EXPLORING THE PSYCHOSOCIAL IMPACT AND SUPPORT NEEDS OF MEN WITH BREAST CANCER FROM THE PERSPECTIVES OF PATIENTS, INFORMAL CARERS AND HEALTHCARE PROFESSIONALS

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Abstract

Although rare, the prevalence of Breast Cancer in Men (BCiM) is increasing worldwide. It is commonly perceived as a female disease, despite being responsible for proportionally more deaths annually than some male-specific cancers such as testicular cancer. There is often a lack of awareness of BCiM and the role their Informal Carers (ICs) play in supporting men with the disease. Little research has explored the psychosocial impact of BCiM on patients and their ICs. This PhD aimed to address this gap by conducting three complementary studies to gain a holistic understanding of the impact of the disease from multiple perspectives.

Study 1 was an exploratory online mixed methods study conducted with 87 men in nine countries worldwide who had received a diagnosis for breast cancer. The study explored their experiences, body image concerns, quality of life and masculine self-esteem. The results guided study 2 which interviewed 12 ICs of men with breast cancer in the United Kingdom (UK) and explored their experiences and psychosocial support needs. Together, the results emphasised the lack of awareness of BCiM among both healthcare professionals (HCPs) and the general public, inappropriate provision of support materials, lack of social and emotional support and an overwhelming sense of isolation for both men with breast cancer and their ICs. Study 3 was an online survey with 62 UK-based HCPs with experience of working with patients with breast cancer. The study explored their experiences and perceptions of the support needs of men with breast cancer and their ICs. The results highlighted that they provide a variety of resources and support to these groups, although most feel these are unsuitable for this population.

This body of work explored previously unresearched areas and the results make a novel contribution to the literature. The use of different methods and the involvement of patients, ICs

and HCPs provide an increased understanding of the wider context in which BCiM occurs. Collectively, the studies highlight the negative psychosocial impact of BCiM and a lack of appropriate support, which is often challenging and isolating for both men with breast cancer and their ICs. The findings from patients, ICs and HCPs indicate the current available sources of support for this population to be overwhelmingly unsatisfactory, inappropriate and insufficient. There is a vital need to raise awareness of BCiM, to include more men in breast cancer research and an urgent requirement for the provision of support specifically tailored to men with breast cancer and their ICs. Finally, the work identified important areas of future research and recommendations needed to improve the current provision of support and information for all men with breast cancer and their ICs. These include professional education and training of HCPs on the information and resources available and a proposed stepped care approach to the provision of evidence-based psychosocial support for men with breast cancer and their ICs.

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Chapter one: Introduction

1.1 Thesis structure

The thesis has been divided into the following chapters:

- Chapters 1 to 3 present the structure of the thesis, literature review and methodology and outlines the psychosocial approach to the PhD.
- Chapters 4 to 6 present three research studies and their findings.
- Chapter 7 presents the final general discussion, which triangulates the findings and identifies points of congruence and/or divergence between the perspectives of patients, ICs and HCPs. Practical implications and recommendations for future research are also outlined.

1.2 Writing style

The thesis is written in the third person, apart from the reflective components which are written in the first person. The researcher engaged in reflective practice throughout the PhD and has incorporated reflexive sections at the end of each study. These provide situated and reflexive personal accounts of aspects of the research process including the methodology, PPI and lessons learned. There is a larger reflective section in the final general discussion chapter (section 7.15) which includes a reflexive overview of the PhD.

1.3 Doctoral descriptors

A list of the Doctoral descriptors at UWE Bristol and an outline of where these are demonstrated in the current thesis is presented in Appendix 1. The reader is also signposted to these throughout the main body of the thesis.

1.4 Terminology

1.4.1 Breast cancer in men (BCiM)

The researcher recognises how language surrounding breast cancer in men continues to evolve. It is acknowledged that the term male breast cancer (MBC) is often used in published literature, however, medical terminology does not generally refer to the gender of the patient. Furthermore, following feedback and discussions with patient advisors and contacts throughout the PhD, BCiM is considered a less contentious term, as MBC may be misconstrued as being a type of breast cancer. Therefore, in the absence of a consensus and for clarity and consistency, the term BCiM will be used throughout the thesis. The term 'patient' has been used interchangeably with 'BCiM patient' or 'men with breast cancer'.

1.4.2 Informal carers (ICs)

The term ICs is commonly used to refer to someone who actively participates in sharing the patient's illness experience on a practical and/or emotional level. It does not include those who provide professional paid care (for example, nurses) or the voluntary sector (for example, charities and support groups). Most ICs are wives, husbands, partners, children, relatives, and friends of men with breast cancer. A more detailed description of the role of ICs is provided in chapter 2 (section 2.6).

1.4.3 Medical and technical terminology

The medical and technical terms used within this thesis are defined in the glossary in Appendix 2.

1.5 Setting the scene

1.5.1 The Centre for Appearance Research

This PhD was undertaken at the Centre for Appearance Research (CAR), based at The University of the West of England, Bristol. CAR is the world's largest research group focusing on the role of appearance and body image in people's lives. It is also a centre of excellence for psychological and interdisciplinary research in appearance, visible difference, body image and related studies. Among other areas of interest, research is undertaken which explores the psychological and social impact of living with cancer and the impact of cancer treatment on appearance. Ultimately, the research conducted at the centre aims to make a real difference to the lives of people living with appearance altering conditions.

1.5.2 The impact of the Covid pandemic on the PhD

The PhD commenced in January 2019 and the global pandemic of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes coronavirus disease 2019 (Covid), spread to the UK in January 2020. Transmission within the UK was confirmed in February, leading to an epidemic with a rapid increase in cases in March. On March 11th, 2020, The World Health Organisation declared the outbreak a pandemic of Covid.

Consequently, the pandemic was present and evolving throughout most of the PhD, and life was constantly impacted. Government restrictions and guidelines were placed on people to slow the spread of the virus. Measures ranged from full lockdown (including stay-at-home orders, schools, universities and non-essential shops and services closed, travel restrictions, prohibited households meeting and social movement was limited to 15 minutes exercise per day) to social distancing, working from home and mandatory face mask-wearing. Some restrictions were eased in 2020 as the virus weakened, however, there were subsequent lockdowns, and the ever-changing landscape of the pandemic continued to present challenges. Social interaction finally returned to ‘normal’ in 2022, towards the latter stages of the PhD.

The impact of Covid on each study is addressed and reflected upon in the corresponding chapters. In the final general discussion chapter, a reflexive section presents an overview of the impact of the Covid pandemic on the PhD as a whole (chapter 7, section 7.14). This includes reflections on issues faced, obstacles encountered, and lessons learnt from both a personal level and researcher perspective.

1.6 Literature in this thesis

This section will outline how the literature will be presented and incorporated throughout the thesis. Firstly, a review of the literature will be presented in a chapter 1. This will provide an overview of the pertinent issues surrounding BCiM and outline gaps in the literature conducted to date. It will also serve to situate this body of research and establish the aims and rationale of the PhD. Secondly, research will be presented at the beginning of each study to guide the research aims. Thirdly, at the end of each study, literature will be used as a basis for comparing findings. Related literature will again be integrated in the final general discussion chapter.

The initial literature review was conducted at the outset of the PhD in 2019 and updated throughout. Several strategies were integrated to stay up to date with new research published in the field: Firstly, authors who had published in the area were followed on Google Scholar and email alerts were received regarding new publications, papers which cite them, as well as new articles related to their research. Secondly, EBSCO search alerts were emailed monthly, which enabled an advanced search, across a range of databases (including AMED, Medline, CINAHL, PsycInfo and PscyArticles). A list of the search terms used is included in Appendix 3. Thirdly, several researchers were followed on ResearchGate which provided updates on their new publications. Finally, several academics were followed on Twitter which proved a good way to keep abreast of their work in the area.

In accordance with the doctoral descriptors, this chapter demonstrates a critical understanding of the current state of knowledge in the field.

Chapter two: Literature Review

This chapter will firstly present an overview of the topic. Secondly, a literature review of the main psychosocial issues facing men with breast cancer is presented. This will serve to contextualise the research. Finally, the rationale and aims of the thesis will be stated.

2.1 Overview of BCiM

Breast cancer is a disease in which abnormal cells in the breast tissue begin to grow and divide in an uncontrolled way and eventually form a growth (tumour). The most common type of breast cancer in men, as women, is invasive breast carcinoma, where cells have spread through the lining of the ducts into the surrounding breast tissue. Some also develop rarer types of breast cancer, such as invasive inflammatory breast cancer. Men may also develop conditions related to breast cancer, including ductal carcinoma in situ (DCIS), invasive lobular cancer and Paget's disease of the breast, although these are very uncommon (Cancer Research UK, 2020).

2.1.1 Epidemiology

Breast cancer is the world's most prevalent cancer (World Health Organisation, 2021). Although common in women, it is rare in men (Konduri et al., 2020); In the UK, 1% of breast cancer cases are male; approximately 370 men are diagnosed and around 85 men die annually from the disease (Breast Cancer Now, 2021). However, BCiM is responsible for proportionally more male deaths annually than some male-specific cancers such as testicular and penile cancer (Cancer Research UK, 2022/WHO 2021). The lifetime risk in the general female population is 12%, whilst it is 0.1% in the general male population (Sonnenblick et al., 2018). The median age at initial diagnosis of invasive breast cancer is typically older in men than in women (68 vs. 62 years)

(Giunta et al., 2017). The prognosis of male breast cancer patients is worse than female patients, and the overall survival rate for men with breast cancer is 82.8% compared to 88.5% in women with breast cancer (Wang et al., 2018; Younas et al., 2019). In a study which identified 19,785 male patients with breast cancer from the National Cancer Database (2004-14), the overall median survival for females was 13.2 years vs 11.4 years for male patients. The higher mortality rates among men may be due to a variety of factors, such as socioeconomic status, lack of awareness and subsequent late detection (Konduri et al., 2020).

The prevalence of male breast cancer is increasing worldwide (Konduri et al., 2020; Ruddy & Winer, 2013a; Siegel et al., 2016). More research is needed to understand whether the rise in the number of BCiM can be attributed to unhealthier lifestyles, rising obesity levels, environmental factors or more men presenting with symptoms (Breast Cancer UK, 2021). It is estimated that approximately 2,800 new cases of invasive breast cancer in men will be diagnosed in the United States (US) for 2022 (American Cancer Society, 2023), whilst in Australia, 212 new cases are estimated annually (Cancer Australia, 2023). Incidences of male breast cancer rates are higher in Africa compared with Europe and the US (Ndom et al., 2012).

Research has shown racial and ethnic differences in prevalence of men with breast cancer. African American men have higher incidence of breast cancer than white men and are also more likely to be diagnosed at a younger age (Sineshaw et al., 2015). Race is a significant prognostic factor. Black men have significantly worse overall survival compared to other races (White, Hispanic, and Asian), which may be due, in part, to more advanced disease presentation (Shin et al., 2014). Additionally, Black men with breast cancer have a higher risk of mortality than their White counterparts, although the differences reduce after adjustment for insurance levels and income (Sineshaw et al., 2015). This may be linked to lower socioeconomic status, barriers to health care and in the US, a lack of adequate insurance coverage (DeSantis et al., 2019). However, no research to date has specifically explored differences in BCiM incidence by ethnic group in the UK. Black men also have less awareness of breast cancer (Rayne et al., 2017) and tend to present with advanced-stage disease, larger tumour sizes, higher grade tumours, more lymph node metastases, and fewer hormone receptor positive tumours compared to their White counterparts (Korde et al., 2010).

Jewish men, especially those of Ashkenazi origins, are at higher risk of developing breast cancer than the rest of the population. This may be linked to the higher rates of breast cancer gene abnormalities, BRCA1 or 2 gene mutations, in the Ashkenazi Jewish population (Laitman et al., 2015).

2.1.2 Risks factors for developing BCiM

Whilst the exact cause of BCiM is unknown, there are several risk factors associated with the disease. Older age is the single biggest risk factor (Cancer Research UK, 2020), with the average age of onset of the disease being 67 years (Methamem et al., 2020). However, cases of the disease have been reported in male adolescents and young adults (Flaherty et al., 2017).

Men who have a significant family history of breast cancer are at heightened risk of developing the disease. BRACA genetic mutations also increase the risk (Lukong, 2017), with approximately 10% of male cases having BRCA2 mutations, whilst less than 1% are associated with BRCA 1 mutations (Sousa et al., 2013).

Breast cell growth, both normal and abnormal, is stimulated by the presence of oestrogen. High oestrogen levels from taking hormonal medicines, being overweight, excess alcohol consumption, liver disease and exposure to oestrogens in the environment can elevate the risk of men developing breast cancer (Cancer Research UK, 2020).

Some genetic conditions, such as Klinefelter's syndrome (men who have one or more extra X chromosomes and have endocrine abnormalities) is characterised by hypogonadism and low testosterone levels and has been associated with an increased risk of BCiM (Swerdlow et al., 2005). Klinefelter's syndrome (XXY) is associated with a 50-fold increase in incidence of BCiM compared with XY males (Fentiman, 2018a). Recent research has shown that risk of breast cancer is increased for infertile men, although the reasons are not clear and warrant further investigation (Swerdlow et al., 2022).

Occupational risks including exposure to high temperatures (e.g., blast furnaces, steel works and rolling mills) can elevate risk, possibly because long lasting exposure to high ambient temperatures can lead to testicular failure. Exposure to radiation, including receiving treatment with radiation to the chest for conditions such as for Hodgkin lymphoma, can also increase the risk of men developing breast cancer (Giordano, 2018).

2.1.3 Clinical features of BCiM

As men have a paucity of breast tissue, the nipple is mostly involved at early stages of breast cancer and tends to be in the areolar region (Korde et al., 2010). The most common symptom in men, as in women, is a painless breast lump. Other presenting symptoms can include nipple retraction and discharge, a rash on or around the nipple, swelling and ulceration of the skin

(Fentiman, 2018a). Cancer is more likely to be diagnosed in the left breast than the right breast among men (Goodman et al., 2006) and less than 2% of cases are bilateral (Caridad Rubio Hernández et al., 2013)

The rarity, low levels of awareness of BCiM in the public and the lack of mammographic screening in men often results in a delay of recognition and advanced clinical stage diagnosis (Monticciolo, 2020). Consequently, diagnosis is often late, with more than 40% of men presenting with advanced or metastatic disease (stage III or IV) at diagnosis (Fentiman, 2018). This compares with 6% of women who have metastatic breast cancer when they are first diagnosed (Cancer.Net, 2023).

2.1.4 Differences in male and female breast cancer

While there are similarities in male and female breast cancer, there are important biological, epidemiology and prognosis differences (Chen et al., 2012; Fentiman, 2016; Gucalp et al., 2018). Results of a critical review highlighted how BCiM is not congruent with the female disease (Fentiman, 2016). A key biological difference between men and women is tumour type. In more than 90% of male patients, the tumour is oestrogen receptor positive (ER+), whereas in female breast cancer, it is between 60–70%. Additionally, the molecular profile indicates that BCiM and female breast cancer are very different diseases (Fentiman, 2016).

However, despite these substantial differences, treatment recommendations for BCiM are based on trials of female breast cancer (Fentiman, 2016; Methamem et al., 2020). There is a call to recognise these important biological differences and develop new treatments for BCiM which are based on differences rather than similarities with female breast cancer (Fentiman, 2016).

