part 3

Critical Appraisal

1. Introduction

The purpose of this section is for the reflection upon both my personal and professional development throughout the research process, and to take forward some learning points. The writing of this section was founded on the reflective research diary, which was kept from the point of choosing the research topic to the completion of this thesis.

2. Development of the Research Topic

Many of my life experiences and interests have led to my choosing this research topic. My introduction to cancer was a life-changing one. When I was 21 years old, following a routine appendectomy, I was told that the doctors had found cancer in my body. They told me I would have to undergo further surgery to assess whether the cancer had spread. Fortunately, the cancer hadn't spread, and apart from some small scars, I had no visible side effects of my treatment. That's where my cancer journey ends, and I felt like I had had a lucky escape. I wondered what it might be like for people who were not so lucky as me. What would it be like to have chemotherapy - to receive a treatment that made me feel sick and tired? A treatment that might make me lose all my hair, or cause me to have fertility problems? What would it be like to have surgery that affected my body image? These questions led me to my interest in the experiences of other people who had been diagnosed with cancer.

The research topic is also of significance to my research supervisor, who sadly lost his wife, Charlotte, to breast cancer in 2015. I am sad to say that I never met Charlotte, but it is important to acknowledge her because she proposed the idea of exploring the experiences of husbands of women with breast cancer during her illness. Perhaps she was able to identify this as an important area of research from her own lived experiences.

I also have a personal interest in gender issues. One of my interests is societal expectation associated with gender. Since training, I have become more aware of the pressures placed on men because of the direct influence that I think it has on my work as a clinician. I have noticed over the course of my placements

that more women than men access psychological services. I have also heard male clients repeat unhelpful (and sometimes harmful) messages that they have picked up from society, such as 'man-up' and 'be a man'. I have also been quite interested in some of the more recent media campaigns fighting against these societal expectations, such as the 'Boys Do Cry' campaign by Huffington Post (Hartley, 2015).

Men experience considerable pressure to endorse dominant Western ideals; that men should have control over their emotions at all times, and the expression of sadness in particular is discouraged (Connell, 2005). This has been linked to men's difficulties in talking about emotions, the use of alcohol and drugs to manage stress, and the use of more lethal methods of suicide (Samaritans, 2012). Whilst these messages to men are never helpful, I have contemplated over the years about how men cope when they are faced with a traumatic event, such as the breakdown of a relationship, the loss of a job or the illness of a partner.

3. Choosing a Methodology

I decided to choose to use a qualitative approach because of the limited research in this area. I also felt that conducting a piece of qualitative research would help me to develop my skills as a researcher, since I had only carried out quantitative research previously.

Before settling on the experiences of male partners, I also considered a piece of research exploring the experiences of couples coping with cancer. In order to overcome the ethical issues presented when interviewing couples separately (such as maintaining confidentiality), a number of researchers have recommended joint couple interviews (Bjørnholt & Farstad, 2012; Holstein & Gubrium, 1995; Radcliffe *et al.*, 2013). The use of IPA to analyse joint interviews is a contentious issue; some have questioned whether this method fits with the principles underlying phenomenological research (Dowling, 2007; Smith, 2004; Tomkins & Eatough, 2010). Instead, I would have chosen Narrative Analysis, which would have offered an insight into the couples' lived

experiences (Bruner, 1990) whilst also allowing for the analysis of the couples' shared storytelling (Sakellariou *et al.*, 2013).

Given the abundance of research on the experiences of women with breast cancer, I decided that it was important to focus on the experiences of male partners only. I was also concerned that some of the men's experiences and interpretations might be hidden in a joint interview. This certainty seems to have been the case, since one of the sub-themes was about the respondents attempting to hide their own worries and fears in order to protect their wives.

IPA seemed to be the most suitable methodology given my interest in the lived experiences of men whose partners had been diagnosed with breast cancer. Also, the idiographic nature of IPA makes it well suited to a detailed analysis, sensitive to the nuances of particular lived experiences – Such as the experience of breast cancer (Smith *et al.*, 2009). Given the sensitive nature of the research, and the potential for the men to be influenced by social expectations, I thought one-to-one interviews would be the most appropriate methods of data collection. This would allow a rapport to be built between the respondent and the interviewer, and would give respondents the space to think, and to be heard. For this reason, one-to-one interviews are thought to be well suited to IPA research (Smith *et al.*, 2009).

4. Data Collection

I relied on help from the nurses working in the Oncology unit to recruit participants. The nurses were often very busy, and so it seemed important for me to explain the value of my research, to justify their efforts. I also gained a lot of helpful insights from the nurses about their own experiences in working with cancer patients and their partners, which helped me to shape the interview schedule. Gaining their insights struck me as something that was very important; involving healthcare staff in the design of the research is one way in which researchers can help to bridge the gap between evidence-based practice and practice-based evidence (Green, 2008).

During the interviews, I was struck by the men's openness and willingness to share their experiences with me – including some difficult aspects of their experiences. A number of the respondents said that they had never spoken about the things that they had shared in the interview. A number of the men also said that they were surprised at how helpful they had found it to reflect on their experiences, and to share their stories during the interview. At the same time, a number of the respondents said that they weren't sure how other men could be given a similar opportunity, since they said that men would be unlikely to seek any sort of official support (such as a support group). Indeed, most of the research suggests that men are less likely than women to attend support groups (Grande *et al.*, 2006; Krizek *et al.*, 1999; Stevinson *et al.*, 2011). This made me reflect on the difficulty in meeting the needs of men who are informal caregivers, especially if they view the caregiving role as their responsibility (and therefore they may feel reluctant in accepting support; Greenwood & Smith, 2015).

The men's priorities were clear in the interviews, as many of them spent a lot of time talking about their wives. At times, I found this frustrating, as I had to keep prompting the respondents to bring them back to talking about their own experiences. However, it also made me appreciate how intertwined the men's experiences were with those of their wives. Despite some initial difficulties in interpreting these sections of data, I realised that by closely reading and reflecting upon the men's words, I was able to obtain clues about their own stance and meanings associated with their wives' experiences.

I did notice that some participants had difficulties with talking about changes in intimacy in their relationship. Some of the men may have questioned the appropriateness of discussing this topic with me - a young, female interviewer. Others may have felt that the question was inappropriate; research has suggested that some husbands find information about changes in intimacy inappropriate (Beaver & Witham, 2007; Blais *et al.*, 2014).

5. Transcription and Analysis

I undertook the task of transcription myself in order to familiarise myself with the data. I believe that this really helped me to immerse myself in the men's experiences and gain a sense of the narrative throughout each interview.

The process of analysis itself felt confusing at times, and seemed to take a long time, but I kept reminding myself of the importance of some of the rich interpretations that I was making. I also found it helpful to have time away from the transcripts to reflect on what I had read.

I found some of the transcripts felt very poignant and difficult to read; partly because of the moving descriptions the men made, and partly because some of their experiences reminded me of my own experience with cancer. In IPA, the researcher uses themselves as a tool to make sense of the participant's experiences (Smith *et al.*, 2009). It is inevitable that the results are biased by the researcher's own assumptions, since the findings emerge from a co-created relational process between the researcher and participant (Finlay & Evans, 2009). However, whilst the researcher's preconceptions can blinker their interpretations, they can also enable insight (Finlay, 2011). This is something I reflected upon with my research supervisor, since the project had personal meaning for both of us. I believe that these discussions helped me to strike a balance between open and non-judgemental curiosity (reduction), and acknowledgement of my role in the construction of the meanings arising from the research (reflexivity)(Finlay, 2011). I also tried to ensure that my interpretations were grounded in the text by checking that they were prompted by the spoken words of the respondent (Smith *et al.*, 2009)

I found the final process of analysis very difficult, in which I attempted to remain faithful to each participant's lived experience; acknowledge similarities, paradoxes and interrelationships; and reduce down the volume of detail enough to produce coherent and convincing findings. Good qualitative research should engage 'with the messiness and complexity of data interpretation in ways that... reflect the lives of... participants' (Savin-Baden & Fisher, 2002, p.191). Indeed,

this was very much the advice given by Michael Larkin in an IPA workshop I attended at the University of Leicester. He suggested that the researchers should attempt to tolerate the complexity of the data for as long as possible in order for these complexities to be reflected in the findings. I found this a helpful way of working, since I felt naturally drawn to wanting to reduce down the data (and thus feel assured that I had nice, neat 'categories' to describe the experiences of the respondents). However, taking such an approach could have led to very descriptive findings that may not have been completely grounded in the experiences of the respondents.

6. Dissemination Plans

I plan on presenting my findings at the Trainee Research Conference in September 2017. However, I also feel that it is very important to present my findings to the service from which I recruited participants. I think it would be helpful to present not only to the healthcare professionals, but also to management, so that allowances could be made to better support women with breast cancer and their partners. I will also be providing a summary of the research to the Oncology unit and to respondents who had said that they were interested in this.

I also plan on plan on submitting my literature review and research report for publication. This will require me to format the documents differently, and also to considerably reduce the word counts. I think this will be a difficult task (especially for the research report), and I will have to be careful to make sure that I include the key points.