2.1.5 Treatment options for men with breast cancer

Despite the unique characteristics that distinguish BCiM (Massarweh & Choi, 2016), there is currently no standard of care which exists specifically for male patients (Gucalp et al., 2018). Treatment recommendations and options are generally based on data derived from clinical trials of women with breast cancer (Corrigan et al., 2020; Fentiman, 2018; Hassett, 2020). Treatment depends on the stage and type of the cancer and may include surgery, with or without radiation therapy, chemotherapy, hormonal therapy, and/or targeted therapy (Konduri et al., 2020). Treatment choice may also be influenced by the often-advanced stage at diagnosis as well as high rates of age-related comorbidities (Ottini et al., 2010).

Due to the rarity of the disease in men, there is an under-representation of male patients in research studies (Konduri et al., 2020; Mistry et al., 2015). An analysis conducted of 131 breast cancer randomised clinical trials reported that male patients represented only 0.087% of the total study population (Corrigan et al., 2020). Furthermore, to date, no randomised control trials have been conducted to determine optimal surgical management for male patients (Fentiman, 2018).

2.1.6 Appearance and bodily changes resulting from treatment

All treatment options for male breast cancer can produce various temporary and permanent changes in a patient's physical appearance.

The current surgical gold standard of BCiM is modified radical mastectomy (MRM; Giunta et al., 2017), performed in 75-100% of male cancer patients (da Silva, 2016; Giunta et al., 2017; Korde et al., 2010). This is primarily due to the male breast anatomy and the paucity of breast tissue in men (Korde et al., 2010; Moelans et al., 2018). Surgery for breast cancer can result in breast and arm Oedema (swelling caused by excess fluid trapped in the body's tissues), breast tissue fibrosis (fibrous tissue in an area of the breast) and decreased range of upper arm body mobility (da Silva, 2016). This typically results in an altered appearance, including scarring, a flat or concave chest appearance, asymmetry, and the removal of the nipple (Donovan & Flynn, 2007; Schaverien et al., 2013; Thompson & Haydock, 2020; Vinayagam & Williams-Jones, 2013).

Results frequently include a long transverse scar, which can have a poor overall aesthetic appearance (Levin-Dagan & Baum, 2022). Men are rarely offered reconstructive surgery, although there has been debate about whether men should be offered breast conservation or reconstruction (Wardle et al., 2020).

BCiM is hormone-receptor-positive in 80–90% patients and Tamoxifen is the gold standard adjuvant endocrine therapy for men with hormone-receptor-positive breast cancer (Eggemann et al., 2018). This is often recommended to be taken for five years and is administered in 65-100% of male patients (da Silva, 2016; Eggemann et al., 2018). Side effects can include weight gain, sexual dysfunction, loss of libido, neurocognitive deficits, bone pain, leg cramps, mood alterations, depression, insomnia, gastrointestinal disturbance, increased risk of thrombosis and cataracts. Menopause-like symptoms can also be experienced, including tiredness and hot flushes (da Silva, 2016; Eggemann et al., 2018; Pemmaraju et al., 2012). Side-effects related to Tamoxifen can pose significant challenges to quality of life and well-being, which may lead to problems with patient compliance (Giordano, 2018; Pemmaraju et al., 2012). The discontinuation of medication by patients may lead to serious consequences, and ultimately, can cost lives (Pemmaraju et al., 2012; Visram et al., 2010).

Men who undergo chemotherapy as part of their breast cancer treatment may also experience changes to their appearance, including alopecia; the loss of both head and body hair (Trusson & Quincey, 2019). The impact of these changes on men's perceptions of their body image are explored in section 2.3 and how appearance changes may challenge their perceptions of masculinity in section 2.4.

2.2 Psychosocial issues which affect men with breast cancer

Research to date has highlighted that there are several overarching psychosocial factors which are likely to influence the experiences of men with breast cancer. These are 1) lack of awareness; 2) body image and appearance related concerns and 3) impact on masculinity. Appendix 4 provides a summary of the psychosocial research conducted to date involving men with breast cancer, methodologies and core findings. A critical review of the research in these core areas will now be presented.

2.2.1 Lack of awareness of BCiM

Despite the increase in numbers of BCiM, evidence suggests there is poor awareness among both the general population and health care professionals. These areas will now be explored in greater depth.

2.2.1.1 Lack of awareness among the general population

Several studies have explored awareness of BCiM around the world. Research in Canada with twenty men with breast cancer revealed most participants (*n*=18; 90%) had not known the disease could affect men (Pituskin et al., 2007). Comparably, in the UK, only 40% of participants (*n* = 64) had heard of the condition prior to their diagnosis (Iredale et al., 2005). In the US, interviews with 28 men at higher risk for developing breast cancer (with no personal history of breast cancer, but with at least one maternal blood relative with the disease) found that 79% of participants were unaware that men could get breast cancer, and did not know how to identify signs and symptoms (Thomas, 2010). Al-Naggar and Al-Naggar (2012) interviewed randomly selected male university students in Malaysia (*n* = 36) to examine the perceptions and opinions about BCiM and breast self-examination. Most believed there was a low probability of men developing the disease, with widely reported perceptions that the cause of BCiM was the carcinogens from cigarettes. Furthermore, self-examination was felt to be unimportant for men due to the low probability of getting the disease.

In more recent research, Faria et al., (2021) conducted an exploratory quantitative study (*n* = 299) in Brazil to explore the awareness and knowledge about BCiM among higher education male students (median age 24 years). The majority (65.9%) did not know about BCiM, 66.9% thought it was possible to successfully treat the disease, while 31% thought there was no cure. Regarding predisposing factors in the development of BCiM, most respondents (77.3%) thought that there were no predisposing factors, 68.9% did not know how to perform a self-examination, whilst 76.6% reported having no knowledge of signs and symptoms of BCiM.

In India, a survey of men from the general population in urban Delhi (*n* = 100), highlighted the majority (81%) were unaware breast cancer could affect men (Goyal et al., 2020). Finally, a retrospective study with men with breast cancer in Hong Kong (*n* = 56), showed the majority (*n*= 26; 83.9%) were unaware of BCiM prior to diagnosis (Co et al., 2020).

Although these studies were conducted in isolation and most study had a small sample size, collectively, they clearly demonstrate a poor level of awareness among the general population of BCiM around the world. Ultimately, lack of awareness often results in delays in seeking medical attention, late presentation and poor prognosis (Co et al., 2020), which may result in men with breast cancer facing breast cancer isolated and alone.

Due to the general lack of awareness of BCiM, concern about the reaction of others and perceived stigma associated with being a man diagnosed with what is commonly perceived as a female disease, many men with breast cancer choose to conceal their diagnosis (Donovan & Flynn, 2007; France et al., 2000; Iredale et al., 2005; Midding et al., 2018; Pituskin et al., 2007; Thompson & Haydock, 2020b). For example, one participant in the cited research did not tell anyone about his diagnosis, apart from his wife, for ten years (Thompson & Haydock, 2020). This meant that during this time, even his children did not know he was living with breast cancer. For others, the perception of breast cancer as a gendered illness resulted in some participants referring to the illness as "chest cancer" when disclosing their diagnosis (Walker & Berry, 2019). The concealment of diagnosis for men with breast cancer may negatively impact potential practical and emotional support and may lead to isolation, as they experience the disease alone.

2.2.1.2 The 'Pinkification' of breast cancer and its impact on low societal awareness of BCiM

The first breast cancer campaign was founded in 1992, by the late Evelyn H. Lauder, to raise awareness about the importance of breast health and to place breast cancer at the public forefront. Today, there are numerous campaigns around the world and October has become known as Breast Cancer Awareness Month (Sulik, 2012).

Although the campaigns have undoubtably raised awareness of the disease, promoted screening and early diagnosis (Patel et al., 2020), the use of the signature pink ribbon (the internationally recognised symbol of breast cancer awareness) serves to portray breast cancer as a female only condition (Sulik, 2012). The colour pink is widely considered to be a visual marker of femininity, traditionally associated with gender and sexuality (Sulik, 2012). Campaigns construct mainstream contemporary understanding of the disease (Gibson et al., 2014) and consequently serve to reinforce gender misconceptions that breast cancer only affects women (Francis, 2018; Quincey et al., 2016; Sulik, 2012; Thompson & Haydock, 2020).

Studies have explored the impact of breast cancer campaigns; Pituskin et al., (2007) showed how participants were aware of public health campaigns which promoted breast cancer in women but were not aware of the disease in men, as they were not mentioned in any of the campaigns. Further research showed how men (without a personal history of breast cancer) associated the pinkness of campaigns with femininity and female breast cancer and were reluctant to wear a pink ribbon (Rabbee & Grogan, 2016).

Thompson and Haydock (2020) interviewed men (*n* = 17) in the USA. Their research investigated men's experiences with their breast cancer diagnosis and post-mastectomy lives in two incompatible cultures (namely, the pink ribbon culture of breast cancer and the everyday ideals of masculinity and the male body). Some participants felt marginalised by the feminisation of the disease constructed in breast cancer awareness campaigns:

"We're men in this pink world and it's uncomfortable" (p.33).

These findings were supported by Quincey et al., (2016) whose qualitative synthesis of men's accounts of living with breast cancer explored how current campaigns serve to reinforce the perception of breast cancer as a women-only disease and marginalise men with breast cancer. The 'pink ribbon culture' was felt to disregard the illness in men, resulted in delayed detection of breast cancer and negatively impacted support. The strength and dominance of the pink ribbon were encapsulated by a male participant with breast cancer in research conducted by Halls (2013);

> *"For men with the disease, it's like swimming against a tide of pink'* (p.204).

The evidence presented clearly demonstrates how the prevailing pinkness of breast cancer awareness campaigns, which focus on women with breast cancer and continue to exclude men with the disease, serve to perpetuate a general lack of awareness of BCiM among the general population. As a result, men may feel isolated and alone when diagnosed with an illness which continues to be constructed as a female disease.

Campaigns in the UK, such as Walk the Walk, have aimed to include men by designing pink t-shirts with a blue bra to represent BCiM, which were co-created with male patient survivors (www.walkthewalk.org, 2023). Some men with breast cancer strongly support the initiative and feel the t-shirts symbolise men can also get breast cancer (Jenkins, 2018). However, PPI in this PhD questioned the pink colour of the t-shirt and felt strongly that the bra did little to represent BCiM.

How breast cancer awareness campaigns may impact masculine self-esteem and perceptions of masculinity following diagnosis is discussed further in section 2.4.2.

2.2.1.3 Lack of awareness of BCiM among HCPs (and female patients with breast cancer)

There is often a general lack of awareness of breast cancer in men from HCPs and men have reported having to attend several medical consultations before their concerns were taken seriously (Quincey et al., 2016). This was further evidenced in Halbach et al.'s (2019) study in which physicians only assumed 62.8% of male patients presenting with suspected symptoms of cancer were related to breast cancer. Participants also reported a wide disparity of experiences during the diagnostic phase. Whilst some men were immediately referred for further tests, others experienced delays, as healthcare professionals failed to recognise their symptoms or recommended a 'wait-and-see' approach. These findings were supported in a qualitative study with the female partners of men with breast cancer in Denmark (Egestad et al., 2019). A main theme in this research was "A wall of ignorance" which encapsulated the lack of knowledge of BCiM among health care professionals. One participant stated;

> *"We had a consultation with a young female doctor…. she told us, "He could experience vaginal bleeding." (p.4).*

The lack of knowledge among HCPs can foster uncertainty and a sense of distrust among male patients (Egestad et al., 2019).

Additionally, research has shown hospital settings to be inappropriate and reflect a lack of awareness of the needs of male patients with breast cancer. Throughout the diagnostic process for symptomatic men and whilst undergoing mammography, men reported feeling uncomfortable and awkward in a predominantly female environment (Brett et al., 2014). Breast imaging centres are often designed for women and consequently feel 'female-centric' and ‘gender-exclusive’ (Walker & Berry, 2019). A study in Canada with men with BRCA gene mutations and an increased risk of breast cancer, reported how undergoing mammography made them feel awkward and out of place. The process of having a mammography resulted in men expressing sentiments of *“othering”* and *“excluding”,* as it is traditionally viewed as a procedure for women (Skop et al., 2018, p. 966). Similar findings were reported in research with men with breast cancer in Germany where all breast cancer patients are treated in outpatient gynaecology practices and hospital gynaecology departments (Halbach et al., 2019). Due to the female only wards, men reported single rooms having to be arranged specifically for them which left them feeling excluded. Furthermore, the pervasive female environment resulted in some participants feeling very uncomfortable and isolated. Such sentiments were supported by Sime (2012), who reported that a participant who attended appointments in a gynaecology department in the UK felt so out of place and uncomfortable that he pretended to be a doctor in order to overcome the embarrassment.

Further research has shown how men with breast cancer are at times made to feel uncomfortable and unwelcome by hospital staff. Participants reported how clerical staff questioned their presence, and often presumed they were accompanying their wives to an appointment and not there for their own treatment (Walker & Berry, 2019). Others experienced insensitive and embarrassing interactions with healthcare staff, including being called “Mrs” (Sime, 2012, p. 146) whilst another recounted;

> *“I think I was called as ‘Mrs. Miller’ once (laughing). Something like this is also unpleasant.”*
>
> (Midding et al., 2018, p2219).

The behaviour of female patients with breast cancer can also leave male patients feeling awkward and uncomfortable. Men reported feeling scrutinised and viewed with suspicion by the women in the waiting areas at breast cancer departments (Sime, 2012), whilst others received *‘questioning glances’* and uncomfortable comments from women in the same waiting area;

> *“I remember that woman in the breast cancer clinic. She said: ‘What do YOU want here? (Laughing) You don’t belong here.’”*
>
> (Midding et al., 2018a, p. 2198)

The evidence presented in this section clearly demonstrates how men with breast cancer frequently experience unsatisfactory treatment due to a lack of awareness of BCiM among healthcare professionals. This can foster uncertainty and may lead to a sense of distrust in patients. The findings also show how men are often made to feel unwelcome and uncomfortable by remarks made by female breast cancer patients as well as the unwelcoming, predominantly female breast cancer setting. These factors often leave men feeling isolated and alone.

2.2.1.4 Lack of awareness of the need for gender appropriate materials for men with breast cancer

There are gender disparities in the provision of materials provided to men with breast cancer compared to female patients, and insufficient male-specific information. Women with breast cancer frequently receive pre-surgical information and decision aids providing information about surgical options (e.g., mastectomy or breast conserving surgery), treatment (e.g., chemotherapy and/or endocrine therapy) and breast reconstruction (e.g., fat grafting, implants, tissue transfer). Furthermore, they are often provided with information on nipple reconstruction, tattooing, scar revision and wigs (Clarke et al., 2020; Zdenkowski et al., 2016). However, information provided to men with breast cancer often lacks relevance and includes irrelevant content which affect only women, such as bra fittings, menstrual functioning and vaginal dryness (Egestad, Gyldenvang, & Jarden, 2019; Farrell et al., 2014). Information and decision support specifically for men with breast cancer are lacking and there is a paucity of information materials designed to explain male body image changes resulting from the disease and its treatment (Fentiman, 2018). There is a further lack of information regarding side-effects of breast cancer treatment, including the impact on treatment on sexual dysfunction or how a changed body image may cause significant distress (Donovan & Flynn, 2007).

A study by with men with breast cancer in the UK (*n* = 161) reported that 92% received only verbal information about their breast cancer, with 71% (*n* = 114) receiving leaflets and 53% (*n* = 85) booklets, and 20% (*n* = 32) had used the internet for information (Iredale et al., 2005). Much of the information received was inappropriate and covered topics such as menstruation, vaginal dryness, breast reconstruction and bra fitting. Only 12% (*n* = 19) saw a photograph prior to their surgery, however, the authors do not stipulate the content of the photograph and do not indicate whether it was illustrating potential post-surgical results of a male after a mastectomy. More than half the participants (56%, *n* = 90) wanted to receive more information specific to BCiM. However, due to the increase in internet use, this figure is likely to be much higher today.

The lack of information was further supported in research by Sime (2013) who interviewed men with breast cancer in the UK (*n*=19). Ten (53%) said they did not get enough written information and felt there was a general lack of information for men with breast cancer. Eight men (42%) said they had received enough information, but only three of these had read the information.

Nine men discussed the inappropriate content of the information which had been written for female breast cancer patients and failed to mention men nor provide advice for male patients with breast cancer.

The under-representation of men in patient information resources can be a major concern for men with the disease (Pituskin et al., 2007) and can lead to men feeling ill-informed and marginalised (Quincey et al., 2016);

> *"EVERYTHING [information] is for women. There's nothing suitable [for men with breast can- for a man with breast cancer], so you feel like you're totally misplaced."*
>
> (Egestad et al., 2019a, p. 4).

2.2.1.5 Summary of section

Research in this section has spanned from 2000 to 2019 and represents men's experiences of breast cancer in a variety of countries. Throughout this time, the concerns facing men with breast cancer around the world have remained largely unchanged. Low awareness among HCPs can lead to delays in diagnosis and treatment, this coupled with a lack of awareness among the general public can result in awkward and distressing situations at an already difficult time and may lead to a lack of confidence in their treatment. Furthermore, the body of evidence presented shows a lack of gender specific information provided to men with breast cancer and the under-representation of men in patient information resources.

The next section will address the second psychosocial issue identified in the literature facing men with breast cancer; body image and appearance related concerns. It will examine research conducted to date which has explored the impact of treatment on body image and appearance related concerns in men with breast cancer.

2.3 Body image concerns

As discussed in section 2.1.6, men who undergo treatment for breast cancer may experience various temporary and permanent changes in physical appearance as well as functional impairment.

2.3.1 Definition of body image

Body image is a fluid, multidimensional construct defined as "a person's perceptions, thoughts, and feelings about his or her body." (Grogan, 2021). It is related to both the functioning and appearance of the body (Teo et al., 2016) and is influenced by many internal and external factors (Cash & Pruzinsky, 2004). It encompasses both the perspective of one's appearance based on self-observation, and the reaction of others (Rhoten, 2016). It is a subjective measure, and objective assessment of an altered appearance or function, which does not always correspond to the degree of distress experienced (Rumsey & Harcourt, 2004). Body image can be significantly impacted by disease and functional loss experienced due to treatment (Manier et al., 2018). Body image concerns can be a critical psychosocial issue for patients with cancer (Paraskeva, Clarke & Harcourt, 2018), as the disease and its treatment can result in profound changes to one's appearance and/or bodily functioning (Fingeret et al., 2014).

However, to date, only one study conducted with men with breast cancer has used a standardised body image measure to quantify the extent to which they are impacted by changes to their appearance. Brain et al., (2006) administered the Body Image Scale (Hopwood, 2001; a 10-item measure of body image changes in patients with cancer) in a cross-sectional survey to determine the prevalence of psychological distress in men with breast cancer and associated factors (*n* = 161). Results indicated higher anxiety, depression and distress scores among men who had undergone mastectomy, and depressive symptoms were associated with altered body image (35% variance, p <.0001). However, the authors do not report the body image scores in their paper as they do not reach the threshold for significant psychological distress.

2.3.2 Scarring due to treatment

As mentioned previously, mastectomy is performed in 75-100% of male cancer patients (da Silva, 2016; Giunta et al., 2017; Korde et al., 2010). This typically results in an altered appearance, including scarring, a flat or concave chest appearance, asymmetry, and the removal of the nipple (Donovan & Flynn, 2007a; Schaverien et al., 2013; Thompson & Haydock, 2020; Vinayagam & Williams-Jones, 2013). Although mastectomy occurs more frequently in men than women (da Silva, 2016), clinicians generally assume that the cosmetic implications are not as problematic for men (da Silva, 2016; Ruddy & Winer, 2013). However, the permanence of mastectomy scars and asymmetry of the chest may serve as a lasting visual reminder to men that they have or have had breast cancer:

> *"Surgery scar is change and a constant reminder of cancer"*
>
> (Rabbee & Grogan, 2016, p. 214)

Conversely, for some men who have undergone mastectomy, their scars are perceived as a badge of honour and a symbol of survival (Thompson & Haydock, 2020). In an exploratory study which investigated young men's understandings of BCiM, one participant hypothetically likened his mastectomy scar to his “warrior wound” (Rabbee & Grogan, 2016). Similarly, in other research, a male participant with breast cancer used imagery and language to evocatively describe his scar; *‘I could tell a very good story about how I was in the Hussars’* (France et al., 2000 p.345), thus implying his mastectomy scar to be a “battle wound” and a symbol or metaphor of surviving the fight with breast cancer and declaring victory. Such use of language highlights how men with breast cancer may subscribe to hegemonic notions of masculinity discussed in section 2.4.3. However, there are similar accounts in the literature of women describing their bodies following mastectomy and perceiving their scars as battle wounds and symbols of triumph, “*…my war wounds of life*” (Grogan & Mechan, 2017, p. 1618).

Conversely, others are self-conscious and anxious about being seen in public with post-surgical bodily changes and scaring. To manage the embarrassment of scars, some men choose to ignore people's shocked expressions (Pituskin et al., 2007), whilst others develop coping strategies to manage living with an altered body following mastectomy. These may include avoiding situations such as swimming which would expose their scars or avoiding wearing tight clothing which would show a *‘lopsided’* profile (Levin-Dagan & Baum, 2021; France et al., 2000). Some men are self-conscious of their altered appearance and ashamed to show themselves shirtless in public, for example, at the beach, and consequently wear clothes to cover themselves and conceal their scars;

> *“I want to take my shirt off – but I can’t now.”*
>
> (Donovan & Flynn, 2007, p. 467)

‘Everybody can see that I lack a nipple, and everybody can see the scar. I do not know what they think, but in my mind, I do not want them to see the scar. I used to put a towel over my left shoulder. I turn away from the other swimmers.’

(Donovan & Flynn, 2007a, p. 467)

In more recent research, Thompson and Haydock (2020) interviewed men with breast cancer (*n* = 17) in the USA. Four participants (23.53%) reported feeling stigma due to their breast cancer scars. Whilst some experienced difficulties adjusting to their altered appearance due to mastectomy surgery, others were less concerned about their appearance and learned to embrace their altered appearance over time;

“So when I looked in the mirror the first time, it was a little scary because I had a scar all the way from under my arm all the way down to my navel diagonally. And, um, you know it’s strange because by then I had accepted it and I said to myself ‘Well this is just something I’m gonna have to live with.’”

(Thompson & Haydock, 2020, p.33).

Men often associate the body, especially the chest area, with masculinity (Midding et al., 2018), and thus, the deformity of the chest and changes to the symmetry of appearance may compromise aspects, such as self-perception and sexual identity. This may have emotional and sexual consequences and men may experience difficulties adjusting to appearance related changes (da Silva, 2016). How appearance related changes may negatively affect men’s gendered identity is discussed in section 2.4.3.

Although some men with breast cancer admit to experiencing body image difficulties, others use downward comparisons (whereby a person experiencing negative affect can enhance their subjective wellbeing through comparison with someone less fortunate (Wills, 1981)) as a coping mechanism. They lessen the extent of their problems or express that breast cancer has had less impact on them than for their female counterparts (Levin-Dagan & Baum, 2021; Thompson & Haydock, 2020). Men often view their breasts as less important to them than women's breasts are to women. They depict breasts as strongly associated with femininity, inherently linked to female sexuality, as well as encompassing the identity of motherhood and nurturance (Haines et al., 2010; Manganiello et al., 2011; Rabbee & Grogan, 2016). In line with the common belief that men have chests and not breasts (da Silva, 2016; Thompson & Haydock, 2020), some men express how having a gendered part of the body removed must be harder for women than men;

> *'Breast cancer for a women is a lot more traumatic than it is for a man. It's just got to be."*
>
> (Thompson & Haydock, 2020a, p. 33)
>
> *"I mean look at me it's gone hah I've never used those [puts hands on breasts] for anything hah so yeah it's unimportant. I've got a scar there now, well I had a bunch o' those anyway so it's just one more."*
>
> (Trusson & Quincey, 2019 p. 5)

2.3.3 Bodily changes and functionality due to treatment

As well as surgery-related scarring and changes of the chest from mastectomy, breast cancer patients can suffer with loss of arm strength, postoperative shoulder pain and diminished range of motion after treatment, which can last for many years (Baima et al., 2017; Pituskin et al., 2007). These side-effects can impact bodily function, and may be a barrier to exercise, which can lead to a withdrawal of activities enjoyed pre-diagnosis. A study with female breast cancer and prostate cancer survivors found exercise barriers may impact social interaction and lead to isolation (Ottenbacher et al., 2011). Furthermore, changes to bodily function have also been associated with emasculation, challenges to male embodiment, altered body image, and perceived decrease in personal attractiveness and desirability (da Silva, 2016) (discussed in more detail in section 2.4.3).

Cancer treatment is also associated with fluctuations in weight (in either direction) which may pose a direct threat to body image (Raggio et al., 2019). Weight loss can be interpreted by patients and their families as a visible sign of cancer and its progression (Rhondali et al., 2013). Such changes in appearance may result in patients avoiding social activities and increase distress (Hinsley & Hughes, 2007; Rhondali et al., 2013).

Additionally, weight change may threaten masculine identities, as the body deviates from the normative, muscular, and fit ideals (Gattario et al., 2015) discussed in section 2.4.3. However, no research to date has specifically explored the impact of weight change due to cancer treatment in men with breast cancer.

As discussed earlier, the standard adjuvant endocrine therapy for men with hormone-receptor-positive breast cancer is approximately five years of treatment with Tamoxifen (Gui, 2012). Side-effects may alter appearance and impact bodily function, and can include venous thrombosis, leg cramps, cataracts, loss of libido, erectile dysfunction, mood changes as well as symptoms similar to menopause, including tiredness and hot flushes (Pemmaraju et al., 2012; Visram et al., 2010). These can pose significant challenges to quality of life and well-being in men with breast cancer (Giordano, 2018). The impact of side-effects on men’s perceptions of their masculinity is discussed in section 2.4.3.

2.3.4 Treatment induced hair loss

A further change to appearance for men who undergo chemotherapy as part of their breast cancer treatment is alopecia; the loss of both head and body hair (Trusson & Quincey, 2019). The speed of chemotherapy-induced alopecia is very fast compared to natural hair loss and can be difficult to conceal (Dua et al., 2017). This can result in a "cancer look", an appearance linked to cancer treatment (Rabbee & Grogan, 2016). Cancer-related alopecia and subsequent stereotypical cancer identity can cause feelings of stigmatisation by changing the individual's identity from that of a healthy person to that of a cancer patient (van den Hurk et al., 2010). This not only affects how individuals perceive themselves but also how they are perceived by others (Dua et al., 2017). Facial hair (eyebrows, moustaches, beards) and chest hair are synonymous with masculine embodiment (Midding et al., 2018), and distress caused by hair loss and difficulties adjusting to appearance related changes can further negatively affect men's gendered identity (da Silva, 2016; Trusson & Quincey, 2019) (discussed in section 2.4.4).

For many people, hair is a physical attribute which plays a significant role in identity (Cash, 2001), and both men and women express their individual identities through their hairstyles (Saed, Ibrahim & Bergfeld, 2016). Trusson & Quincey (2019) compared men's and women's breast cancer experiences of treatment-induced alopecia. The following quotes from male participants encapsulate the impact of losing hair which can be emotional, stressful and long-lasting;

> *"…the horrors of losing hair (…) it's not very nice."*

"Losin' my hair it's had a really negative affect on me personally…the lack of 'air still affects me, fact that I lost a load of my hair."

(Trusson & Quincey, 2019, p. 3-4)

The visibility to others and the inability to conceal hair loss is often more difficult for men with breast cancer to cope with than their surgical scars;

"Nobody sees the surgery. There is a shirt over it. You have your scars, [. . .] but you can hide them. But when the hair is gone, moustache away, eyebrows away."

(Midding et al., 2018, p. 2200)

Prior to hair loss, some patients prefer to conceal their illness from others and only share their experience with close family and friends, however, the visibility of hair loss can force them to confront their illness publicly (Hilton et al., 2008). This can be particularly traumatic for men with breast cancer, who often conceal their life-threatening cancer and its location, owing to a fear of sympathy and feeling stigmatised due to lack of awareness of the condition in men (Rabbee & Grogan, 2016).

Some men with breast cancer make the choice to dye their hair or decide to shave their heads before their hair falls out due to treatment. Trusson & Quincey (2019) describe how some men make concerted acts and take control of their hair loss; one participant dyed his hair bright red whilst another shaved it and posted pictures of himself in a pink wig on social media. Such 'acts of defiance' signify them taking control of the cancer rather than the cancer controlling their lives. This may serve to increase their sense of control over some of the outward appearance changes taking place in their bodies as a result of breast cancer treatment, and empower them to make a proactive choice regarding their overall response to cancer;

‘It was gonna go when I wan’ed it t’go, not when the chemo told it t’go it was gonna go when I wanted it to go’

(Trusson & Quincey, 2019, p.4)

‘First of all my hair fell out because of the chemo, and I immediately cut the rest of it off. I told the people at work that I just liked to have a bald head’

(Thompson & Haydock, 2020, p. 33).

Similar to how men with breast cancer frequently make downward comparisons with women regarding loss of breasts due to mastectomy (section 2.3.2), participants often remark how baldness is considered an acceptable look and natural ageing progression for men, whereas it is considered significantly worse for women;

“..kind of nobody would’ve particularly commented on the fact that y’know I was going around with a bald head, whereas if you’re a woman it’s different, but it was just nice err well thinking oh well”.

(Trusson & Quincey, 2019, p.7)

Appearance is again altered when the hair begins to regrow. It often grows back a different colour or texture, or in some cases, the hair does not grow back at all, all of which can have a long-lasting impact on body image (Watanabe et al., 2019). However, for some men, the regrowth of hair is viewed positively, signaling new life, hope and renewal and is symbolic of leaving the cancer identity behind (Trusson & Quincey, 2019).

Whilst healthcare professionals often provide women with breast cancer advice and support with the psychosocial distress associated with treatment-induced alopecia, including ways to disguise hair loss by using wigs and make-up, men are often not offered such support and information (da

Silva, 2016; Trusson & Quincey, 2019). Due to the visibility of hair loss, some men may restrict their social activities and interactions to conceal their health status. Such social withdrawal and isolation may have a negative effect on quality of life, social and emotional support (Dua et al., 2017).

2.3.5 Summary of section

This section has demonstrated how body image concerns have been raised within studies exploring men's experiences of breast cancer. However, it should be noted that this was not usually the main focus of the research discussed, and appearance related concerns were explored alongside other issues (Brain et al., 2006; Donovan & Flynn, 2007; France et al., 2000; Iredale et al., 2005; Pituskin et al., 2007; Quincey et al., 2016, 2021; Rayne et al., 2017; Thompson & Haydock, 2020; Williams et al., 2003). Further, these studies have been predominantly qualitative, with only one study using a body image scale to quantify the extent to which men are impacted by changes to their appearance (Brain et al., 2006). The lack of body image research in men with breast cancer is surprising given the substantial body of work exploring the impact of breast cancer treatment on female body image.