7. Reflection on Personal and Professional Development

I learnt many things during the research process, and some were quite unexpected. Some of the learning points I will take forward are related to my work as a clinician, some related to my work as a researcher, and some related to my personal development.

Conducting research that had personal meaning to me allowed me to fully

experience the importance of reflexivity and its role in transparency. At first, I thought it might be inappropriate to talk about my previous experiences, and how they have shaped the research. However, I came to realise that the type of research I had chosen to undertake would inevitably involve me using myself as an instrument to interpret the data. It then became clear to me why it might be so important to be open about my research interest, and how it has developed; this acts as an audit trail that can be scrutinised by the reader (Finlay, 2011). The process also made me question whether the researcher can ever be truly subjective, since they inevitably bring themselves into the research process. It also made me reflect on my role as a clinician; using myself as a tool for interpreting the data felt familiar, because I also use myself as a tool when working therapeutically with clients. This made me think about the importance of reflexivity not only in research, but also in clinical practice.

Although the process of undertaking research felt very difficult at times, I feel proud of the work that I have produced. I felt honoured that the men chose to share their experiences so openly with me, which made me even more determined to represent their experiences well in the research findings. The process of using IPA as a methodology was very different to my previous experience with research (which was mostly quantitative). Although I found the process of analysis slow, and sometimes confusing, I really enjoyed attempting to immerse myself in the respondents' experiences. I enjoyed looking at their unusual choice of words, or the use of phrases, and the freedom that the analysis allowed me in terms of making my own interpretations (as long as they were still grounded in the data). I learnt about the value that this type of research, in that it adds such a rich understanding of the lived experience of a particular phenomenon.

I have learnt to have confidence in my own abilities, and to trust in my preferred way of working. I have learnt how to use strategies to help me to remain organised and to help me to plan my time. During the later stages of completing this thesis, I found mindfulness in particular very helpful. Indeed, research suggests that helping professionals are susceptible to occupational burnout

(Rosenberg & Pace, 2006), poor attention and concentration (Skosnik *et al.*, 2000) and anxiety (Radeke & Mahoney, 2000; Tyssen *et al.*, 2001). However, the use of mindfulness by therapists in training was associated with increased self-compassion and significant decreases in stress, rumination and anxiety (Shapiro *et al.* 2007). I think that all of these learning points will serve me well in my future carer; to help me to work effectively and confidently, whilst maintaining my own personal wellbeing.

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Appendix A: Guidelines to authors for journal targeted for literature review

Guidelines for the SciFed Oncology and Cancer Research Journal, retrieved April 2017 from: <http://scifed.com/oncology-cancer-research-journal/instructions-for-authors.php>

Authorship

Scifed consider author as someone who has involved in the following activities according to the ICMJE:

1. Substantial contributions to the conception or design of the work.
2. The acquisition, analysis, or interpretation of data for the work
3. Drafting the work or revising it critically for important intellectual content
4. Final approval of the version to be published
5. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Contributors who are not involved in all the above could not be included in the authors list but should be acknowledged. The contribution of each author should be clearly disclosed.

The corresponding author is supposed to take responsibility of the manuscript submission and be in contact with the editorial office throughout the publication process and after publication to respond to critiques of the work and cooperate with any requests from the journal for data or additional information should questions about the paper arise after publication.

Conflict of Interests

Every author of the manuscript must disclose the conflict of interest. We recommend the authors to disclose both financial and non-financial competing interests using conflict of interest form of the ICMJE which can be downloaded

from below link. The authors should submit the form along with the manuscript even there are no competing interests.

Clinical Trial Information

SciFed follows the definition of Clinical Trail given by World Health Organization. The study involving the humans and animals should get proper permissions from the respective institutional review boards and the studies should be reported following the standard reporting guidelines given by CONSORT, STROBE, PRISMA, ENTREQ and COREQ. The trail information such as approval details, name of the ethics committee and the reference number for their judgment should be stated in the cover letter. To know more about how to report the clinical trial data please visit ICMJE FAQ section.

Cover Letter

Cover letter is mandatory for the manuscript submission and the letter should include the importance of your manuscript and reasons to publish your manuscript in the particular journal. The letter should contain the complete title, short title, list of authors with their affiliations, complete details of the corresponding author with mailing address, contribution of each author, and conflicts of interest. The letter should give any additional information that may be helpful to the editor, such as the article type, prior submission or parallel submission of the manuscript, withdrawal of the manuscript from another journal and presentation of the manuscript data at any conferences etc.

Plagiarism Policy

SciFed follows strict plagiarism policy and do not encourage any kind of plagiarism. Manuscripts containing plagiarized text more than ten percentage will be rejected and the decision will be at the discretion of the editor. We recommend the authors to check the manuscript for plagiarism using licensed software.

Manuscript Preparation

General

Peer Reviewers

SciFed encourage authors to suggest six peer reviewers to reduce the peer review time, however the selection of the reviewers depends on the editor. Authors can also provide list of candidates to exclude from the review process.

File Formats

Manuscript should be submitted in the MS word and PDF formats only. Tables and Figures with appropriate figure legends are to be submitted as separate files. Figures should be clear and of high resolution in the formats of JPEG, JPG, TIFF.

Style Guide

Entire Manuscript should be in font Times New Roman and size 12. The bold and italics should be used for sub headings and sub sub headings respectively. Entire text should be justified.

Manuscript Sections

Title Page

Title page should accommodate the meaningful title, author names, details of the corresponding author, disclaimers, funding support, word count, tables and figures count and conflict of interest statement.

Abstract

All types of manuscripts except editorial and letter to editors should contain structured abstract of 250 words. In case of original research manuscripts, the abstract should provide the background of the study, materials and methods used, results obtained, discussion and conclusion. In case or reviews, the aim of the review should be clearly stated and how the review was performed is to be mentioned.

Keywords

Minimum six keywords which describes the manuscript should be provided here

Abbreviations

All the abbreviations which are used in the text should be elaborated here.

Introduction

This section should provide background for the study that is, the nature of the problem and its significance. The research objective and the hypothesis tested by, the study should be clearly mentioned. Every sentence should be properly cited with pertinent references and unnecessary data should be avoided.

Methods

The materials, equipment and procedures used in the study should be provided in detail. The established methods including statistical methods must be properly referenced. If any new methods are used, they are to be supported by the proper reasons and their limitations should be evaluated. Standard protocols should be credited with appropriate references. Any information related to clinical trials including the number of patients, the drugs, doses and routes of administration should be clearly mentioned.

Results

The most important findings should be presented first and the data can be reported in the form of tables and figures. The big data/large data should be represented in the graphs. Do not repeat all the data in the tables and figures in the text. Lay emphasis only on the most important observations. The data which obstructs the flow of the text can be produced as supplementary materials.

Discussion

The discussion should be started by briefly summarizing the main findings, and investigate possible mechanisms for these findings. The new and important

aspects of the study should be clearly emphasized. Compare and contrast the results with other relevant studies, state the limitations of the study, and explore the implications of the findings for future research and for clinical practice. Don't repeat the statements already mentioned in the introduction and other parts of the manuscript.

References

References of articles, books, conferences, blogs, and websites, should be organized in this section. The reference should contain names of the authors, title of the referenced article/book, name of the journal/publisher, year of publication, volume number/edition and page number. References are numbered consecutively in the order in which they are first cited in the text. Inline references are not allowed and the reference numbers should be mentioned in the text (in parenthesis) in an order. The conference abstracts, unpublished materials (submitted manuscripts), and personal communication should not be referenced unless it provides very essential information. We suggest authors to use electronic tools like zotero, endnote to manage the references in correct format.

References should follow the standards summarized in the NLM's International Committee of Medical Journal Editors (ICMJE) Recommendations.

Tables and Figures

Tables and figures should be uploaded in separate word document. Tables should have a short descriptive title, should be numbered using Arabic numerals, and should be cited in the text. Symbols and abbreviations represented in the table should be explained in footnotes below the table. For example, 'The results from the In-Vitro dissolution testing are presented in Table 1'. Figures of high resolution in the formats of JPEG, TIFF and PNG should be submitted. A suitable title and short explanation should be provided in the figure legend. Figures should be numbered using Arabic numerals and cited in the text.

Pubmed Mandate

Manuscripts having funding from NIH, FDA, CDC, WHO Bill and Melinda gates foundation, Howard Hughes Medical school, US department of Veteran Affairs will get indexed in pubmed immediately after publication.

Manuscript Submission

We request others to use our online system in order to maintain records of the manuscript.