Research with female patients with breast cancer has shown how bodily changes after treatment and surgery can lead to poor body image, body dissatisfaction and the long-term impact of appearance related concerns (Chen et al, 2012; Przezdziecki et al., 2013). This can also result in depression and anxiety, sexual functioning difficulties and impairments in overall quality of life (Fingeret, Teo, & Epner, 2014). Additionally, female breast cancer survivors report significant body image concerns post-treatment and may represent a vulnerable subgroup to developing sexual dysfunction (Boquiren et al., 2016). Indeed, body image concerns in women following treatment for breast cancer can have lasting effects on psychological and emotional well-being (Brunet et al., 2013), which can continue for years following diagnosis and treatment (Przezdziecki et al., 2013).

At the time of designing the first study for the PhD, no research had specifically explored men's experiences of body image following treatment for breast cancer. This changed towards the end of the research programme, when Levin-Dagan & Baum (2022) conducted a qualitative study exploring the way Israeli men with breast cancer experience their post-surgical bodies. The results of their research showed how men with breast cancer experienced negative body image and the perception of an *'altered and violated body'* (p.35).

Furthermore, research exploring body image in older men (those typically at risk of breast cancer) is currently under studied (Jankowski et al., 2016). The field of oncology and male body image has tended to focus on male specific cancers such as prostate cancer, penile and testicular cancer (Taylor-Ford et al., 2013). Within these patient groups, body image distress and impairments in sexual quality of life are common (Farrell et al., 2014), as well as concerns about sexuality and masculinity (Harrington et al., 2009).

Finally, treatment for men with breast cancer is invasive and appearance-altering and may impact men's physical appearance and their perceptions of their bodies. Surgery and treatment for breast cancer may alter bodily aesthetics and functioning, both in the short and long term, and may lead to protracted body disturbance, bodily changes and functional decline. Furthermore, patients continue to manage the physical changes resulting from treatment for many years after the cancer itself has been treated. The effects of an altered appearance may serve as visual, constant reminders of breast cancer and its treatment, well into survivorship. Although appearance related concerns in men with breast cancer have been underrepresented in the literature, men are at risk of experiencing difficulties adjusting to body changes resulting from breast cancer surgery and its treatment. It is considered an important area to study in more depth as concerns about body image may lead to avoidance or withdrawing from social contact which may render them isolated and alone.

The next section addresses the third psychosocial factor identified in the literature as likely to influence the experiences of men with breast cancer; the impact of breast cancer on masculinity.

2.4 Masculinity

Much of the research on men's experiences of diagnosis, treatment and living with breast cancer is based on the idea that men subscribe to notion of hegemonic masculinity (Connell, 1995). This refers to the dominant social construction of masculinity, shaped through social processes and social context and is historically shifting (Connell & Messerschmidt, 2005). It subordinates femininities and other marginalised masculinities, which may be perceived as feminine, and helps shape relationships between men and women, and men and men. It refers to the 'male script' or valued markers of masculinity which exist within society which determine social practice, legitimise behaviours, and encourage men to behave in stereotypically acceptable ways. It further influences how men should think, feel and behave (Lohan, 2010). An essential feature of masculinity is relational, contextual and in opposition to women (Connell & Messerschmidt, 2005). Furthermore, traditional masculinities and gender role beliefs may be more entrenched in older adults as they have been influenced across their life course (Pudrovska, 2010).

2.4.1 Masculinity and health

The concept of masculinity may have particular implications for men's health (Connell & Messerschmidt, 2005) and is among the most significant risk factors associated with men's illness' (Kimmel, 1995). In contemporary Western society, concern for health is considered a feminine characteristic (Noone & Stephens, 2008), whilst traditional characteristics of hegemonic masculinities position men as independent, strong, stoic, emotionally restricted, tough, physically competent and self-sufficient (Smith et al., 2007). Displaying concern for one's well-being may be coded as feminine and weak (Courtenay, 2000), and internalised masculinity and conformity to these traits may mitigate against health help seeking (Himmelstein & Sanchez, 2016).

As a result, men may delay health seeking and consequently suffer worse health outcomes associated with late presentation (Himmelstein & Sanchez, 2016; Jeffries & Grogan, 2012). This has been evidenced within the BCiM literature, whereby men are frequently reticent to seek medical advice for their initial concerns about breast cancer symptoms. This often results in delayed diagnosis and poorer prognosis for male patients with breast cancer than their female counterparts (Co et al., 2020; Donovan & Flynn, 2007; Iredale et al., 2005; Quincey et al., 2016; Sime, 2012; Wang et al., 2018). The ways in which men with breast cancer may experience, encounter, and navigate masculinities throughout their breast cancer journey is now discussed.

2.4.2 The social construction of breast cancer

Social construction of the term "breasts" is synonymous with femininity and sexuality and incongruent with maleness (Co et al., 2020; Thompson & Futterman, 2022). Men are often unaware that anatomically they have breasts, captured by previous research where a participant in research exclaimed how men *"don't even have breasts, we have chests!"* (Sime, 2012, p. 49), and supported in other research in which participants used gender-specific language and associates chests as a male body part and breasts as a female body part (Skop et al., 2018). Furthermore, men often associate their bodies, particularly their chests, with masculinity (Donovan & Flynn, 2007; Midding et al., 2018; Pituskin et al., 2007), and pecs are seen as a symbol of strength and an embodiment of masculinity (Pituskin et al., 2007). Consequently, for men being diagnosed with a "woman's disease" associated to a part of the body that men do not identify with, this may be considered a direct threat to their masculinity (Nguyen et al., 2020).

Men with breast cancer may express self-stigma though their own behaviours, beliefs, and attitudes towards masculinities (Quincey et al., 2021). This has been shown to occur through their use of language such as *"freak"* (Quincey et al., 2021, p.694) to refer to themselves or other men with breast cancer. Despite being diagnosed with breast cancer, some men still refer to it as a female illness; "*Of all the cancer to get I had to get a bloody women's cancer"* (Quincey et al., 2021; p.694) thereby perpetuating the misconception it is a gendered illness. Such remarks demonstrate how men may perceive the disease a threat to their masculinity.

As discussed in section 2.1.1.2, the social construction and 'pinkification' of breast cancer as a female disease is inconsistent with hegemonic masculinity (Donovan & Flynn, 2007; Levin-Dagan & Baum, 2022; Midding et al., 2018; Nguyen et al., 2020; Quincey et al., 2016, 2021; Sime, 2012). This can have profound consequences for men's perceptions of their masculinity and may impact the way they experience breast cancer. Thompson & Haydock (2020) investigated the 'marginal man' and discussed the dichotomy facing men with breast cancer as two incompatible cultures, namely, the pink ribbon culture of breast cancer and the everyday ideals of masculinity and the male body. The development of breast cancer challenged not only men's perception of their own masculinity, but they also expressed their concerns of how others may perceive them and their sexuality;

> *"men don't get breast cancer...if I start[ed]telling people they were gonna think I'm gay or something."*
>
> (Thompson & Haydock, 2020, p. 37)

> *"My biggest problem was how to tell my wife that I have a woman's disease? Because I thought maybe you're not a real man, perhaps half woman?"*
>
> (Nguyen et al., 2020, p.8)

2.4.3 Treatment and its challenges to masculinity

Treatment for men with breast cancer and the associated side-effects and bodily changes may further challenge masculine ideals and alter men's perceptions of their own masculinities (Nguyen et al., 2020). For some men, post-mastectomy scarring, the deformity of the chest and changes to the symmetry of appearance due to treatment may comprise aspects such as self-perception and sexual identity. This may have emotional and sexual consequences and may negatively impact the successful adjustment to appearance related changes (da Silva, 2016). Furthermore, mastectomy scars and asymmetry of the chest area often serve as a constant reminder of having had a female disease (Thompson & Haydock, 2020) and the 'permanent stigma' associated with breast cancer (Quincey et al., 2016). A participant in research by Quincey et al., (2021) expressed concern about his scar and appearing different to male body norms which may impact how they may be perceived by others;

"They might think he was a woman one time?"

(p. 695).

Such reactions reflect both internalised stigma and the stigma of others which may challenge men's perceptions of masculinity as their bodies post-surgery may not meet societal expectations of masculinity (Levin-Dagan & Baum, 2022).

As discussed in section 2.3.2, men with breast cancer often downplay their experiences as less important or impactful than those of women with breast cancer, as they have not lost a gendered part of their bodies, that society values as feminine (Iredale et al., 2005; Quincey et al., 2021; Sime, 2012; Thompson & Haydock, 2020);

"Obviously for a woman it is a much bigger issue I would have thought than it is for me. I haven't got to worry about a beauty contest"

(Iredale, 2005, p338).

Such use of language and positioning of men and women demonstrates how men may enact masculinity to maintain and reinforce hegemonic masculinities.

Participants often use military style language to invent stories to conceal the true origin of their mastectomy scars. The use of language often depicts war against the disease and the perception of scars as symbols of triumph. One participant referred to his scars as a *"Vietnam war wound"* (Sime, 2012 p. 201), whist others similarly describe their scar as a *'war wound'* (Pituskin et al., 2007).

Furthermore, the reaction of others and their use of language to describe male mastectomy scars may also serve to reaffirm dominant masculine status;

“My daughters says ‘‘Oooh it looks like you’ve have had a fight with a shark Dad. It makes you look really hard.’’

(Iredale et al., 2005, *p.337)*

Additional physical consequences associated with breast cancer treatment such as loss of arm strength, weight gain and weight loss may result in men feeling emasculated and their masculinity challenged. This may be due to dimensions such muscularity, leanness and fitness which are important correlates to men’s conformity to masculine norms (Bunkley et al., 2000; Donovan & Flynn, 2007; Gattario et al., 2015; Levin-Dagan & Baum, 2022; Quincey et al., 2016).

As a result, some men with breast cancer feel ashamed to show their altered appearance and adopt concealment strategies such as wearing t-shirts in public places such as the swimming pool and the beach where men typically bare their chests (Levin-Dagan & Baum, 2022; Midding et al., 2018; Quincey et al., 2021). Such actions may shield them from potential comments laden with the cultural stigma associated with breast cancer and thereby serve to protect their masculinity;

“I try to never take my shirt off.”

(Levin-Dagan & Baum, 2022, p. 40)

Further treatment side-effects, in particular, loss of libido and erectile dysfunction associated with Tamoxifen therapy, may further impact men’s sense of masculinity, as male sexual potency is a central component to hegemonic masculinity (Donovan & Flynn, 2007; Farrell et al., 2014; Nguyen et al., 2020; Quincey et al., 2021; Sime, 2012). One participant in a study conducted by Quincey et al., (2021) sought extramarital sex to affirm his hegemonic masculine status which values virility and dominance over women (Connell & Messerchmidt, 2005).

Additional side-effects of Tamoxifen may include hot flashes flushes and night sweats, which are commonly associated with the menopause (Farrell et al., 2014; Ruddy et al., 2013), and thus, may threaten men's gendered identity. A participant in a study conducted by Nguyen et al., (2020) considered themselves to be *"menopausal women"* (p9), whilst another in research conducted by Sime (2012) commented;

> *"Men aren't supposed to have menopause but I had the night sweats"* (p. 182).

2.4.4 Hair loss and masculinity

As discussed in section 2.3.4, chemotherapy-induced alopecia can result in changes to appearance including the loss of both head and body hair (Trusson & Quincey, 2019). Men with breast cancer report how society often holds stereotypical assumptions that head hair loss is a natural consequence of ageing for men, and they are often considered to be less affected by hair loss than women (Trusson & Quincey, 2019). Furthermore, facial hair (eyebrows, moustaches, beards) and chest hair are synonymous with masculine embodiment (Midding et al., 2018; Trusson & Quincey, 2019), and distress caused by hair loss and difficulties adjusting to appearance related changes may negatively affect men's gendered identity (da Silva, 2016; Midding et al., 2018). A participant in a study by Sime (2012) reported concealing his chest hair loss over the mastectomy site so he did not offend or embarrass others.

The visibility of cancer due to the loss of facial hair, and in particular, the loss of a beard, was described as losing *"a typical element of masculinity*" (Midding et al., 2018, p. 2203), thereby affecting their gendered identity. However, visibility to others and the inability to conceal head hair loss is often more difficult for men with breast cancer to cope with than their surgical scars;

“Nobody sees the surgery. There is a shirt over it. You have your scars, [. . .] but you can hide them. But when the hair is gone, moustache away, eyebrows away.”

(Midding et al., 2018, p. 2200).

In a similar coping strategy often adopted by men regarding their appearance after mastectomy (section 2.3.2), men often downplay the impact of their hair loss and describe it to be more traumatic for women. In a qualitative study comparing similarities and differences in men’s and women’s hair loss experiences due to breast cancer treatment (Trusson & Quincey, 2019) men adopted downward social comparisons and compared their hair loss as easier to manage and more socially acceptable than hair loss in women, thereby both protecting and asserting their masculinity identity (Quincey et al., 2021);

‘It’s made me realise y’know what a difficult journey it is for a woman, more so than a bloke as a say y’know I lost ma hair but I didn’t ‘ave a lot of ‘air t’ start with.’

(Trusson & Quincey, 2019. p. 5).

Some men in the study used humour as a defence mechanism to make light of losing their hair, whilst another participant wore a pink wig. Such acts were adopted to reduce tension thereby exhibiting the importance of emotional resilience associated with hegemonic masculinity (Connell & Messerschmidt, 2005). However, others were upset by their hair loss and distressed their hair had not regrown to how it had been pre-treatment. Embarrassment regarding appearance and gendered stereotypes can make it difficult for men to openly discuss their concerns with healthcare professionals (Trusson & Quincey, 2019).

2.4.5 Breast cancer care settings and masculinity

As stated in section 2.2.1.3, throughout the diagnostic process for symptomatic men and whilst undergoing mammography, men reported feeling uncomfortable and awkward in a predominantly female environment. As discussed in section 2.2.1.4, information regarding disease and treatment for men is lacking and most information provided to them is written specifically for women and much of the information provided is inappropriate for men and addresses issues specific to women such as menstrual functioning, vaginal dryness and bra fittings. As well as feeling isolated (section 2.2), these factors can result in men perceiving themselves as stigmatised, marginalised and emasculated (da Silva, 2016; Egestad et al., 2019; Fentiman, 2018; Iredale et al., 2005; Levin-Dagan & Baum, 2021; Midding et al., 2017; Quincey et al., 2016; Younas et al., 2019).

However, not all BCiM patients' perception of their own masculinity are impacted by having a cancer commonly associated with women. Rayne et al., (2017) conducted a study in South Africa and reported that BCiM only had a limited effect on survivors' perception of their masculinity. The majority of participants did not experience feelings of affected masculinity or alteration in sexual function and body image, nor did they experience feelings of emasculation by having what is commonly perceived as a "female" disease. However, some participants within the study did express how perceptions of their masculinity were profoundly affected; these men tended to be of Black race, lower socio-demographic status and were less likely to be aware of BCiM. This supports how gendered behaviour is embedded in culture, and as such, constructions of masculinity may vary according to the cultural context, and may influence perceptions of masculinity (Courtenay, 2000; Connell & Messerschmidt, 2005; Rayne et al., 2017; Rochelle, 2019).

2.4.6 Non-hegemonic masculine identities

Despite much of the literature focusing on conventional theories of hegemonic masculinity and the perceived emasculation caused by having a female cancer, research has shown how some men reconfigured softer masculinities. This is generally achieved following their breast cancer experiences and into life post-breast-cancer through becoming advocates for BCiM (Quincey et al., 2021; Sime, 2012). Participants experienced personal growth through raising awareness and supporting other men more recently diagnosed with the illness. They expressed how they felt they had become better versions of themselves through their breast cancer experience;

> *"I think I am a kinder man now….I think how I feel about myself has changed for the positive."*
>
> *"makes y'a better person in how you deal with people….more considerate….more understanding."*
>
> (Quincey et al., 2021; p.699).