You may submit the manuscript at our online submission system or send to editorial.sfocrj@scifed.com

Appendix B – STROBE Quality Assessment Tool used for Quantitative Papers

Quality appraisal of (name of study)	
Section	Comments
Title and abstract	
1. Background /rationale	
2. Objectives	
Introduction	
3. Rationale and aims	
Methods	
4. Study design	
5. Setting	
6. Participants	
7. Variables	
8. Data sources /measurement	
9. Bias	
10. Study size	
11. Quantitative variables	
12. Statistical methods	

Results	
13. Participants	
14. Descriptive data	
15. Outcome data	
16. Main results	
17. Other analyses	
Discussion	
18. Key results	
19. Limitations	
20. Interpretation	
21. Generalisability	
Other information	
22. Funding	

Appendix C - Summary of Quality Appraisal for the Quantitative Papers

	Quality appraisal criteria and number																					
	Title and abstract		Intro	Methods									Results					Discussion				Other
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Kilpatrick <i>et al.</i> , 1998	Green	Green	Green	Green	Green	Green	Green	Green	Red	Green	Red	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Nikoletti <i>et al.</i> , 2003	Green	Green	Green	Orange	Green	Orange	Green	Green	Red	Red	Green	Green	Orange	Green	Green	Green	Green	Green	Green	Green	Green	Red
Pauwels, Hoof <i>et al.</i> , 2012	Orange	Green	Green	Red	Orange	Green	Green	Green	Red	Red	Green	Green	Orange	Green	Green	Green	Green	Green	Green	Green	Green	Red
Pauwels, Bourdeaudhuij <i>et al.</i> , 2012	Orange	Green	Green	Orange	Orange	Green	Green	Green	Red	Red	Green	Orange	Orange	Green	Green	Green	Green	Green	Green	Green	Red	Red
Rees & Bath, 2000a	Green	Green	Green	Green	Green	Green	Green	Green	Red	Red	Green	Orange	Orange	Orange	Green	Green	Green	Green	Green	Green	Green	Green
Salminen <i>et al.</i> , 2004	Red	Orange	Orange	Red	Orange	Green	Green	Orange	Green	Red	Green	Green	Orange	Orange	Green	Green	Green	Green	Green	Green	Red	Red
Beaver & Witham, 2007	Green	Green	Green	Green	Green	Green	Green	Orange	Red	Red	Green	Green	Green	Orange	Green	Green	Green	Green	Green	Green	Green	Red

Green = fully meets the criteria

Orange = partially meets the criteria

Red = does not meet the criteria

1 = background/rationale; 2 = objectives; 3 = rationale and aims; 4 = study design; 5 = setting; 6 = Participants; 7 = Variables; 8 = data sources/measurement; 9 = bias; 10 = study size; 11 = quantitative variables; 12 = statistical methods; 13 = participants; 14 = descriptive data; 15 = outcome data; 16 = main results; 17 = other analyses; 18 = key results; 19 = limitations; 20 = interpretation; 21 = generalisability; 22 = funding

Appendix D - CASP Quality Assessment Tool used for Qualitative Papers

Appraisal questions
1. Is there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Appendix E - Summary of Quality Appraisal for Qualitative Papers

Article	Criteria type and number									
	1: Aims and background	2: Methodology	3: Design	4: Recruitment	5: Data collection	6: Researcher bias	7: Ethical issues	8: Data analysis	9: Findings	10: Research value
Beaver & Witham, 2007	Green	Green	Green	Orange	Green	Red	Green	Green	Green	Green
Blais <i>et al.</i> , 2014	Green	Green	Orange	Green	Green	Orange	Green	Green	Green	Green
Chen <i>et al.</i> , 2014	Green	Green	Red	Orange	Green	Orange	Orange	Green	Green	Orange
Fitch & Allard, 2007	Green	Green	Green	Orange	Orange	Orange	Red	Orange	Green	Orange
Lindholm <i>et al.</i> , 2007	Orange	Green	Green	Orange	Orange	Red	Orange	Red	Orange	Orange
Marshall & Kiemle, 2005	Green	Green	Green	Green	Green	Orange	Green	Green	Green	Green
Rees <i>et al.</i> , 1998	Green	Green	Green	Orange	Green	Orange	Orange	Green	Green	Orange

Green = fully meets the criteria
Orange = partially meets the criteria
Red = does not meet the criteria

Appendix F - Data Extraction Form

Citation		
Country		
Aims		
Design		
Sampling approach	Sampling method	
	Setting	
	Period of recruitment	
	Inclusion and exclusion criteria	
Participants	Total number	
	Response rate	
	Did the study include men and their partners as participants?	
	Participant characteristics	
	Patient characteristics	
Data collection methods		
Data analysis		
Findings		
Limitations		
Recommendations made by authors (clinical implications and further research)		

Appendix G: Statement of Epistemological Position

The principle investigator's epistemological position provides an underlying philosophical framework regarding the nature of knowledge, which has helped to guide the research process (Soini & Kronqvist, 2011).

The current research was conducted from a critical realist position, which lies between the two extremes of radical relativist and naïve realist (Madill et al., 2000). A realist position makes the assumption that the researcher is able to gain objective knowledge about the world as it really is (Finlay, 2011). On the other hand, a relativist position adopts the view that experiences have no absolute truth or validity because reality is context-dependent and socially constructed (Willig, 2008). A critical realist approach assumes that there is a 'true' reality, but that the researcher may not be able to gain direct access to this 'reality' because they are inherently biased by their own values, experiences and beliefs (Willig, 2008).

Since it is not possible to directly access 'reality', the researcher has to adopt the role of analyst in order to interpret the data (Smith, 2004). The respondents and researcher are linked in a double hermeneutic: 'the participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world' (Smith & Osborn, 2009, p. 51). Therefore, it is important that the researcher reflects upon how their own personal experiences and beliefs might influence their interpretation of the data. Many researchers keep a journal to reflect on their own personal position in relation to the topic of research, and how this might influence their interpretation of the data.

The primary investigator acknowledges the reality of the respondents' experiences, but also recognises that these experiences can only be accessed via interpretations. The respondents' interviews provide a narrative of their interpretations and meanings associated with the experience of having a wife diagnosed with breast cancer. Similarly, the researcher can only access these interpretations via their own interpretation. This demonstrates

the double hermeneutic in the research. The findings of this research are therefore the researcher's own interpretations, and not absolute truths..The researcher is aware that the interpretations are inevitably influenced by their own values, beliefs and assumptions. However, the researcher has tried to make these biases transparent to the reader (MacNaughton, 2001), and has also attempted to ground all of the findings in the original data by sustaining engagement with the transcripts, and checking that interpretations fit with the original data. The primary investigator also kept a reflective journal to help recognise and bracket off any pre-conceptions before interpretation of the data.

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Appendix H: Participant Information Sheet

(Form to be on headed paper)

Study number:

Participant Information Sheet

Short study title: Men's experiences of their partner's breast cancer

Investigator: Sarah Thomas

Date:

You have been invited to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part.

Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The researcher is interested in men's experiences after their partner is diagnosed with breast cancer. Much of the existing research focuses on the

woman with breast cancer, and her experiences. However, evidence suggests that cancer has a huge impact on the family as well as the woman. In particular, partners can be quite vulnerable to stress because they often become the main carer when their partner is diagnosed.

The researcher is hoping to recruit up to six men.

Why have I been chosen?

You have been chosen because your female partner has been diagnosed with breast cancer in the last year.

What would taking part involve?

If you agree to take part, the researcher will arrange to meet with you to ensure you have understood the information sheet and to sign a consent form. You will then take part in an interview with the researcher. The interview will last up to 1 hour in length, and the researcher will ask you questions about your experiences with regards to your partner's breast cancer.

You will be given a choice as to where you would like the interview to take place; either in your own home or in a room on the hospital site. It is important that the interview takes place in a private and quiet setting where the interview will not be interrupted or overheard. You will be reimbursed for any expenses you have incurred in order to attend the interview. You are free to leave at any point during the interview if you wish.

The interview will be recorded on an audio recorder. The researcher will then write up the interview so that it can be analysed. The interviews will be anonymous; any information that is personal, such as your name or your partner's name, will be changed so that people cannot identify you.

Quotations from the interviews will be included in the research paper in order to demonstrate themes.

The interview in its raw form will be accessed by the researcher only (who will also be the interviewer). Once identifiable information (such as your name) has been removed or changed, some of the interviews may be read by the researcher's academic supervisor for the purposes of analysis.

What are the possible benefits of taking part?

Many people find talking about their experiences a positive and therapeutic process. In addition, many people gain a sense of satisfaction contributing to research, knowing that the research might benefit others in a similar situation. For example, it is hoped that the results of this research will help to inform the support given to men who have a partner with breast cancer.

However, it is important to note that none of these benefits are guaranteed from taking part.

What are the possible disadvantages and risks of taking part?

It is possible that you will find it upsetting talking about your experiences. The interviewer will be sensitive to this, and you are able to leave the interview at any point. You will also be offered contact details for other organisations that might be able to provide you with support, such as Macmillan Cancer Support.

Risks to confidentiality are very low since personally identifiable information (such as your name) will only be accessed by the researcher. All information will be kept in a locked cabinet in a locked room. The interview transcript will be kept on a password-protected computer at the University of Leicester.

Further supporting information

- What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any point, without being questioned about your reason and without any consequences. You also have the right to withdraw your data any time up until the data has been analysed.

- How will my information be kept confidential?

The interviews will be audio recorded, and will then be written up. Both the written interviews and the audio recorder will be kept in a locked cabinet. The written interview transcript will be kept on a password-protect computer at the University of Leicester. Any information that is personal to you (such as your name) will either be changed or deleted.

- What will happen to the results of this study?

The results will be written up into a research paper, which will include some quotes from the interviews. The research paper will be published and made available to the public. The results may also be presented at a research conference.

- Who is organising and funding this study?

The study is being funded by the University of Leicester.

- Who has reviewed this study?

This study has been reviewed by the University of Leicester, and has also undergone ethical review by the NHS.

Further information and contact details

If you would like to ask any questions or would like further information, please feel free to contact the chief investigator:

Sarah Thomas
Trainee Clinical Psychologist
104 Regent Road
Leicester
LE1 7LT

St335@le.ac.uk

07544293042

Appendix I: Participant Consent Form

(Form to be on headed paper)

Sponsor number:

Study number:

CONSENT FORM

Title of Project: Men's experiences of their partner's breast cancer

Name of Researcher: Sarah Thomas

Please initial all boxes

- I confirm that I have read the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- I understand the interview will be audio-recorded, and quotes from my interview may be used anonymously in the research paper, which will be available for the public to view.
- I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person	Date	Signature

taking consent

Appendix J: Research Summary and Expression of Interest Form

(Form to be on headed paper)

Sponsor number:

Study number:

Patient Identification Number:

Research Summary and Expression of Interest

Title of Project: Men's experiences of their partner's breast cancer

Name of Researcher: Sarah Thomas

We would like to hear from you about your experiences.

The researcher is interested in men's experiences after their partner is diagnosed with breast cancer. Much of the existing research focuses on the woman with breast cancer, and her experiences. However, evidence suggests that cancer has a huge impact on the family as well as the woman. In particular, partners can be quite vulnerable to stress because they often become the main carer when their partner is diagnosed.

The researcher is hoping to recruit up to six men.

What do we already know from existing research?

Most of the research has focused on the experiences of women after their breast cancer diagnosis. Research indicates that women can experience distress during diagnosis and treatment. Breast cancer can challenge a woman's identity, self-esteem, and relationships. However, there are certain protective factors that can help women to cope, such as support from family and friends, support groups and professional resources provided by clinical staff. Since the experiences of women have been researched so extensively, the researcher decided to focus on the experiences of the male partners of these women.

We currently know very little about male partners' experiences. This is surprising because male partners are the most likely to become their partner's primary care giver. It is hoped that by understanding the experiences of men better, so that we might have a better understanding of how we can support them better.

What does participation involve?

The researcher would like to ask for your contact information so that she can send you a participant information sheet, and so that she can call you to see if the male partner would like to take part.

Participation will involve taking part in an interview (either in your home or at the hospital), that will last no longer than one hour. During the interview, the researcher will ask him some questions about his experiences since his partner has been diagnosed with breast cancer.

If you do decide to provide contact information, this will be kept in a locked cabinet, and will only be used by the researcher for the purposes of this study. The information will not be passed onto (or viewed) by anyone else outside of your usual healthcare team.

If you feel you would be interested in finding out more, please provide your contact information on the next page.

Expression of Interest

Who completed this sheet? (please circle)

Male partner

Oncology patient

Your name:

Your partner's name:

Address

(to send participant information sheet):

.....
.....
.....
.....

Your telephone number:

Best time to contact you

(time and day of the week):

.....
.....

Appendix K: Semi-structured Interview Schedule

1. Could you describe what it has been like for you since your partner received her diagnosis?

Prompts:

- The experience of receiving diagnosis
- The experience of treatment
- Impact on everyday life

2. Couples often turn to each other for support. Could you tell me about your experience of supporting your partner through her breast cancer?

Prompts:

- Practical support.
- Emotional support.
- What has been the most difficult part of supporting your partner?

3. What has your experience been of receiving support?

Prompts:

- Support from professionals, your partner, family, friends.

4. Could you tell me about what you feel has helped you to cope?

Prompts:

- Is there anything that has made it difficult to cope?
- On reflection, do you think that anything could have been different to help you to cope better?

5. Do you feel that the diagnosis has influenced your relationship with your wife? If so, how?

Prompts:

- Changes in roles at home
- Changes in intimacy in the relationship

6. Have you witnessed any changes in your partner's physical appearance as a result of treatment? If so, what has this been like for you?

Prompts:

- How do you feel about the changes?
- Have the changes affected your relationship?

Appendix L: Letters to and from LREC

16/SW/0118



Health Research Authority

11 April 2016

Miss Sarah Thomas
[Redacted]

Dear Miss Thomas

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis
REC reference: 16/SW/0118
IRAS project ID: 187903

Thank you for your application for ethical review, which was received on 31 March 2016. I can confirm that the application is valid and will be reviewed by the Proportionate Review Sub-Committee on 18 April 2016. To enable the Proportionate Review Sub Committee to provide you with a final opinion within 10 working days your application documentation will be sent by email to Committee members.

One of the REC members is appointed as the lead reviewer for each application reviewed by the Sub-Committee. I will let you know the name of the lead reviewer for your application as soon as this is known.

Please note that the lead reviewer may wish to contact you by phone or email between today and 18th April to clarify any points that might be raised by members and assist the Sub-Committee in reaching a decision.

If you will not be available between these dates, you are welcome to nominate another key investigator or a representative of the study sponsor who would be able to respond to the lead reviewer's queries on your behalf. If this is your preferred option, please identify this person to us and ensure we have their contact details.

You are not required to attend a meeting of the Proportionate Review Sub-Committee.

Please do not send any further documentation or revised documentation prior to the review unless requested.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	5	08 April 2016
IRAS Checklist XML [Checklist_08042016]		08 April 2016

Letters of invitation to participant [Participant invitation]	3	08 April 2016
Participant consent form [Consent form]	1	08 April 2016
Participant information sheet (PIS) [Participant information sheet]	2	08 April 2016
REC Application Form [REC_Form_31032016]		31 March 2016
Research protocol or project proposal [Proposal]	5	08 April 2016
Summary CV for Chief Investigator (CI) [chief investigator CV]	2	08 April 2016

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the Sub-Committee's decision

We aim to notify the outcome of the Sub-Committee review to you in writing within 10 working days from the date of receipt of a valid application.

If the Sub-Committee is unable to give an opinion because the application raises material ethical issues requiring further discussion at a full meeting of a Research Ethics Committee, your application will be referred for review to the next available meeting. We will contact you to explain the arrangements for further review and check they are convenient for you. You will be notified of the final decision within 60 days of the date on which we originally received your application. If the first available meeting date offered to you is not suitable, you may request review by another REC. In this case the 60 day clock would be stopped and restarted from the closing date for applications submitted to that REC.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at <http://www.rdforum.nhs.uk>. There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/SW/0118 Please quote this number on all correspondence

Yours sincerely

[Redacted signature]

REC Assistant

Email: [Redacted email address]

Copy to: [Redacted recipient]

22 April 2016

Miss Sarah Thomas

Dear Miss Thomas

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis
REC reference: 16/SW/0118
IRAS project ID: 187903

The Proportionate Review Sub-Committee of the [redacted] Ethics Committee reviewed the above application on 18 April 2016.

Provisional opinion

The Sub-Committee would be content to give a favourable ethical opinion of the research, subject to clarification of the following issues and/or the following changes being made to the documentation for study participants:

1. The sub-committee noted the interviews would be one-on-one with possible home visits and requested the submission of the Lone Worker Policy in place.
2. The Sub-Committee showed concerns about the student lack of experience in conducting interviews alone during home visits. The Sub-committee would like the supervisor or similar attend the first few home visits. Please update the interview related documentation to allow a third part on the initial interviews.
3. It was noted the student would be approaching potential participants in the oncology clinic. The Sub-Committee requested further clarification on whether the applicant was part of the current clinical care team.
4. The Sub-Committee decided it would be appropriate for someone from the clinic care team to identify the patients and inquire about their wiliness to speak to the applicant.

When submitting a response to the Sub-Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: <http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/>

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

Authority to consider your response and to confirm the final opinion on behalf of the Committee has been delegated to [REDACTED].

Please contact [REDACTED] (REC Assistant) if you need any further clarification or would find it helpful to discuss the changes required with the lead reviewer.

The Committee will confirm the final ethical opinion within 7 days of receiving a full response. A response should be submitted by no later than 22 May 2016.

Summary of discussion at the meeting

Ethical issues raised and noted in discussion:

- **Social or scientific value; scientific design and conduct of the study**

The sub-committee noted the interviews will be one-on-one with possible home visits. Safeguards were mentioned in A26, but there no Lone Worker Policy had been submitted.

- **Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

1. A29 stated that the student will be approaching potential participants in the oncology clinic. The Sub-Committee requested further clarification on whether the student was part of the clinical care team.
2. The Sub-Committee decided it would be appropriated for someone from the clinic care team to identify the patients first and ask if whether they would willing to speak to a researcher, especially as this may be a difficult or emotional time for them.

- **Suitability of the applicant and supporting staff**

The Sub-Committee noted the student did not have much experience conducting interviews alone during home visits and that she might be put in a potentially harmful situation. The Sub-committee suggested to request supervisor or similar attend the first few home visits.