Their transformation into better, more thoughtful men who help support other men with breast cancer represents freedom from the constraints of hegemonic masculinity (Quincey et al., 2021).

2.4.7 Gender nonconforming persons and breast cancer

As well as discussing how hegemonic conceptions of masculinity shape men's experiences with breast cancer, it is important to address concerns facing gender nonconforming persons and breast cancer. Much of the BCiM research conducted to date adopts a binary classification system and fails to acknowledge broader concepts of gender. Furthermore, the theory of hegemonic masculinities, widely referred to in the literature, is criticised for being framed within a heteronormative conception of gender (Connell & Messerschmidt, 2005) and theories of masculinity in general are critiqued for being inapplicable to gender-variant people (Gardiner, 2013). Research has shown how those people whose gender expression does not correspond to societal norms frequently face stigma and discrimination in health care settings (Clifford, 2018). As the population of people who identify as transgender, gender diverse and non-binary is increasing (Cundill, 2020), it is important to consider the impact and experiences of gender-diverse people with breast cancer, including transgender patients.

Transgender patients are defined as those whose gender identities do not align with their biological sex, and is independent of genotype sexual orientation, and behaviour (Sonnenblick et al., 2018). Although studies exploring the experiences of transgender people in healthcare are limited, the existing evidence shows they are often marginalised and face significant health disparities (Goldberg et al., 2018). Furthermore, they disproportionately experience discrimination in the healthcare setting and may face stigma or negative behaviour from hospital and medical staff (Ehrenfeld et al., 2018).

Research exploring the experiences of transgender patients with breast cancer is limited. Chotai et al., (2019) presented a case study of a FtM transgender patient (female sex assigned at birth, male gender identity), where they reported that the barriers to the quality of healthcare faced were primarily due to social stigma. Recommendations for improvement of care included health professionals needing a better understanding of this patient demographic though gender-sensitive training and education. Additional recommendations include the importance of a welcoming clinic environment and medical staff to utilise accepted terminology (Sonnenblick et al., 2018). The provision of culturally sensitive services for transgender people would potentially improve the equity of health access and outcomes for people who are not cisgender (Peters et al., 2022).

When discussing gender and healthcare in general, there is a need to move away from gender binary terms in healthcare literature and a need for more fluid and flexible constructs to allow for multiple dimensions of gender (Hart et al., 2019). This could potentially improve the equity of health access and outcomes to people who are not cisgender (Kuhlmann & Annandale, 2012). This is particularly relevant to trans men who have a higher risk of breast cancer compared with cisgender men (de Blok et al., 2019). Finally, despite the gendering of breast cancer as a female-illness, breast cancer has no gender and wherever someone falls on the gender spectrum, they are at risk.

2.5 Summary of section

This section has illustrated how men's experiences of being diagnosed and treated with breast cancer are inextricably linked with the complexities of masculinities. It has demonstrated how the concept of hegemonic masculinity can shape men's experiences from awareness of BCiM, from diagnosis through treatment, and throughout the whole breast cancer trajectory, and how men construct their masculine identities while experiencing a predominantly female cancer. Embedded notions of gender and gender identity, stigma and challenged masculinities, often result in worsened psychosocial functioning and adjustment to the disease, whilst barriers and stigma faced by minority gender and sexuality status persons may result in health disparities and poorer health outcomes. Finally, the impact of breast cancer and the resulting perceptions of a threat to patients’ sense of masculinity may lead to men with breast cancer feeling marginalised and isolated.

The literature presented so far has discussed the psychosocial factors identified in the literature; lack of awareness among both the general population and HCPs, body image and appearance related concerns, and impact on masculinity, which are prevalent in the lives of many men with breast cancer. Ultimately, these factors may render men with breast cancer feeling isolated and alone. As men with breast cancer often experience their illness in isolation, it raises the question of “Who provides them with care and support?”. The following section will now introduce the role of ‘Informal Carers’ (ICs), discuss their role in supporting men with breast cancer, and briefly explore the impact of the disease on their lives.

2.6 Informal carers (ICs)

It is evidenced that men with breast cancer receive less social and emotional support than female breast cancer patients (da Silva, 2016), and a comprehensive review of evidence clearly indicates their emotional support needs are often not met (Fentiman, 2018). Men with breast cancer tend to rely on the support of their partners for emotional and social support rather than formal support services (Iredale et al., 2005; Thompson & Haydock, 2020b).

The term ‘ICs’ is commonly used to refer to someone who actively participates in sharing the patient’s illness experience on a practical and/or emotional level (Beaver & Witham, 2007). It does not include those who provide professional paid or voluntary care, such as healthcare professionals working in the community or charity volunteers providing support. Providing care is often a gradual process and carers do not immediately identify with being a ‘carer’ (Carduff et al., 2014). Furthermore, male patients with breast cancer often experience comorbid physical conditions (Andrykowski, 2012), consequently, ICs also support additional health concerns and complications.

The vital role ICs play has been acknowledged in government policy documents (Department of Health, 2018). The 'Carers Action Plan 2018-2020' (2018) recognises;

> *'The enormous contribution of our country's carers not only makes an invaluable difference to the people they support, it is an integral part of our health and social care system…. Within our communities they are vital partners, bridging the gap between local health and care services.'*
>
> (Department of Health, 2018, p. 5).

Research conducted with caregivers of people with advanced cancer has shown that their role is not well defined, and their experiences are poorly understood (Ugalde et al., 2012). The role of support of men with breast cancer falls primarily on partners, close family members or female friends who have had breast cancer (Midding et al., 2019), and they typically face caring responsibilities with little to no formal training and additional support (Kim & Given, 2008). The physical, emotional, financial, and social impact of caring for an individual with cancer can be considerable; ICs may experience anxiety and depression, anxiety about the future and losing the patient, financial worries, and strain in family and marital relationships (Kim & Given, 2008). They may also experience poor physical health, The 'Carers Action Plan 2018-2020' (2018) acknowledges how *'caring can take a toll on the carers' own health, relationships and finances'* (Department of Health, 2018, p. 5). This can include sleep difficulties and fatigue, cardiovascular disease, poor immune functioning, and increased mortality (Beaver & Witham, 2007).

However, as well as the negative outcomes associated with caring, positive psychological outcomes have also been explored. A systematic review identified personal resources, including confidence and self-esteem, which facilitated positive aspects of caring, as well as the ability to construct meaning from the experience of caring (Young & Snowden, 2017).

A body of research has been conducted with the ICs of cancer in general (Li et al., 2013; Seal et al., 2013; Young & Snowden, 2017), as well as with ICs of specific cancer patient groups, including women with breast cancer (Beaver & Witham, 2007; Lafferty et al., 2011a; Regan et al., 2015), head and neck cancer, and cachexia (Balfe et al., 2016; Halkett et al., 2020; Wheelwright et al., 2016a). Further areas which have been explored include ICs of male-specific cancers, including prostate cancer (Sinfield et al., 2012) and testicular cancer (de Padova et al., 2019). However, the consequences of caring for a man who has been diagnosed and treated for what is commonly perceived as a ‘female’ illness (Midding et al., 2018) may make the experiences of their ICs different to those carers of other cancer groups due to the lack of awareness and potential lack of support.

Despite the integral role of ICs in supporting men with breast cancer and the impact of the disease on their lives, there was no existing research exploring the experience of this population at the outset of the current programme of research. During the course of the PhD, a Danish study was published which explored the experiences of partners (*n* =12) of men with breast cancer. Results indicated their lives were negatively affected by the illness, they reported a lack of information, and often assumed the role of advocate and information seeking on the patient’s behalf (Egestad et al., 2019).

2.7 Conclusion

The first section of this chapter presented a review of the BCiM literature to date and discussed pertinent issues surrounding BCiM. The second section presented a literature review of the core psychosocial issues facing men with breast cancer identified in the research to date, namely; lack of awareness, body image and appearance related concerns, and impact on masculinity. There is a clear interaction and overlap between these issues and they are often experienced in conjunction. The role and impact of caring on ICs was also discussed. It is evident that the perception of breast cancer as a female illness may result in men with breast cancer and their ICs facing unique issues which are absent in other disease profiles. Based upon the literature reviewed in this chapter, despite the increasing numbers of men being diagnosed with breast cancer, there remains an inadequate understanding of the psychosocial consequences of the disease on men and their ICs. Ultimately, more research in this area is crucial to improve understanding of the issues facing men with breast cancer and their ICs. This may identify causes of concern and distress, and ultimately, lead to ways to improve the lives of those affected by the disease. Consequently, the psychosocial impact faced by men with breast cancer and their ICs render in this field an important topic needing further research.

2.8 Aims of the current thesis

The overarching aims of this PhD are:

- To better understand the psychosocial impact of BCiM and to explore how the illness is experienced by patients and their ICs
- To explore healthcare professionals’ perceptions of the support needs of men with breast cancer and their ICs

Next step

To fully explore these in more depth it is essential that the research is both pragmatic and appropriate. Accordingly, the following chapter presents the methodologies used in this thesis.

Chapter three: Methodology

3.1 Overview

This chapter details the mixed methods approach chosen for this PhD. It provides justification for the multi-phase explanatory sequential design and pragmatic approach. The next section will discuss the key role and integration of Patient and Public Involvement (PPI) throughout the PhD, ethical considerations and recruitment challenges in psychosocial research and rare conditions, such as BCiM. It will conclude by discussing the role of reflexivity and present the broad biopsychosocial model as a lens used to guide the research. In accordance with the Doctoral descriptors, this chapter will demonstrate a critical understanding of the methodology of enquiry.

3.2 A brief history of mixed methods in health research

Historically, quantitative methods have dominated health research (Tariq & Woodman, 2013). This positivist, deductive approach believes that there is one truth or reality and 'that reality is universal, objective and quantifiable' (Dures et al., 2010, p 333). Within this framework, the researcher values detachment and impartiality between the researcher and the object of study to uncover the truth (Johnson & Onwuegbuzie, 2004; Guba & Lincoln, 1994). Research methods used in quantitative research adopt a deductive approach using experimental designs. These are conducted to find cause and effect links and to prove and support hypotheses and theories (Creswell, 2013). The relationship between variables is examined, typically using numerical data, which is analysed using statistical procedures. Designs include randomisation, control and manipulation to ensure the study is as free as possible from confounding variables (Willig, 2022). Rigour is ensured through the validity and reliability of measures (Vogt, 2011). Research typically uses large sample sizes to generate statistical power and researchers aim to be able to replicate the findings with the objective of generalising the findings to a wider population (Florczak, 2014).

However, a more qualitative, pragmatic approach has gained momentum among the health researcher community (Tariq & Woodman, 2013). This rejects positivist assumptions and argues there are multiple versions of reality, truth and knowledge which are shaped by personal viewpoints, context and meaning (Tariq & Woodman, 2013; Willig, 2019). Whilst quantitative methods use numbers as data, qualitative researchers use words (both written and spoken) and pictures as data (Dures et al., 2010).

Within this approach, researcher subjectivity is valued bringing their perspectives, values, social experiences and viewpoints into the research process. This has been conceptualised by Dodgson (2019), who asserted that 'the Researcher is the research instrument' (p. 220). It requires researchers to be reflexive (Berger, 2015) and to consider their social position (e.g., gender, age, race, immigration status, sexual orientation) as well as personal experiences, political and professional beliefs and how these may shape their research (Willig, 2022). It further proposes that knowledge is co-constructed as the researcher and participants work together (Christ, 2013). Compared with quantitative research, sample sizes tend to be smaller and findings are not generalisable to a wider population as it is acknowledged that people and phenomena may change according to their circumstance (Dodgson, 2019).

However, methodological purists considered traditional quantitative and qualitative approaches to be distinct, underpinned by fundamentally different assumptions (Dures et al., 2010). Between the 1970's and the 1990's, there was fervent debate that it was not possible to combine or merge quantitative and qualitative approaches. The so-called ‘Paradigm wars’ centered on the perceived differences in philosophical assumptions between the positivist and the constructionist or interpretivist paradigms (Tashakkori & Teddlie, 2010). This debate led to the ‘incompatability thesis’ (Howe, 1988) which claimed that the two paradigms should never be mixed due to the inherent different ontological, epistemological and methodological assumptions. Historically, the inability to mix and the incompatibility of methods have been likened to ‘oil and water’ (Shaw et al., 2018, p. 228).

However, the incompatibility thesis has largely been discredited (Tashakkori & Teddlie, 2010) as researchers have demonstrated it is possible to successfully use a mixed methods approach (Denzin, 2012). Consequently, the integration of quantitative and qualitative methods, termed as mixed methods research, has been heralded as the ‘third paradigm’ in research (Johnson, Onwuegbuzie, & Turner, 2007). This aims to provide a bridge between quantitative and qualitative research approach (Onwuegbuzie & Leech, 2005) and to increase the breadth and depth of research by combining the attributes of both sets of data (Creswell & Creswell, 2018). It is widely agreed that the integration of quantitative and qualitative data can dramatically enhance the value of research and yield a broad spectrum of insights beyond the information provided by standalone methods (Bryman, 2006; Creswell, 2018). This has been expressed “quantitively as 1 + 1 = 3, that is, qualitative + quantitative = more than the individual components” (Fetters & Freshwater, 2015, p. 116).

A review of 232 mixed methods studies (Bryman, 2006) identified 16 benefits of this approach. These include (i) enhancing or building upon quantitative findings with qualitative findings, and vice versa; (ii) providing a comprehensive understanding of a phenomenon (e.g. variables and viewpoints); (iii) triangulating results can corroborate findings; (iv) combining diverse viewpoints; (v) facilitating the sampling (e.g. using a survey to select interview participants); and (vi) developing and testing instruments (e.g. develop a questionnaire using focus groups).

3.3 Mixed methods research designs

Similar to purely quantitative and qualitative research, mixed methods designs should be driven by the research question and purpose (Tashakkori & Teddlie, 2010; Bishop, 2015). There are numerous research design typologies (Schoonenboom & Johnson, 2017) however, it is recognised these should be adapted by researchers to provide the optimal framework to fit the research question (Bishop, 2015). In the current PhD, the creative, flexible and adaptive framework for designing and conducting mixed methods research (Creswell & Plano Clark, 2017; Dawadi, 2021) was particularly appealing due to the underdeveloped field and the exploratory nature of the PhD.

3.3.1 Mixed methods in health research

It is widely acknowledged that the use of mixed methods in health research is increasing (Wasti et al., 2022). The results obtained from integrating different methods can provide a holistic understanding of complex and multifaceted areas such as health-related issues (Doyle et al., 2016), health services interventions and living with chronic illness (Tariq & Woodman, 2013). The combination of methods provides the researcher with the scope to explore and gain the perspectives and experiences of multiple stakeholders (Kajamaa et al., 2020). In health research, examples of mixed methods include providing insight into the perspectives of patients as well as to explore health policy and doctor/patient interactions (Braun & Clarke, 2019). In addition, it has been used to identify cancer nurses' and patients' research priorites (Cadorin et al., 2020), highlight the supportive care needs of breast cancer patients post treatment (Cheng et al., 2018) and explore the perspectives of male carergivers for women with breast cancer (Bamgboje-Ayodele et al., 2021).

At the time of writing, only two mixed methods studies with BCiM patients have been published (Midding et al. 2017; 2019) which were both part of the N-MALE project (to explore BCIM patients' needs in prevention, diagnosis, treatment and follow-up care between 2016-2018). Midding et al., (2017) used a mixed methods approach to explore the stigmatisation of men with 'a woman's disease' and secondly, to explore the social support of male breast cancer patients (Midding et al., 2019). However, these studies were both conducted in Germany and consequently the experiences of men treated in Germany may not represent those of men treated elsewhere in different healthcare systems. Furthermore, the quantitative questionnaires were developed by the authors and did not use standardised measures. Accordingly, the findings are limited as the results cannot be compared to other studies (Casu et al., 2022).