Documents reviewed

The documents reviewed were:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	5	08 April 2016
IRAS Checklist XML [Checklist_08042016]		08 April 2016
Letters of invitation to participant [Participant invitation]	3	08 April 2016
Participant consent form [Consent form]	1	08 April 2016

Participant information sheet (PIS) [Participant information sheet]	2	08 April 2016
REC Application Form [REC_Form_31032016]		31 March 2016
Research protocol or project proposal [Proposal]	5	08 April 2016
Summary CV for Chief Investigator (CI) [chief investigator CV]	2	08 April 2016

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

16/SW/0118	Please quote this number on all correspondence
-------------------	---

Yours sincerely




Vice Chair

Email: 

Enclosures: *List of names and professions of members who took part in the review*

Copy to: 

6th May 2016

Dear [REDACTED]

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis

REC reference: 16/SW/0118

IRAS project ID: 187903

Thank you for your letter regarding the review of my application by the sub-committee. I have read the issues raised, and have made the following changes in order to address these:

- The sub-committee noted that interviews would be on a one-to-one basis, and noted that a Lone Working Policy had not been submitted. I have now attached a Lone Working Policy for the host site, which I will adhere to when conducting this research.
- The sub-committee wanted further clarification as to whether the researcher is part of the clinical care team. They also decided that it would be appropriate for someone from the clinical care team to identify potential participants first, and ask whether they would be willing to speak to the researcher. The researcher has now made it clear in section A29 that she is not part of the usual care team, and has also amended section A29 to say that the outpatient nurses will approach potential participants first. The researcher has also amended the procedure in the research proposal to reflect these changes.
- The sub-committee raised concerns that perhaps the researcher does not have much experience in conducting interviews alone during home visits, and that she might be putting herself potentially in a harmful situation. The researcher suspects that she may not have been clear about her experience in this area. The researcher works as a trainee clinical psychologist, and has conducted many assessment and interviews alone with clients in their homes. The researcher has tried to clarify the procedures in place to protect herself from potential risk in

16/SW/0118

section A26, and has also made amendments to the research protocol documents to reflect this. If the sub-committee still feel that it is appropriate for a supervisor to attend the first few interviews, then obviously the researcher will amend the procedure to reflect this.

Yours sincerely,

Sarah Thomas
Chief Investigator

CC: [REDACTED] (Academic Supervisor)
[REDACTED] (Field Supervisor)
[REDACTED] (Sponsor representative) [REDACTED]

19 May 2016

Miss Sarah Thomas

Dear Miss Thomas

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis
REC reference: 16/SW/0118
IRAS project ID: 187903

Thank you for your letter of 11 May 2016, responding to the Proportionate Review Sub-Committee's request for further information on the above research, and enclosing the following revised documents:

Document	Version	Date
IRAS Checklist XML [Checklist_11052016]		11 May 2016
Other [Lone Working Policy]	1	06 May 2016
Research protocol or project proposal [Proposal]	6	06 May 2016

The Sub-Committee has reviewed the revised documentation and concluded that it remains unsatisfactory for the following reasons:

Point 2 of the Provisional Opinion letter where the Sub-Committee showed concerns about the student lack of experience in conducting interviews alone during home visits and requested the supervisor or similar attend the first few home visits and update of the interview related documentation to allow a third part on the initial interviews was not properly addressed.

Please provide evidence of what experience the researcher has conducting home visits, and further justification as to why he/she will not be accompanied at her visit

I would be grateful to receive further revised versions of relevant documents addressing these points. The revised documents should be given a new version number and date.

A final ethical opinion on this application will be issued within 7 days of receiving a further response and revised documentation.

16/SW/0118

Please quote this number on all correspondence

Yours sincerely

[Redacted signature]

[Redacted text]

Copy to: [Redacted text]

16/SW/0118

Sarah Thomas

27th May 2016

Dear [REDACTED]

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis
REC reference: 16/SW/0118
IRAS project ID: 187903

Thank you for your letter of 19th May 2016, regarding the review of my application by the sub-committee. The committee raised concerns relating to my experience in conducting home visits alone, and asked for evidence to be provided with regards to my experience. Therefore I have made the following changes:

- I have made changes to section A26 on the IRAS form, entitled 'What are the potential risks for the researchers themselves?', to reflect my relevant experience in lone working with individuals. I have also made changes to my academic CV to further highlight my relevant experience. For ease of reference, I have enclosed section A26, with my amendments underlined.

I understand that by conducting home visits alone, there is a potential for very serious risks to myself. In addition, I have considered the potential risks in being a young female researcher interviewing male participants. I have thought about the risks carefully during supervision, and have reflected on how these could be reduced. My previous experience includes interviewing clients in a one-to-one setting and working with clients displaying challenging behaviour. In this work I felt well aware of the potential risks and how I might be able to reduce them, and I would endeavour to use my experience and awareness of risk in my research in order to keep myself and participants safe. Furthermore, I feel that having a second person in the room when I am asking about topics that are potentially very sensitive and emotive is not ideal for the participant.

16/SW/0118

I have sought supervision with both my academic and field supervisors to try to address these issues and reduce potential risk, whilst maintaining optimal conditions for the participants being interviewed. I would really appreciate further ideas from the committee if they have any further thoughts about how I could manage risk.

Yours sincerely,

Sarah Thomas
Chief Investigator

CC: [REDACTED] (Academic Supervisor)
[REDACTED] (Field Supervisor)
[REDACTED] (Sponsor representative for [REDACTED])

Encl.

A26: What are the potential risks for the researchers themselves?

The researcher will be conducting one-to-one interviews, so there might be risk related to being on their own with the participant, especially if the interview takes place in the participant's home. In order to manage the risk, the researcher will:

1. Gain information about the patient and the participant via the chemotherapy nurses, to see if any concerns have been raised regarding risk. If concerns have been raised, the researcher will not offer a home interview.
2. The researcher will inform both her academic supervisor and field supervisor when and where she will be conducting an interview, and will call them before the interview starts, and when the interview has ended, or prior to that if the interview goes longer than average or expected.
3. If the researcher is facing considerable risk that she does not feel she can manage during a home interview, she will have an agreed phrase ('red diary'), which she will quote on the phone to either her field or academic supervisor, to indicate that she is at risk and requires assistance. If the researcher was unable to do this for any reason, or if she felt that the risk was significant, she would call '999' and try to leave the house as soon as possible.
4. The researcher has taken training in 'MAPA disengagement skills' on 7th November 2014, and took a refresher course on 11th January 2016. Should the researcher experience any violent behaviour during a home visit, she will utilise the skills learn during the MAPA disengagement course.
5. There is also a lone working policy in place for people working at the host site, which will be adhered to and is attached as a document to this application.

Interviewing participants in their homes poses an increased risk to the researcher. However, the researcher also works as a trainee clinical psychologist, and has conducted both interviews and assessments on her own in client's homes. The researcher has been conducting interviews, primarily for the purposes of assessment, since she began training for Clinical Psychology in September 2014. Her first work placement (which was a year-long placement) involved working in the community with older adults. Since many of these clients found it difficult to attend the health center, the researcher would go to their homes to conduct both assessment and intervention work. In the team that the researcher was working in, it was commonplace to conduct home visits. The researcher would have some information about the clients before she visited them at home, and would not visit clients at home if they posed a significant risk to her. She also followed the lone-working policy to ensure her own safety. The researcher would visit

both male and female clients at home, aged from [REDACTED] years old. Sometimes client's adult children would also be in the house at the time of the visit. Sessions would typically last 60 – 90 minutes, and discussions with clients could elicit some very emotive and distressing topics for them (which the research would have to manage). The clients' presenting problems included [REDACTED]. Some of the clients had been based in the community throughout the researcher's involvement with them, whereas others had been followed-up by the researcher following discharge from an inpatient unit. The researcher conducted approximately 40 sessions (involving assessment and/or intervention) on her own in clients' homes over the course of the placement. At the beginning of her work placement, the researcher's first few home visits were supervised (to ensure that she was competent at interviewing), and after that, the researcher would visit clients on her own in their homes.

Therefore I feel I am familiar with the potential risks of lone working in client's homes and how to manage these risks. It is also felt that some participants may feel more comfortable being interviewed in a familiar environment (i.e. at home). Whilst the researcher could arrange for a supervisor to attend interviews with her, having another professional attending the interview is not ideal for the participant; they may feel less able to build a relationship with the interviewer, and therefore may feel less able to be open about their experiences. This could potentially significantly limit the richness of the data, which is particularly problematic for research using an IPA method, in which the focus is on developing an in-depth understanding of the participant's lived experiences. Therefore, the researcher believes that the potential benefits of offering home interviews outweigh the potential risks, and the researcher has plans in place to reduce potential risks.