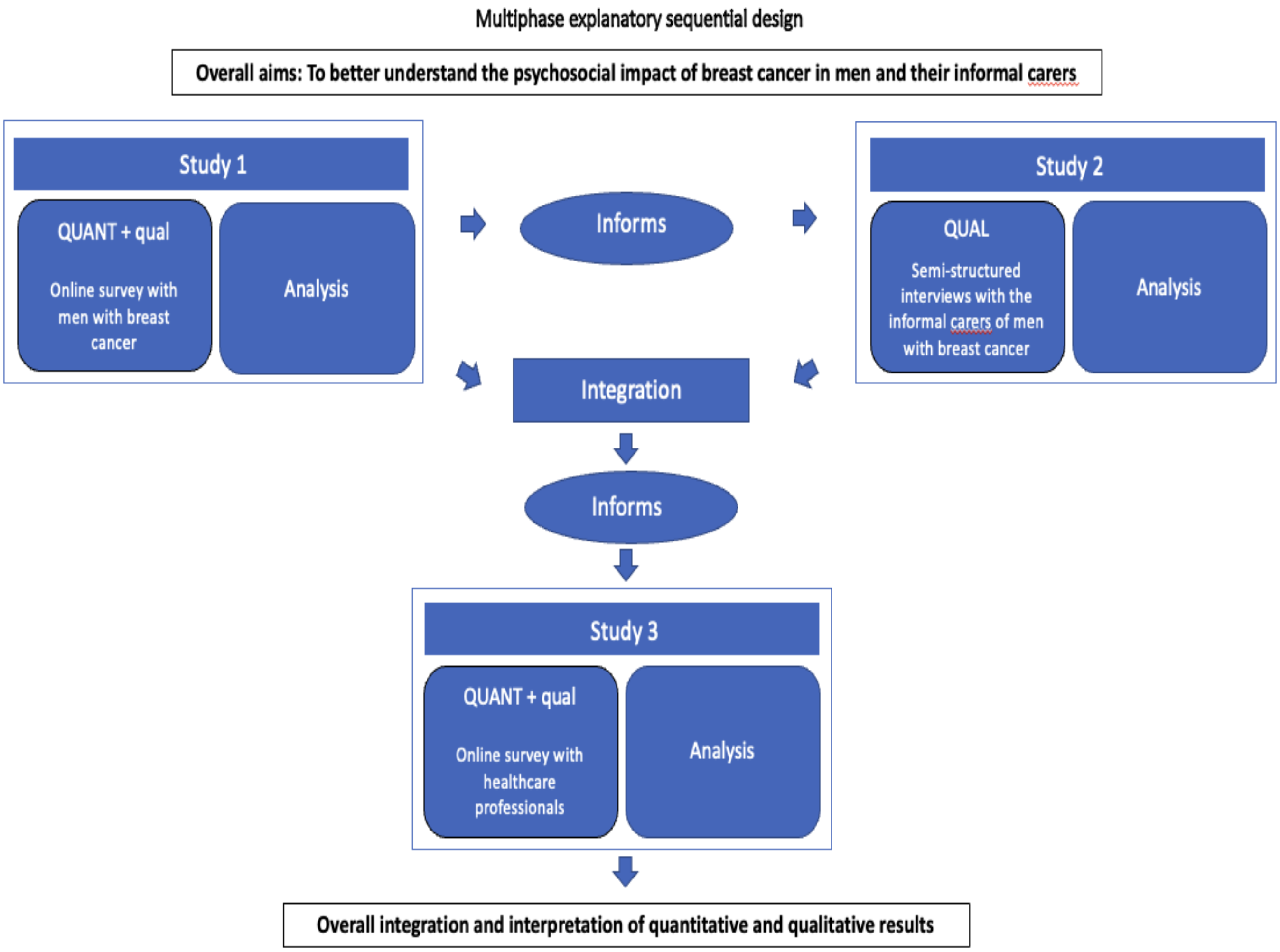
3.4 The use of mixed methods in the current PhD and rationale for choosing a multi-phase explanatory sequential design

This thesis adopts the position that the strengths of both quantitative and qualitative data in a mixed methods design can generate important and complementary insights and information in order to offer a better undertanding of the experiences of men with breast cancer and their ICs. The approach also enables the researcher to explore healthcare professionals' perceptions of the support needs of men with breast cancer and their ICs and to synthesise the results to provide a holistic understanding of the impact of the disease from multiple perspectives.

BCiM has received limited research to date and the studies that have been conducted are predominantly qualitative analyses of men's experiences. Although these have provided interesting insights, it was considered during the design phase that an initial qualitative study in the PhD may merely replicate published findings. Further consideration was given to carrying out a qualitative synthesis of the published research, however this has already been undertaken by Quincey et al., (2016). It was deemed that insufficient psychosocial research in men with breast cancer has been conducted since to warrant a further qualitative synthesis at this stage. Therefore, to gain a holistic understanding of BCiM and potentially broaden the field of research, a multi-phase explanatory sequential design is considered the best approach for the PhD (Figure 1).

Figure 1.

Illustrates the multi-phase explanatory sequential design of the PhD



Note: "Quant" stands for quantitative; "qual" stands for qualitative; "+" stands for concurrent and sequential is indicated with an arrow, "→"; capital letters – "QUANT" and "QUAL" denote higher priority or weight; lower cases – "qual" denote lower priority or weight; QUANT+ QUAL indicates equal status. Adapted from Tashakkori and Teddlie (2010).

3.5 Methodological issues in mixed methods designs and how these were addressed in the current design

When adopting a mixed methods approach, it is necessary to consider seven key components of the research design, namely; purpose, theoretical drive, timing, integration, planned vs emergent design, typological versus interactive design approaches and complexity (Schoonenboom & Johnson, 2017). The following section presents how these components were considered in the current multi-phase explanatory sequential design of this PhD:

1. Purpose

As outlined in chapter 2 (section 2.8) the purpose of this research is to better understand the psychosocial impact of BCiM and their informal carers. The aim of the sequential explanatory approach is to develop a nuanced understanding of the phenomenon from multiple perspectives (Younas et al., 2020). The principle purpose of adopting a mixed methods approach in this research is to corroborate findings across methods (Bryman, 2006b) to drive and develop the research, whereby one method informs the development and direction of the next approach (Halcomb & Hickman, 2015). Together these aim to expand the field of research of BCiM.

2. Theoretical drive

This relates to the dominant method in data collection and analysis and which steers the research. These are namely quantitatively dominant, post-positivist mixed methods research which adopts a deductive approach; qualitatively dominant, constructivist mixed methods research with an inductive approach or equal-status mixed methods research in which each component is of equal weight and value (Johnson, 2017).

This body of research starts with a quantitatively dominant study 1 (QUANT + qual). To address the key issues arising from the first data set, the results give prominance to the qualitative findings which drives the following study 2 (QUAL). Together the findings of studies 1 and 2 guide the design of the third study, with heathcare professionals (QUANT + qual).

3. Timing (simultaneity and dependence)

This relates to the timing of the research components. Simultaneity is essentially the difference between concurrent designs (both components are conducted simultaneously) or sequential designs (whereby the quantitative component precedes the qualitative component, or vice versa). The dependence of timing has two aspects; firstly, dependence relates to whether the second study in the design relies on the results of the data analysis of the first component or independence whereby the second component does not rely on the results of the data analsysis of the first study (Younas et al., 2020).

In the current research design, the components are dependent on the preceding study; the initial, mixed methods online survey (study 1) is conducted and analysed before the qualitative interviews (study 2) are conducted. The findings of studies 1 and 2 are integrated before study 3 (mixed methods online survey) is conducted. The analysis of the datasets are independent (Younas et al., 2020). A strength of a sequential design, which was appealing for this particular programme of research, was the ability to retain the integrity of the individual components and evaluate each method as each study is completed before the next begins (Bishop, 2015). A reflexive section on the methods adopted is provided in each study chapter.

4. Point of integration

The point of integration is the intentional process whereby the researcher brings together the quantitative and qualitative approaches in a study (Creswell & Creswell, 2018). The integration of findings can dramatically enhance the value of mixed methods research (Younas et al., 2020) and is considered the foundation for conducting high quality and rigorous research (Bazeley, 2018). In the design for this PhD, integration occurs to connect the phases (Creswell & Plano Clark, 2018). The analysis of one dataset and the generated findings are used to inform the subsequent study (Guetterman et al., 2015). The integration of results at different stages in the process allows the research to be driven by the findings (Fetters et al., 2013). This was considered important due to the broad research question and the exploratory nature of the current research.

In this body of research, study 1 (chapter 4) involves an online survey for men who had been diagnosed with breast cancer. It consists of an initial primarily quantitative phase using standardised measures with a small number of open qualitative questions (QUANT + qual). The qualitative questions are included as they have the potential of capturing unanticipated aspects of the topic as well as helping in the interpretation of the quantitative data (Creswell & Plano Clark, 2018; Wasti et al., 2022).

The results of study 1 informs the subsequent qualitative stage (QUAL) (study 2, chapter 5) with the ICs of men with breast cancer. The main research question at this point is ‘What are the experiences and main psychosocial issues that face the ICs of men with breast cancer?’ Semi-structured interviews are considered the method best suited to answer the research question as they provide the opportunity to gather in-depth accounts of personal experiences (Braun &

Clarke, 2022). The results of studies 1 and 2 are integrated and the main findings are embedded in the design of study 3 (chapter 6). This consists of an online non-standardised quantitative survey with HCPs and a number of open questions (QUANT + Qual) (study 3, chapter 6). Finally, the results of the three studies are integrated to connect the findings and are included in the final discussion chapter (chapter 7). Together the studies provide an overview of the psychosocial impact of BCiM.

5. Typological versus interactive design approaches to design

The design of a mixed methods study can be categorised as either a product or a process (Schoonenboom & Johnson, 2017). Numerous typologies of mixed methods designs have been proposed which are characterised by the level of mixing, time orientation and emphasis of quantitative and qualitative approaches (Halcomb, 2019). Creswell & Plano Clark (2011) identified 15 commonly used designs in which the research can fit. However, these are flexible and researchers are recommended to use a more interactive 'hybrid design'. These can include combinations of two or more design types as it is acknowledged that no single typology exists that is perfectly suited to the range of research questions (Teddle & Tashakkori, 2010; Schoonenboom & Johnson, 2017).

Within an interactive approach, the researcher is recommended to ensure the fit between the research goals, conceptual framework, research question, methods and validity are retained throughout the process and to adapt if necessary (Maxwell, 2012; Schoonenboom & Johnson, 2017).

As already discussed, in this programme of research a multi-phase explanatory sequential design was designed by the researcher. The interactive, flexible approach was considered beneficial and enabled the design to suit the research questions and purpose rather than to fit the research into the constraints of a predetermined framework.

6. Planned vs emergent design

In a planned design, the use of quantitative and qualitative methods is predetermined and planned at the start of the research process. Whereas in an emergent design, the components are not planned at the start of the research but are fluid and build on the relationships among variables once the process has started (Creswell and Plano Clark, 2018). In the current research, an emergent design is adopted which enables the framework to be driven by the results.

7. Complexity

This refers to the number of components or phases in a mixed methods design and the points of data integration. In a simple design there is a single point of integration whereas complex designs include numerous points of integration (multiphase design) (Guest, 2013). The complexity of designs also refers to whether the components are interdependent or the extent to which one approach determines the subsequent approach (Schoonenboom & Johnson, 2017). The current research adopts a complex design whereby the results are integrated at a number of timepoints (Figure 1).

Whilst the technical decisions relating to mixed methods designs are important, in order to conduct rigorous research it is also necessary to consider the chosen philosophical approach that best fits the research question and purpose (Bishop, 2015). The following section will outline the chosen pragmatic approach for this research.

3.6 Pragmatic approach in this thesis

A paradigm is used to describe to the researcher's perspective, school of thought or set of shared beliefs that informs the selection of methods best suited to address the research question (Guba, 1990). It also refers to the philosophical orientation and the conceptual lens though which the researcher sees the world and how this informs the meaning or interpretation of the research data (Creswell & Creswell, 2018).

There has been much discussion concerning the relationship between methods and paradigms in mixed methods research (Hathcoat & Meixner, 2017). This arises from quantitive approaches being traditionally associated with positivist epistemologies, whilst qualitative approaches are associated with constructionist or interpretive epistemologies (Onwuegbuzie et al., 2009). Pragmatism acknowledges the philisophical differences between various epistemologies, it has been positioned as a middle ground and is considered to be well suited to mixed methods research (Johnson & Onwuegbuzie, 2004). Accordingly, it rejects a single method approach to research and supports the joint use of quantitative and qualitative methods to come to a broader understanding of a problem. Consequently, pragmatic researchers are free to adopt multiple stances, to combine both inductive and deductive approaches and use both quantitative and qualitative methods within a single study or series of studies (Creswell & Creswell, 2014). It further advocates the use of the most appropriate research methods to address the research question (Creswell, 2014; McChesney & Aldridge, 2019). The freedom afforded to the researcher by adopting a pragmatic approach is considered beneficial to the current PhD and the exploratory nature of the research. The dynamic flexibility results in a range of studies which constitute the overall PhD (study 1, QUANT + qual; study 2, QUAL and study 3, QUANT + qual).

Furthermore, pragmatism rejects the notion of absolute truth and accepts there can be single or multiple realities which change over time (Johnson & Onwuegbuzie, 2004). Accordingly, Pragmatism asserts that knowledge is intrinsically linked with experience (Denzin, 2012) which is both constructed and based on the reality of the world we experience and live in (Johnson & Onwuegbuzie, 2004). In accordance to Yardley & Bishop (2015), pragmatism is considered a suitable paradigm when undertaking 'real-world' research such as healthcare research which requires a multipronged approach. Furthermore, it is considered the guiding paradigm when conducting patient-oriented research which seeks to address practical issues arising directly from communities (Allemang et al., 2022).

The involvemment of people with lived experience in the design and execution of this PhD is deemed integral to strengthen the process and outcomes of the research. Through all stages of the research process it actively engages men with lived experiences of breast cancer as well as ICs and HCPs through Patient and Public Involvement (PPI). The following section outlines the role of PPI in this PhD and thereby further strenghtens the rationale for using a pragmatic approach in this PhD.

3.7 Patient and Public Involvement (PPI)

PPI is defined by the National Institute for Health Research (NIHR) advisory group supporting PPI in health as:

> *"Research being carried out "with" or "by" members of the public rather than "to," "about" or "for" them. It is an active partnership between patients, carers, and members of the public, with researchers that influences and shapes research" INVOLVE (2021).*

PPI in research can also include input from organisations and health professionals (Staley et al., 2021). Together, these are experience-based experts who can offer a unique perspective and provide knowledge, insight and lived experience that is different to that of clinicians and academics (Karazivan et al., 2015).

PPI can potentially enhance the quality of research (Thompson et al., 2014) and ultimately help achieve the goal of improving health and services (Staley et al., 2021). The benefits of PPI in research in rare conditions, such as BCiM, are particularly important due to the low incidence and unique challenges faced by patients associated with the rarity of their disease (Velvin et al., 2022).

PPI is not a single activity but should be incorporated throughout the research process (Staley et al., 2021), including the development of focus and design, recruitment, data generation, data processing and dissemination (Pii et al., 2019). The role and structure of PPI can vary from sitting on an advisory group to being a co-researcher (Marks et al., 2018).