07 July 2016

Miss Sarah Thomas



Dear Miss Thomas

Study title: Men's experiences after their partner is diagnosed with breast cancer: an Interpretative Phenomenological Analysis
REC reference: 16/SW/0118
IRAS project ID: 187903

Thank you for your letter of 24 June, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager 

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

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

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

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	5	08 April 2016
IRAS Checklist XML [Checklist_24062016]		24 June 2016
Letters of invitation to participant [Participant invitation]	3	08 April 2016
Other [Lone Working Policy]	1	06 May 2016
Other [Response letter to IRAS committee]	2	24 June 2016
Participant consent form [Consent form]	1	08 April 2016
Participant information sheet (PIS) [Participant information sheet]	3	27 May 2016
Participant information sheet (PIS) [Participant information sheet]	3	27 May 2016
REC Application Form [REC_Form_31032016]		31 March 2016
Research protocol or project proposal [Proposal]	6	06 May 2016
Summary CV for Chief Investigator (CI) [chief investigator CV]	3	27 May 2016

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/SW/0118

Please quote this number on all correspondence

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

Yours sincerely

[Redacted signature]

[Redacted name]

Enclosures: *"After ethical review – guidance for researchers"*

Copy to:

[Redacted recipient]

Appendix M: Strategy for the Analysis of Transcripts

Each transcript was read and reread individually, which helped the researcher to enter the participant's world by immersing in the data (Finlay, 2011). A detailed line-by-line analysis was used to make initial notes in the left-hand margin, highlighting the things that mattered to the participant, and the associated meaning (Larkin & Thompson, 2011). The researcher used different coloured pens to make descriptive notes (describing key subjects, phrases or experiences), linguistic notes (exploring the use of language, including metaphors, repetition and fluency), and conceptual notes (more interpretative) (Smith *et al.*, 2009).

The right-hand margin was used to note down emerging themes. The researcher was careful to balance the 'phenomenological' aspects of this method (i.e. grounded in the participant's experiences) and the 'interpretative' aspects (i.e. the analyst's interpretations and conceptual meaning-making) (Smith *et al.*, 2009)

The researcher attempted to explore how the themes might fit together. The themes were written on post-it notes, which were arranged on the floor to help the researcher visually identify clusters. Distance was used to represent connectedness, with similar themes being placed next to one another. Some of these 'clusters' formed superordinate themes. Alternatively, some of the themes seemed so critical, and encapsulated some of the other themes, that they were developed into a superordinate theme. The researcher also kept a tally on each post-it note to keep note of how many times a theme emerged. The frequency in which a theme emerges can sometimes be linked to the salience that the theme holds. Whilst mapping the themes, the researcher tried to keep in mind the narrative nature of the respondent's account, and how each theme fit into this narrative (Smith *et al.*, 2009). A picture demonstrating this process can be found in Figure 3.

Once the researcher felt satisfied with the connections developed between the themes, a table was created to describe the connections observed in the

process of analysis, alongside quotes taken directly from the transcripts to support these observations.

The researcher then moved on to reading the next transcript, treating it as a separate entity and attempting to bracket off emerging ideas from the previous transcript. The previous steps were repeated for each transcript until each transcript has been analysed individually. The researcher then laid out the tables of analyses developed for each transcript to identify connections, similarities, differences, and common themes. The researcher considered whether themes across cases, and whether these reflected higher theoretical concepts. The researcher completed a new table to demonstrate themes for the group, and how each theme is illustrated for each participant; for example by including super-ordinate themes and quotes from individual transcripts.

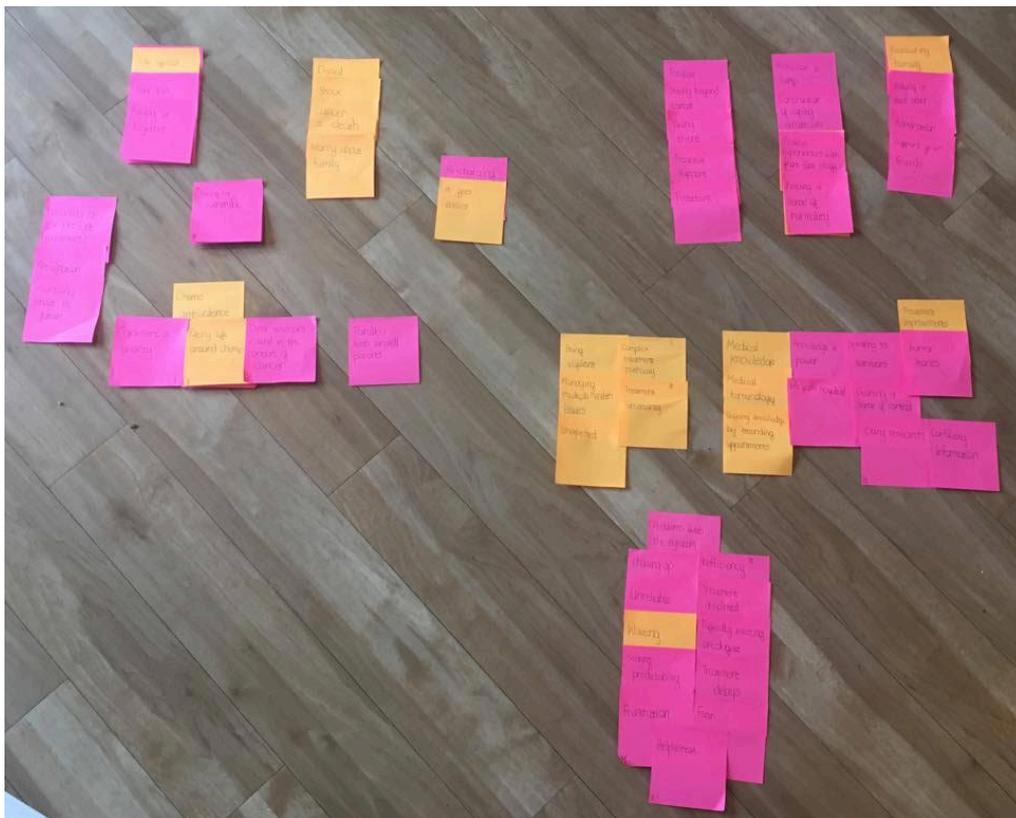


Figure 3 The use of Post-it Notes to Explore the Relationships Between Themes

References

- Finlay, L. (2011). Engaging Phenomenological Analysis. *Qualitative Research in Psychology, 11*(2), 121-141.
- Larkin, M. & Thompson, A.R. (2011). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A.R. Thompson (Eds.). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (1st ed., pp. 99-116). Oxford, UK: John Wiley and Sons.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications.

Appendix N: Examples of Emergent Themes for John, Including Quotes

Emergent Theme	Quotes
<p>Making sacrifices to prioritise her chemo</p>	<p>'My whole thing through this has always been getting [wife] right, you know. I've never been concerned about <i>myself</i> and I've never considered myself or my feelings or emotions or anything', lines 28-32</p> <p>'The breast came off, within 3 or 4 weeks of being diagnosed... So, there was that to deal with, and that... for me... physically, that's, that's not a problem, that never bothered me... The overriding factor in everything is you want this disease out of your body', lines 223-230</p> <p>'We'd got a dream holiday booked to [location] next year, 3 weeks, and we just booked it just before [wife] got diagnosed... So we cancelled it anyway and she was upset, and I said 'no, you won't be ready', you know, 'you won't be ready in yourself, it will be too close to the end of chemo', lines 440-447</p> <p>'Well there's been no intimacy all through this treatment... it's not a massive thing, you know, I want her to live, you know? I want her to <i>live</i> and be healthy, you know, and that's the massive priority', lines 881 - 894</p>
<p>Maintaining hope in the face of uncertainty</p>	<p>'It's an eye-opener. You get to your 50's and this things turns up on your door and it does re-focus the mind definitely. This was a close shave', lines 743-750</p> <p>'And I'm saying 'we've kicked it', you know, or we certainly will in the next few weeks... But always in the back of your mind is... Will it come back?, Will the kids get it? Will it miss their generation? Will one of the grandchildren get it eventually? Do you know what I mean?', lines 959-967</p> <p>'We've probably been more fortunate than most couples in that, [wife] didn't have to hold down a job, and I didn't have to be at a job 9 till 5 so... we've been very, very fortunate, and I, I do know that and I tell myself that every day', lines 628-635</p> <p>'My whole way forward is being positive until something happens that's different, you know, 'We're going to get through this'. And that's what's helped this year, definitely with me', lines 563-567</p>
<p>The hidden fear of losing her</p>	<p>'When she was diagnosed, this is my own thoughts, this is me in my head, but I've never said this to [wife], but she could die. You could lose her. I'm [mid 50s] and you think, what happens next? And many people do lose their wives and partners, there's thousands every week. We had some friend over the road - he lost his wife – breast cancer. We didn't know her very long... that came back to me when [wife] got</p>

	<p>diagnosed -his wife and I could be next. And you don't really want to be thinking about being on your own at [mid 50s]', lines 323-347</p> <p>'These thoughts do come to your mind, the big 'C' word is the dreaded word. It kills thousands of people. So I didn't... and I <i>still</i> think about that, I still me in myself and my own thoughts, 'This could come back and get [wife]', do you know what I mean? So that doesn't go away, that's always there, but I would never, I would never sit down with [wife] and say 'I could lose you', lines 421-429</p>
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Appendix O: Examples of Emergent Themes for Matthew, Including Quotes