As well as improving research, PPI contributors can personally benefit from the process. In a review conducted in the UK, PPI participants reported an increased sense of self-worth and having gained beneficial skills (Thompson et al., 2014a). The benefits of being involved as a patient advisor in this PhD are presented in the final discussion chapter (chapter 7, section 7.15). However, the negative impacts of PPI involvement must be acknowledged and may include the potential for emotional burden and disillusionment with research processes and outcomes (Brett et al., 2014).

3.7.1 PPI in this thesis

This PhD followed the six core elements outlined by the UK Standards for Public Involvement in research (INVOLVE, 2021) and adhered throughout to the values and principles of respect, support, transparency, responsiveness, fairness of opportunity and accountability (INVOLVE, 2015). Table 1 details how the researcher addressed each standard in the current PhD.

Table 1.

UK standards for PPI in research and how these were addressed in the PhD.

Standard	Definition	How the researcher addressed each standard
Inclusive opportunities	Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.	Flexible in terms of time and corresponded via email, telephone or Microsoft Teams.
Working together	Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.	Discussed roles, responsibilities and expectations of PPI. Invested time developing and building

		relationships with a number of men with breast cancer, charities and healthcare professionals. Included relevant PPI input at each stage of the research process. Recognised PPI contributions, discussed and developed research ideas together.
Support and learning	Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.	Provided details of on-line public involvement training.
Governance	Involve the public in research management, regulation, leadership and decision making.	PPI voices were heard, valued and respected throughout the research planning and design process.
Communication	Use plain language for well-timed and relevant communications, as part of involvement plans and activities.	Lay language was used in all materials and correspondence.
Impact	Seek improvement by identifying and sharing the difference that public involvement makes to research.	Experiences of PPI and their value in this PhD were shared within the research centre and with fellow PhD researchers. Summaries and feedback of research was provided to all PPI

Considerable planning and design were undertaken to incorporate PPI at each stage of the research process. A reflection of these will now be presented.

3.7.2 PPI involvement in the planning stage of the PhD

At the outset of the PhD, discussions were held with several breast cancer charities about the intention to conduct a PhD on BCiM. The need for more research was apparent and the charities were extremely supportive. These conversations formed an important part of the research design and helped identify research priorities.

Reflection on PPI

A patient research partner (‘PI’) was recruited from a local breast cancer support charity. He had been diagnosed with breast cancer in 2015 and is a passionate advocate for raising awareness of BCiM. During our initial meeting, we discussed the role of PPI in research and clarified what this would entail and how we would work together. Our contact throughout the PhD included face-to-face meetings, phone calls and email correspondence. From the outset our conversations were extremely open and honest about his personal experiences of the disease and the impact on his life and relationships. His experience really brought to life the value and importance of conducting this research. He has been a constant source of help and support throughout the PhD and his contribution and guidance has formed an integral part of the research process from beginning to end.

Additionally, I spent time in the breast cancer clinic at a local hospital. It was invaluable to see a working breast cancer clinic, to witness the different roles of healthcare professionals and to be present during the screening process and consultations with breast cancer surgeons. I also had several telephone conversations with a professor of breast oncology in Australia who has written a book on BCiM. The role and incorporation of PPI in each study will be outlined in the corresponding chapters and an overall reflection on the role and impact of PPI in this PhD is included in the final discussion chapter (chapter 7, section 7.15).

3.8 Ethical considerations

Ethical approval for each study was granted from the University of the West of England Faculty of Health and Applied Science Research Ethics Committee (see study chapters for further details). It is important to highlight that the present PhD did not recruit participants through NHS services. There is no central coordinating site for BCiM patients within the UK and men are treated in general hospitals nationwide and it was deemed to be potentially problematic if only one site participated and consequently the research would become a case study of one hospital.

Due to the rarity of the disease, there were concerns regarding recruitment. To establish effective pathways to recruit participants, considerable time was invested building relationships and establishing myself as a researcher within the BCiM field of academics, support organisations and health professionals worldwide. Support organisations were directly approached to help with recruitment in study 1, this targeted approach proved successful and was continued for the following studies.

The *'Code of Human Research Ethics'* set out by the British Psychological society were adhered to throughout the PhD. These include: 1) Respect for the autonomy, privacy and dignity of individuals, groups and communities, 2) scientific integrity, 3) social responsibility and 4) maximizing benefit and minimizing harm (BPS, 2021). The code defines risk in research as "the potential physical or psychological harm, discomfort or stress to human participants that a research project may generate" (BPS, 2021, p. 10).

Potential participants were provided with the necessary and sufficient information about each research study to enable them to make an informed choice for deciding whether to participate. They were also able to contact the researcher to ask questions about the study before making a decision about whether to take part. The opportunity to withdraw their data from the study at any time up to four weeks after completing the study with no adverse consequences was clearly outlined. Information on how to withdraw and contact details of the researcher and her supervisor were provided.

An assessment of potential risk of harm to participants and the researcher was conducted prior to each study. For all studies, there was deemed a potential mild level of discomfort to potential participants due to the sensitive nature of some of the questions being asked. A list of sources of support and links to relevant organisations and charities were provided (e.g., Breast Cancer Care). Further details are provided in the corresponding chapters.

For the researcher, the risk of being exposed to sensitive, emotive comments was considered potentially upsetting (Silverio et al., 2022). Therefore, supervisors with experience conducting research in this area were available for debriefing and support if needed.

To respect the privacy of participants, measures were taken to ensure confidentiality and de-identify individuals so that their identity could be tracked back to them (Kayaalp, 2018). This was deemed particularly important in study 2 wherein the ICs of men with breast cancer discussed the impact of BCiM on their lives and relationships. These results also had the potential to negatively impact others who may be affected by the results.

3.9 Recruitment challenges in psycho-oncology research and rare conditions

This section discusses recruitment challenges and barriers in psycho-oncology research and rare conditions, such as BCiM, as well as strategies used to overcome them in the current PhD.

There are numerous barriers to recruitment in psycho-oncology research including, distrust of the research process (Sheridan et al., 2020) and practical difficulties such as travel (Grand & O'Brien, 2012). The perceived magnitude of the burden associated with study participation can further hinder recruitment (van Lankveld et al., 2018). Age is a constant barrier; despite older people constituting the largest population of cancer patients, they are underrepresented in research (Sedrak et al., 2021). Furthermore, the prospect of discussing sensitive topics can also affect willingness to participate (Jennings et al., 2014). Finally, recruitment in psycho-oncology research can also be affected by the health of potential participants at the time of the study being conducted (Jennings et al., 2014). Additional barriers to conducting research with patients with rare diseases, such as BCiM, can also include a lack of disease awareness, lack of funding, recruitment challenges, scattering of patients, difficulties to achieve accurate diagnosis and identify patients in health information systems (Gagne et al., 2014; Rath et al., 2017).

At the outset of the PhD, recruitment was identified as potentially problematic due to the small, geographically dispersed population of men with breast cancer. The following section will outline steps taken by the researcher to overcome potential barriers. Details of how PPI input aided the recruitment process for each study is outlined in the corresponding chapters.

As previously mentioned, at the outset of the PhD, numerous breast cancer charities and HCPs were contacted to introduce myself and discuss the research. Further connections were developed by presenting the research at public events and conferences (including The Male Breast Cancer Coalition (now known as Male Breast Cancer Happens) and The British Psychosocial Oncology Society Conference). I was also invited to attend a session of The Men's Virtual Meet-Up (The Men's VMU) to present my research. These proved to be valuable opportunities to share my research, make important contacts, and to help with recruitment.

Furthermore, social media platforms such as Twitter and Facebook were used to share information regarding the studies. Through these channels several men with breast cancer and academics made contact to discuss my work.

3.10 Reflexivity

Reflexivity is the active acknowledgement that researchers play a dynamic role and actively influence and shape both the research process and outcomes (Bradbury-Jones, 2007). It involves a continual critical self-examination of the researcher's positionality, prior knowledge, social position, assumptions, values and experience (Berger, 2015b; Finlay & Gough, 2003). The critical role of reflexivity is captured by Hesse-Biber who stated that "reflexivity is key at all points of the research process" (Hesse-Biber, 2010; p. 189).

Reflexivity is particularly associated with the qualitative methods and the reflexive Thematic Analysis approach used in the qualitative elements of this thesis (Braun & Clarke, 2022). Due to the philosophical dichotomy between qualitative and quantitative research methods, the use of reflexivity with quantitative research methods is rare (Walker et al., 2013), although it is increasingly recognised as an essential component for all psychology research (Arora et al., 2022). There are calls to incorporate reflexivity in quantitative research methods; whilst it is acknowledged that whilst numbers themselves are objective, the research process of obtaining them and the results are not objective (Ryan & Golden, 2006).

The aim of reflexivity is not simply to reduce bias in the process but to be transparent and reflective in acknowledging potential influences in the interpretation of the data (Creswell & Plano Clark, 2018; Ortlipp, 2008). Furthermore, reflexivity is essential for researchers' personal growth (Probst, 2015). When incorporated throughout the research process, critical reflection can enhance both rigor, quality and the credibility of the research (Bradbury-Jones, 2007; Jootun et al., 2009).

As recommended by Gerstl-Pepin & Patrizio (2009) a reflective journal was kept throughout the PhD to critically reflect on personal thoughts, feelings and observations throughout the research process and extracts are included in the reflective sections of this thesis. This was an extremely valuable tool during the write up phase of the thesis; it was interesting to look back and remember certain events and feelings experienced at different times throughout the process, to reflect on how things may have been done differently and to see how I had evolved as a researcher.

3.10.1 Personal position

Although I have no personal familiarity or experience of breast cancer, I have been involved as an IC supporting a close friend and her family during her diagnosis and treatment for cancer. This experience enabled me to witness the impact of cancer on both the individual and the family, the effects of cancer treatment and how cancer can pervade many aspects of life. As a White cis female researcher, I am aware of my status as an outsider when conducting research with men with breast cancer. However, I have certain attributes which I found were beneficial and countered my outsider status; I felt that being a mother and being middle aged was beneficial and affected access to potential participants in a number of ways: I found I shared certain life experiences with PPI advisors and participants which helped established a common ground on which to build conversations and develop relationships. I had confidence to reach out and contact men with breast cancer, breast cancer charities and HCPs and to create avenues to discuss the research and develop important contacts. Furthermore, I felt my age was of particular benefit when conducting the interviews in study 2; I was a similar age to many of the participants which I felt helped to create a rapport and comfortable environment which enabled them to openly share their experiences and concerns.

In my family, I am the first generation to attend university. Prior to undertaking the current PhD, I completed a MSc in health psychology which explored women's experiences of their appearance after mastectomy and/or breast reconstruction (Herring et al., 2019; Paraskeva et al., 2019). Although my previous experience was primarily as a qualitative researcher, I was motivated to develop a broader skillset that spans both quantitative and qualitative methods and felt this may benefit my future role as a researcher. In line with the pragmatic approach of this PhD, I felt that the flexibility of mixed methods together with the different types of data collected would result in a more comprehensive and in-depth exploration and understanding of the issues pertinent to men with breast cancer. I considered the different methods would work well together, complement each other and ultimately better contribute to the applied potential of the research than a standalone method. Furthermore, it was hoped that the integration of data would help gain a deeper understanding of a complex phenomenon about which there has been very little research and further this specific area of research. I very much hoped that a mixed methods approach would work together to build a broad and rich understanding of BCiM which could ultimately be used to help improve their lives and the lives of those caring for them. I was also aware there may be more opportunities to publish the research, in qualitative, quantitative, and mixed methods journals and thereby enable the research to reach a wider audience. This could potentially serve to highlight the important issues facing men with breast cancer across a variety of disciplines and simultaneously raise the profile of the research.

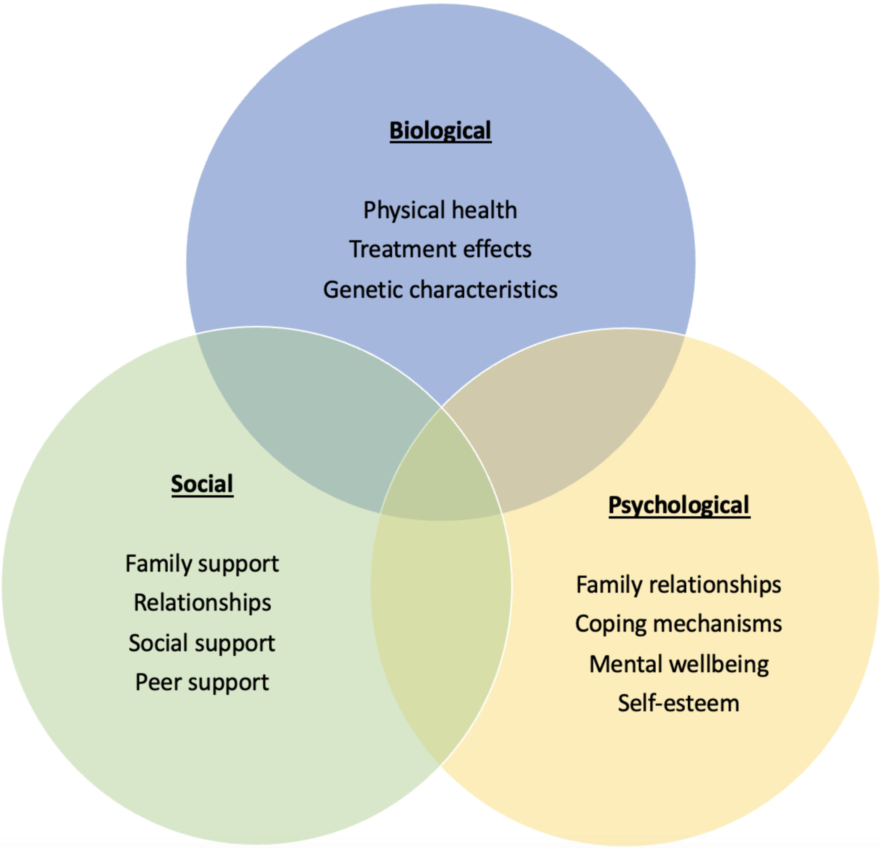
3.11 Biopsychosocial lens

This section will outline the broad biopsychosocial lens used to guide the PhD and presents a diagram of the conceptual framework to illustrate the interactions among the biological and psychosocial components and how they may relate to men with breast cancer and their ICs.

As previously stated, the exploratory approach of the PhD aims to better understand the psychosocial impact of BCiM and to explore how the illness is experienced by patients and their ICs. Consequently, this is unlike a theoretically driven PhD, which may use theory to test or design an intervention such as the Tripartite Influence Model (Thompson et al., 1999) or be guided by a specific theoretical perspective such as social constructivism and masculinity (Connell, 2005; Fried, 2020). The justification of not having a theoretical basis at the outset of study 1 is that the researcher did not want to be restricted by a specific theoretical model or to focus purely on constructs such as masculinity or body image. Whilst it is recognised these are undoubtably extremely important, this was not the aim of the current PhD. However, as the research developed it was deemed important to consider a conceptual framework as a lens to guide the research (Fried, 2020).

Figure 2

Biopsychosocial model adapted from Engel (1980).



3.11.1 Defining 'psychosocial'

Although the term psychosocial is frequently used in research, definitions are rarely offered. According to the American Psychological Association (APA) Dictionary of Psychology (2022) psychosocial is defined as 'the intersection and interaction of social, cultural, and environmental influences on the mind and behaviour'.

The relationships between biological and psychosocial factors and health are interrelated and complex (Public Health England, 2017). The Constitution of the World Health Organisation stipulates that "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2023, p.1).