Emergent theme	Quotes
Changes as a result of chemotherapy	<p>'My wife is totally different you know... With the illness and the chemotherapy, it is the chemotherapy when you get the chemicals in you body it totally changes you. The whole living of your day-to-day activities ... your sleep pattern's upside down you know, like my wife now sleeps in a separate bed', lines 26-33</p> <p>'When you get the chemotherapy, your whole outlook changes. You could have cancer and you could look okay and then when you get the chemotherapy, makes you look 50 times worse; you loose you skin colour, you loose your hair, your whole demeanour is different', lines 77-83</p> <p>'Well to be honest... it's pretty horrific really. I mean one minute you've got, your wife is lovely and nice and silver hair and smart, and the next minute it's aged her considerably, I mean it's totally different', lines 113-117</p>
Protecting her	<p>'I don't let my wife drive. I thought it better right on day one umm that she didn't drive in case there was any stress involved with her driving on her own umm any incidents or accidents or anything like that, so I do all the driving', lines 56-60</p> <p>'It wasn't who she used to be when she looked in the mirror herself, and I knew that I could see that and umm... you just have to keep saying... reassuring her all that time that, 'You will be fine', there's nothing more you can say really', lines 595-600</p> <p>'But they don't do alternative medicines. I wouldn't let her do <i>that</i>, I think umm. She says, 'Look, is there any vitamins I can take?', but they told us up at the hospital not to dabble in anything like that, just to stick to the treatment plan', lines 691-696</p>
Making adjustments to make her life easier	<p>'Well when she first got diagnosed, I was a bit like a chicken with my head cut off. I started running around and... got this done, I got that done, we bought a new bed and I thought, 'Well, if she is going to be ill, I am going to make sure that the house is really comfortable for her'. And so that's what I did. I made sure that it was 100% comfortable', lines 135-142</p> <p>'I hope that I have given her enough support so that she has an easy time of it, which I'm sure I have. I just get on with it, you know, just keep the house clean, keep it tidy, keep the shopping in, making</p>

	<p>sure there is plenty of fresh foods, put the T.V. on when she wants it, and if she goes to sleep then that's the way it is', lines 481-488</p> <p>'Food is the biggest problem. We are constantly going though. I take her out as often as I can to the supermarkets and her brain says 'ooh, I like that', but when she gets it, it's just rubbish. So the amount of food that we have been throwing away. Soups, you open a soup, she takes one spoonful and she can't stand it. Cooking in the kitchen, I have to shut all the doors and keep the extraction fan on, because she can't stand the smell of food cooking. Homemade soups is just nauseous to her, she says it's like vomit', lines 147-159</p>
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Appendix P: Examples of Emergent Themes for Adam, Including Quotes

Emergent Themes	Quotes
The future as uncertain	<p>'I think the worst thing is probably feeling helpless, not being able to comf-... tell her... Do you know what I mean? 'It is going to be alright' 'cause y-you don't know really, at the end of the day', lines 39-44</p> <p>'It kept going through my head sort of thing, if she does die... How am I going to do everything, and I did, I found that hard to speak to her at first because I didn't want to say to her 'Look, if you do die' because, I don't know if its going to get her upset', lines 522-528</p> <p>'Basically in the back of my mind is, well I was thinking 'is she going to die?'. I mean that's deep down, It's in the back of your mind all the time, and it still is now at the end of the day 'cause it's not cured yet', lines 123-127</p> <p>(Talking about hereditary testing), 'I hope its not, but it's not come back yet so we don't know... deep down I'm hoping it's not. But we'll have to deal with that when we come to it, if it comes to that', lines 937-940</p>
Chemotherapy: a medicine and a poison	<p>(Speaking about the side-effects of chemotherapy) 'She was getting a message, she says 'your calf seems a bit swollen', so then she thought 'well it might be a blood clot or something'. Then she come and got checked but she got the all-clear yesterday so that was good', lines 244-248</p> <p>'It's a poison, isn't it? If you look at chemotherapy; it kills everything, it kills all your good cells and your bad cells, which is a good thing and a bad thing really because you know its going make her really ill, it's going to make her poorly.', lines 256-261</p> <p>'My worry was, was how ill she was going to be when she was on it', lines 269-270</p> <p>'Her immune system's down, so visitors we're going to have to, we had to stop visitors for a week or so while her immune system was right down', lines 284-287</p>
Being positive as a way of coping	<p>'I think positivity definitely helps. When [wife] went on the internet everyone was saying, 'you've got to be strong, you've got to be positive', and she goes, 'well, how do you be positive? How do you be strong?', 'I don't know how I do it' I said, 'You've just got to... try. You just can't be moping around, I think you just keep yourself busy, keep yourself motivated', lines 1039-1047</p> <p>'I just keep thinking to myself 'She's doing well at the moment' so that's the way I look at it now. She's doing really well on the treatment, and it seems to be shrinking, that's why I'm positive at the moment, I just</p>

	<p>keep thinking that she's going to be ok.', lines 1055-1059</p> <p>'[Wife] had an aunty who had cancer: She had it all over her body basically – it was in her brain, it was in her bones, it was in her lungs, it was everywhere. And she beat it, and that was back in the 80's.', lines 577-582</p> <p>'She's had family who's had cancer before, and they've come through it so in the back of my mind I'm saying 'look, you've got to be positive'.', lines 128-131</p> <p>'Trying to stay positive I think is one of the best ones. Obviously you've got in the back of your mind all the time 'oh what happens if this happens, or this happens'. You've got to think 'no'... you try and think to yourself, 'well, don't think like that', because if you start going down that road you will get depressed yourself, so you've got to think positive', lines 633-639</p>
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Appendix Q: Examples of Emergent Themes for Ben, Including Quotes

Emergent Themes	Quotes
Juggling responsibilities	<p>'I work long hours and I do have to try and curtail that because I am aware that she is at home on her own quite often. Particularly when she's feeling bad, she doesn't want to see anyone but that does mean that she's stuck in the house on her own all the time and going a bit stir-crazy, so... I'm quite conscious of trying to get home at a reasonable hour so that has a little bit of an effect on work, which is tricky at the minute because I'm responsible for the unit and also some units abroad... it does just mean I've got to be better at planning', lines 305-323</p> <p>'There's only a certain number of hours in the day... getting up, doing the dogs first thing in the morning, then going out to work all day, trying your best to concentrate on stuff there but then coming home and cracking on and doing all the cooking and everything and finally sitting down in a chair at ten o'clock at night or something like that. Umm, certainly <i>that</i> was kind of hard, that was a bit full-on for a while', lines 767-778</p>
Receiving support from others	<p>'I've got a lady at work actually who went through cancer, umm a number of years ago, and she's been brilliant, in just sort of, you know, just setting my expectations on certain things', lines 639-643</p> <p>'I did get parcels sent from family members. My brother was really good to me, he'd send stews and casseroles, and things where I'd only got to heat it up and throw some potatoes in the oven', lines 359-364</p> <p>'The staff have been good, and that again really, really helps. The advice and information that we've been given has been great. That all helps, you're not left sitting in the dark and thinking 'Well, I wonder what's going on next?'. We've always been kept really well informed, and that helps', lines 710-717</p> <p>'One of my friends basically brought a big carrier bag full of frozen food around, really good stuff, and he just said, 'It's just if you don't get time to go shopping or want to give it a miss or whatever' he said, 'if this helps, it's just, there'', lines 554-559</p>
Seeing her suffer	<p>'Watching her go through the surgery was difficult.', lines 191-192</p> <p>'Yeah, it's just... sort of difficult watching her... when she's feeling poorly', lines 263-264</p> <p>'It's going to be hard to watch her going through that, it'll be harder to watch her going through that than it will be to watch her lose her hair... if that makes sense?', lines 353-357</p>

	<p>'It is difficult, you know, she's always been quite proud of her hair... so to actually be faced with losing that, it's a huge deal for her. And it's probably easier for me to be more sort of matter—of —fact about it, but the fact is, her hair is her crowning glory, and she's going to lose that', lines 1069-1080</p> <p>'Yeah, I mean the physical, the looks side of it will... you know, it's hair, its fine. No, what will be harder is actually the psychological effect of that on her. That will be harder for me', lines 1092-1096</p>
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Appendix R: Examples of Emergent Themes for James, Including Quotes

Emergent Themes	Quotes
Life revolves around chemotherapy	<p>'We used to go out shopping occasionally but it's a case of just going out, if we do go out, we go and come back. Basically if there's shopping we need to do, then we do it going to or back from the hospital', lines 426-430</p> <p>'Cancer is the main thing. Everything revolves around cancer. In fact, the more positive you are, you... umm you have things that you have to do because of the going to the hospital and this, that and the other, we try and put those sort of to one side and if it interferes, then it interferes, but otherwise trying to do the things that you normally do', lines 516-524</p> <p>'After the little bits that are stopping what we normally do. It's not so much the cancer as such, its having to go and do this, having to go and do that, so you can't plan a week's holiday because you've got to go to the hospital then, then, whatever. So it's not the cancer as such, it's the things that you have to do.', lines 858-865</p>
Knowledge is power	<p>'Talking to other people who've had breast cancer and doing research she found out that cancerous cells feed on glucose so cut out anything sugary, cut out carbohydrates, pasta, bread, anything like that, because obviously that turns into glucose', lines 461-466</p> <p>'Biggest thing was the initial shock, but then the more you think about it, the more you look into it, you know, the positivity rein-, really comes back and reinforces itself', lines 509-513</p> <p>'If there's something we don't understand then we go and find out about it and obviously you'll get umm... this chemical, this food, this drink is good for you, that's bad for you and then vice versa, you go on a different websites and it's the opposite way around so ... trying to bring all the things together and use your common sense, 'Does that sound right?'. Umm No matter what you read, its not a cure-all, it's not going to (<i>participant clicks his fingers</i>) flick a switch and get her better, but does it sound right? So that's probably, we mainly do just research, look. So yeah, I think that together with the positivity, the more you look into it, the more you try and understand it, helps as well', lines 558-572</p>
Waiting as a source of frustration	<p>'So that was an hour and a half wait, so that was a bit of a pain', lines 172-174</p> <p>'It's wanting the treatment to be done when it said it was going to be done and finish when it said it was going to be finished, and these steps along the way being done as promised', lines 732-736</p>

	<p>'The start of the process from the initial diagnosis seems to take a hell of a long time because meeting up with the Oncologist, you have to wait for that before actually starting treatment whereas [wife]... wanted it basically saying umm diagnosis, therefore we are starting treatment next week rather than a month. I forget how long it was but it seemed like a month, month and a half, before she got to that point and that was a, you know this cancer is growing inside of me, and its getting bigger and bigger and bigger... you're not doing anything. It's waiting and waiting and waiting. Umm so probably that, the initial umm... speed, if that would have been quicker that would have helped', lines 749-763</p>
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Appendix S: Example of the Researcher's Coding

Disagreed with his wife about whether to go or not
 He would sometimes agree with her to pacify her with no intentions to follow through with what he'd said
 ↳ Is this how he'd manage conflict or disagreements?

65
 581 going, just you're going to Japan'. And I'm sort of
 582 'Right, you know, yeah ok, fine, I'm going to Japan'.
 583 Participant whispers behind his hand 'I'm not going
 584 to Japan!'. You know, 'Sorry guys, I'm not going to
 585 Japan'. Umm... but then, then it was, we were
 586 coming up to virtually the week before the holiday
 587 and Grace was really actually upping the pressure,
 588 'You definitely are going', you know, 'Don't think
 589 that you're not going, I'm not going to spoil your
 590 holiday'. And at that point, that was horrible
 591 because I was just so badly torn... between of
 592 course, ok, yes... I'd like to go on the holiday, but
 593 actually I don't care about that, I don't, really don't
 594 care about the holiday, what I don't want to be
 595 doing is leaving you post-surgery before your
 596 chemo starts, I can't, you know, in all
 597 consciousness, do that. In pure conscience do that,
 598 I should say... Umm but this lady at work, she was
 599 the one who actually said 'Does Grace think you
 600 should go?'. I said 'Yes', 'Well you should go then'. I
 601 said 'Yeah but I can't because this, that and the
 602 other' and she said, 'Because the absolute worst
 603 thing for me when I was going through it years ago
 604 was if anyone had to put anything off that they were
 605 doing, it was because of me and my cancer, that
 606 communicate with someone he is not so
 607 emotionally involved with?

Disagreement on what he should do
 Managing disagreement through appeasement rather than communication.
 Dilemma
 Diff. views on the meaning of the holiday.
 Getting advice from someone who has had cancer

31.

The advice from his colleague seemed to allow Ben to view the dilemma in a different way, enabling him to make a decision.

67 elevated the importance of the cancer. Whereas

67 actually, when things go ahead as normal, as they

67 should be, then that's like putting it back in its box

67 and putting it back in its place', so... trying to get

68 back to your question now... other people, the

68 support from other people has been brilliant and

68 has helped me to cope, umm... I think the fact that I

68 do tend to be fairly laid back... I don't... panic about

68 things, the fact that Grace is, has been you know

68 very, sort of, matter-of-fact and, and coped very

68 well with it, that has obviously helped enormously.

68 The staff at the various, over at the umm, the breast

68 centre and here have just been brilliant, they're so

68 lovely. Just the level of care has just been fantastic,

68 and again that all helps as well, I mean... You

68 know, sometimes if participant sighs when things

68 aren't going well, and with the cancer treatment and

68 everything's been fine, but in, in, as a back sort of

68 drop to this, Grace was actually told after one of her

68 ECGs, that at some point they think she's actually

68 had a... a heart attack, which she wasn't aware of.

68 And it could have been sort of anytime in the last

68 nine years sort of since her last previous ECG.

68 Umm... but some of that getting booked in to the

68 ECG, and they lost her paperwork, umm, sorry for

His own personality helped him to cope

Personality

Her coping impacts on him

Her coping helps him

The staff

Staff

Other health issues not related to the cancer - other stressors can make it more difficult to deal with the cancer.

Heightened awareness of the fragility of health

Highlights how fragile health is - he points out that something went wrong that she wasn't even aware of. I wonder what the impact of this was on him, given that he'd said she rarely goes to see the doctor? What was the meaning to him?

Other health issues heighten stress

He perhaps forgot the name of the procedure

70

631 an echocardiogram, you know, sort of lost her

Problems in the system create stress

* Paperwork lost - difficult on top of everything else

632 paperwork and that, that... is kind of hard to deal

633 with when you're trying to deal with everything as

Things not going as planned and other stresses are hard to deal with because they are already trying to cope with a lot.

634 well, and things don't go smoothly. That... A, just

635 elevates your stress levels, and things, and makes

636 everything worse, but as I say the, you know the

637 care of this unit and over at the umm... I can't

lower stress tolerance levels.

Struggles to remember the name of the unit

638 remember... over at the breast care unit... Can't

639 remember the name of it... anyway. But when the

Having to learn medical terminology

↳ perhaps reflects the amount of new info he's had to learn - eg. medical proced

640 treatment is good, and the staff are being, that

641 again just really, really helps, you know, that sort of

Advice & information from staff.

642 advice and things that you're given, and information

643 that you're given has been, has been great. Again,

Not left without the necessary information

644 that all helps, you're not sort of left sitting in the

645 dark and thinking 'Well, you know, I wonder what's

Seeking advice to gain a sense of control.

Kept informed, not left wondering

646 going on next?' We've always been kept really well

647 informed, and again that helps as well.

Getting advice from staff gave a sense of predictability. There

648 **Interviewer:** Ok, umm this can be quite a difficult

649 question... I wonder what has been the most

seems to be a lot of uncertainty about what

650 difficult thing for you... in terms of coping with this

might happen next, which may be hard to tolerate.

651 experience?

Appendix T: Frequency of Themes across Transcripts

Superordinate themes	Sub-themes	John	Matthew	Adam	Ben	James
Treatment as ‘a necessary evil’	Making sacrifices to prioritise treatment	X	X	X	X	X
	Juggling responsibilities	X	X	X	X	
	Balancing the role of husband and carer	X	X	X	X	X
	Seeing her suffer	X	X	X	X	X
His role as protector	Fighting cancer together, alone	X	X	X	X	X
	Protecting her from my fears	X		X	X	X
‘Support’ as a help and a hindrance	Healthcare staff leading the fight against cancer	X	X	X	X	X
	Time is of the essence			X	X	X
	Supporting me to support her; supporting her to support me	X	X	X	X	
Maintaining hope in the face of uncertainty	Coping with an uncertain future	X		X	X	X
	Pulling the good out of the bad	X	X	X	X	
	Reliance on familiar coping strategies	X		X	X	X
	Struggling to get back to normal	X	X	X	X	X

Appendix U: Full Chronology of Research Process

Date	Actions
January 2015- May 2015	<ul style="list-style-type: none"> • Allocation of research supervisor and consultation regarding research topic • Development of the initial research proposal submitted
May 2015- October 2015	<ul style="list-style-type: none"> • Research proposal developed further based on feedback
November 2015	<ul style="list-style-type: none"> • Research proposal submitted for Internal Peer Review at the University of Leicester • Research proposal submitted for Service User Reference Group (SURG) review • Preparation of documents on IRAS for submission to LREC.
December 2015	<ul style="list-style-type: none"> • Identification of field supervisor and consultation regarding the research topic • Commenced R&D application
January 2016	<ul style="list-style-type: none"> • Feedback from Internal Peer Review received
April 2016	<ul style="list-style-type: none"> • 18th April 2016 - LREC sub-committee meeting to consider research. Favourable opinion received 22nd April 2016.

May 2016	<ul style="list-style-type: none"> • 6th May 2016 – Amendments made and letter sent back to LREC with an update of the changes. • 19th May 2016 – LREC considered research again. Requested further changes. • 27th May 2016 – Researcher made further amendments to research protocol and provided evidence to LREC.
July 2016	<ul style="list-style-type: none"> • 7th July 2016 – LREC granted ethical approval
August 2016	<ul style="list-style-type: none"> • R&D approval received 26th August 2016
September 2016 – April 2017	<ul style="list-style-type: none"> • Recruitment and interviewing participants • Transcription
April 2017	<ul style="list-style-type: none"> • Application for deadline extension
January 2017- April 2017	<ul style="list-style-type: none"> • Write up
May 2017	<ul style="list-style-type: none"> • Submission of Thesis to University of Leicester
May 2017-July 2017	<ul style="list-style-type: none"> • Viva preparation