The main issues experienced by men with breast cancer outlined in chapter 1 are conceptualised in the "biopsychosocial (BPS) model" (Figure 2). This model illustrates the dynamic between biological, psychological and social life circumstances and provides a holistic view to addressing health (Engel, 1980). In brief, the biological (bio) is often associated with the relationship of the disease and bodily health. The physiological (psycho) are aspects of mental and emotional wellness that relate to behaviour and the social (social) are interpersonal factors such as social interactions and social support. Crucially, the model illustrates the interconnectedness of these factors, highlighting the complex processes which can impact health (Taukeni, Mathwasa & Ntshuntshe, 2023).

Although this PhD is focused on the psychosocial aspects of BCiM, it is recognised that it is impossible to consider these in isolation to the biological aspects of the disease and treatments.

Consequently, the biopsychosocial model is used as an overarching framework throughout the PhD.

3.12 The next stage of the research

The following chapters will present three research studies and findings. In accordance with the third doctoral descriptor, these chapters will demonstrate the researcher's ability to conceptualise, design and implement a project for the generation of new knowledge. In light of the Covid pandemic, the measures taken to ensure satisfactory recruitment, the use of Microsoft Teams to conduct interviews as well as the 'back-up study' (study 3), illustrate the researcher's ability to adjust the planned project in the light of emergent issues.

Chapter 4. Study 1: An online survey exploring men's experiences and body image concerns following breast cancer. A mixed methods study

4.1 Introduction

This chapter presents the initial exploratory study undertaken in this PhD. As outlined in chapter 2 (section 2.2), the core themes identified in the BCiM literature included: lack of awareness among the general population, body image concerns, impact on quality of life and masculinity. These were considered important areas to study in greater depth in study 1.

A principle aim of this study was to explore body image concerns in BCiM patients. Whilst qualitative research has shown body image is a concern for many men who have received treatment for breast cancer, it was considered important to quantify the extent to which men with breast cancer were affected by cancer and treatment related changes to their body as this is currently missing from the literature. Consequently, one goal of study was to establish the extent of body image concerns in men following treatment for breast cancer, by using several standardised measures (section 4.4.7). The study also aimed to explore men's experiences of support for body image concerns and their experiences of the treatment process more generally, using open-ended questions (Table 3 and 4). These gave participants the opportunity to freely express their experiences and additional concerns in more detail, thereby providing a deeper insight and understanding of their concerns, as well as allowing participants to share areas of concern which may have not been considered by the researcher.

The research presented in chapter 2 (section 2.4) illustrates for many men, breast cancer can have profound effects on masculinity and self-esteem. A growing body of evidence describes masculine self-esteem in the context of prostate cancer and refers to how men appraise their own masculinity after diagnosis and/or treatment, particularly, the extent to which they still consider themselves a “whole man” (Clark et al, 2003; Mcateer & Gillanders, 2019). As outlined in chapter 2 (section 2.1.6), men with breast cancer are often prescribed the same medication as prostate cancer patients. Common side effects of treatment can include fatigue, gynaecomastia, hot flushes and erectile dysfunction and can impact masculine self-esteem (Clark et al, 2003; Mcateer & Gillanders, 2019). A cross-sectional analysis has shown that prostate cancer patients report reduced masculine self-esteem compared to non-cancer populations and that one third of men experience low masculine self-esteem after treatment (Clark et al., 2003). Due to the combination of being diagnosed with what is commonly perceived as a female disease, body image concerns and poor sexual function following treatment, it was deemed important to measure masculine self-esteem in the current study.

Finally, a large body of research with women with breast cancer has shown the physical side-effects of treatment and psychological distress associated with the disease (e.g., depression, anxiety and fear) can adversely affect quality of life (Mokhtari-Hessari & Montazeri, 2020; Nardin et al., 2020). Similar experiences have been shown with other cancer groups including men with prostate cancer (Downing, 2019; Tourvinen, 2013). It was therefore considered important to explore the impact breast cancer has on the quality of life of male patients in more depth.

The aims of the study were:

- To explore the extent of body image concerns in men following treatment for breast cancer.

- To explore the impact of BCiM on masculine self-esteem
- To explore the impact of BCiM on quality of life.
- To explore men's experiences of treatment as well as support for body image concerns.

4.2 Ethics approval

Ethical approval for this study was granted from the Faculty of Health and Applied Sciences Research Ethics Committee at The University of the West of England, Bristol, UWE REC REF No: HAS. 19.05.188 (Appendix 24).

4.3 PPI involvement

PPI feedback was sought from three men with breast cancer (one in the UK, one in the US and one in Australia) and two breast cancer surgeons (one in the UK and one in Australia) who had worked with male patients. It was considered important to include representatives from other English-speaking countries to ensure the language used was acceptable to all participants. Those who were invited to provide feedback were contacts made by the researcher.

A copy of the survey was emailed, and they were asked to provide feedback on the wording of documents. These included the study information sheet and consent forms, the wording of the standardised measures, the open-ended qualitative questions, and the overall survey design. The two surgeons were also asked to provide feedback on the questions concerning breast cancer treatment. The only suggestion for edits were from the three men with breast cancer who advised to use the term "appearance" rather than "body image and appearance" in the survey as they did not identify with the term body image. This was amended. All were happy with the remaining wording of the documents and did not provide further suggestions for edits. PPI feedback estimated that the survey would take approximately 10 minutes to complete. The survey was also previewed and tested by the PPI advisors before it was released.

4.4 Method

4.4.1 Design rationale

As previously discussed in chapter 3 (section 3.4), research to date has been dominated by small group samples and qualitative analyses of men's experiences. It was considered that a further purely qualitative study at this stage could replicate much of this previous work. Furthermore, as previously mentioned, a narrative synthesis of the existing qualitative literature was conducted in 2016 (Quincey et al., 2016), with insufficient new literature published since to warrant a further qualitative synthesis at this stage. Consequently, an exploratory mixed-methods study was deemed the most suitable way to progress research in this field, by providing a better understanding of the extent and variation in men's experiences of breast cancer treatment, body image concerns, and impact on masculine self-esteem and quality of life.

As previously outlined in chapter 3 (section 3.4) the design for study 1 consisted of an initial primarily quantitative phase using standardised measures, with a small number of qualitative questions (QUANT + qual).

4.4.2 Research questions

The following section will present the quatitative research questions and the open-ended qualitative questions. Table 2 presents the aims and objectives of the study, the rationale and the research questions in study 1.

Table 2

Aim and objectives of the study, the rationale and the research questions in study 1

Aims and objectives To explore the extent of body image concerns in men following treatment for breast cancer.	
Current literature which informed the research questions • **Men with breast cancer often experience physical changes and body image concerns following treatment (da Silva, 2016)** • **Men with prostate cancer do not experience poorer body image during treatment than pre-treatment (van den Driessche et al., 2016)** • **Body image predicts quality of life in men with prostate cancer (Taylor-Ford, 2013)**	
Research questions	**Statistical Analysis**
1. Is there a difference in body image scores for men currently undergoing treatment and men not currently undergoing treatment?	1. Independent samples t-tests conducted on each of the body image scales.
2. Are men who undergo a greater number of treatments for breast cancer associated with lower body image scores than those who have fewer treatments?	2. One-way between groups multivariate analysis of variance was performed to investigate the number of treatments and body image scores. Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance- covariance matrices, and multicollinearity, with no serious violations noted. According to Tabacchnick & Fidell (2013, p.253) a sample size of at least 20 in each cell should ensure ‘robustness’. Consequently, due to the small cell sizes in the sample, the cells were grouped together; Group 1 = 1-2 treatments and Group 2 = 3-5 treatments
3. Are body image scores negatively associated with masculine self-esteem?	3. Pearson correlation. Preliminary analysis were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity.

<table>
<tr><td>4. Is body image negatively associated with quality of life scores?</td><td>4. Pearson correlation.</td></tr>
<tr><td colspan="2">Aims and objectives
To explore the impact of BCiM on masculine self-esteem</td></tr>
<tr><td colspan="2">Current literature
• Changes in body image due to treatment for breast cancer can impact men’s self-esteem (Midding et al., 2018)
• Men with breast cancer often feel emasculated (da Silva, 2016)
• Diagnosis and treatment for prostate cancer is likely to negatively impact patients’ masculine self-esteem (Appleton et al., 2015)
• Masculine self-esteem is a significant predictor of distress and quality of life in men with prostate cancer (McAteer & Gillanders, 2019)</td></tr>
<tr><td>Research question
5. How well do the measures of body image, quality of life, self-esteem and the demographic variables (time since diagnosis and age) predict Masculine Self-Esteem?</td><td>Statistical Analysis
Multiple linear regression were used to explore the relationships between variables. Assumptions for multicollinearity, outliers, linearity, homoscedasticity, and independence of residuals were checked.</td></tr>
<tr><td colspan="2">Aims and objectives
To explore the impact of BCiM on quality of life</td></tr>
<tr><td colspan="2">Current literature
• Men with breast cancer have lower quality of life scores than the general population (Kowalski, et al., 2012)
• Men with prostate cancer experience worsening of quality of life during treatment compared to a normal reference population (Schaake er al, 2013)</td></tr>
<tr><td>Research questions
6. Is there a difference in quality of life scores for men currently undergoing treatment and men not currently undergoing treatment?</td><td>Statistical Analysis
6. Independent samples t-test</td></tr>
</table>

7. How well do the measures of body image, self-esteem, and the demographic variables (time since diagnosis and age) predict quality of life? What is the best predictor of quality of life: body image, Masculine Self-Esteem, self-esteem, time since diagnosis, or age?	7. Multiple linear regression were used to explore the relationships between variables. Assumptions for multicollinearity, outliers, linearity, homoscedasticity, and independence of residuals were checked.

Open-ended qualitative questions

Free response questions asked participants about changes to their appearance and the support received since diagnosis (Table 3), as well as their preferences for support and information (Table 4).

Table 3

Free response questions included in the survey

1. Is there anything else about your diagnosis/treatment you would like to share?
2. Is there anything else you would like to tell us about any changes to your appearance that you have noticed since your diagnosis or treatment?
3. Could anything have been done differently by the breast care service that may have improved your experience of changes to your appearance as a result of breast cancer treatment or surgery?
4. Did you seek any support for appearance related issues, at any stage following your diagnosis? If yes, please give details.
5. When did you seek support for appearance related issues?

Table 4

Additional questions included in the survey

1. What format of support would you have preferred?

Options included: Group meetings, online support, peer support and ‘other’, a text box was provided to respond with further suggestions.

2. How do you prefer your Breast Cancer to be called?

Options included: Breast cancer, male breast cancer, cancer of the chest and ‘other’, an open text box was provided to enter preference.

3. Do you think the questions in this survey have addressed your appearance related concerns?

A box was provided to provide their feedback on the survey. The final question in the survey queried participants’ preferred terminology when referring to breast cancer in men. See Appendix 5 for a copy of the survey.

4.4.3 Survey

The survey was designed and hosted on the secure on-line platform, Qualtrics (Qualtrics, 2019). This was considered an efficient method to access people or groups that have been under-represented in research. This approach is also cost effective and more environmentally friendly than a paper format (Evans & Matur, 2018).

The programme provided flexibility in terms of formatting so that respondents could participate either on a desktop or mobile device. The survey was designed using the automatic logic control and branching of questions which enabled the flow of questions to be customised to each respondent. The validation function was used to either force respondents to answer a question or request that they consider answering the question before leaving the page, which helped minimise missing data. Finally, the survey did not have to be completed in one sitting and participants could pause and continue at the same point later if preferred. Participants were required to provide fully informed consent prior to completing the survey.

4.4.5 Demographics

The following demographic data were collected: age, ethnicity, relationship status, sexual orientation, employment status and country of residence. This information was sought to provide an overview of the types of people who participated in the project.

4.4.6 Breast cancer information

Participants were asked to provide disease-related information and details of their treatment, including time since diagnosis and treatment received (current breast cancer treatment, surgery, chemotherapy, adjuvant radiation, hormonal therapy, rehabilitation). Participants were able to select more than one type of treatment, as it was likely they may have received several treatment types (Gucalp et al., 2018). An open-text box was provided for participants to provide details on the type of surgery received and their country of treatment. Details of health comorbidities were also collected.

4.4.7 Selection of outcome measures

Careful consideration was given to deciding what psychosocial variables should be included in this study, with consultation of the current breast cancer literature and wider reading. The psychometric properties of measures were taken into account, including validity (construct validity) and reliability (test-retest reliability, internal consistency). Attention was given as to whether the measure was a generic tool or a disease-specific instrument, and whether it had been used within another male cancer group, such as prostate cancer. Due to the paucity of quantitative research conducted in this field and the rarity of BCiM, it was not considered necessary for the measures to have been used previously with this population, although it was preferable for the measure to have been used with males. Additional consideration was given to whether the language in the measure was easy to understand, the length of the questionnaire, and whether this would affect response burden, and consequently, response rate. It was acknowledged that a longer questionnaire may result in fatigue, reduce data quality, or lead to items being omitted (Rolstad et al., 2011). The measures included in the survey are outlined below. All scales used in the present study had a Cronbach's alpha score of a > 0.7 – 0.9, thereby indicating good internal reliability (Kline, 1999). In this section the researcher will demonstrate she has met the doctoral descriptor of understanding validation procedures.

4.5 Outcome measures included in the survey

4.5.1 Body image

The Body Image Scale (BIS; Hopwood et al., 2001) was specifically designed to be applicable to patients with any cancer site and any form of cancer therapy. It assesses the degree of body dissatisfaction following treatment for cancer, feelings of attractiveness, and self-consciousness. The measure has been widely used in oncology research, including in randomised controlled trials for women with breast cancer (Przezdziecki et al., 2013). The scale consists of 10 items (e.g. 'Have you felt less physically attractive as a result of your treatment?'), with response options of ``not at all'' (score 0), ``a little'' (score 1), ``quite a bit'' (score 2) and ``very much'' (score 3). The 10 item scores were then summed to produce overall summary score for each patient. Permission to change the wording of the item ‘Have you been feeling less feminine as a result of your disease or treatment?’ was granted by the author, and was consequently changed to ‘Have you been feeling less masculine as a result of your disease or treatment?’ Scored between 0-30, higher scores indicate poorer body image and higher levels of psychological distress. The measure has good structural validity, internal consistency, and test-retest reliability in female breast cancer patients (Cronbach's α = .92; Hopwood et al., 2001). It has been used in men with breast cancer (Cronbach's α = .89; Brain et al., 2006). The current sample showed high internal consistency (α = .90).

The Multidimensional Body-Self Relations Questionnaire (MBSRQ; Appearance Evaluation Subscale MBSRQ-AE; Cash, 2000). The seven item sub-scale assesses individuals’ thoughts and feelings regarding their physical attractiveness and satisfaction concerning their overall appearance, for example: ‘I am physically unattractive’. Items were rated on a 5-point Likert scale (1 = definitely disagree to 5 = definitely agree) or ‘not applicable’. Some items (‘I dislike my physique’ and ‘I am physically unattractive’) were reverse scored. Items were summed and averaged to produce a total score between 0-5, with higher scores indicating satisfaction with appearance. In a study of male college students, the MBSRQ-AE had good internal reliability (α = .87; Galli et al., 2015). Adult male norms are reported to be men 3.49, SD .83 (Cash, 2000). The current sample showed high internal consistency (α = .90).

The Objectified Body Consciousness Scale (OBCS); Body Surveillance Subscale; (McKinley & Hyde, 1996). The subscale measures how the person observes their body and thinks of it more in terms of appearance than how it feels (e.g., ‘I think more about how my body feels than how my body looks'). The OBCS has been widely used within the wider body image literature (Moradi & Varnes, 2017). It has also been used with female breast cancer survivors (Boquiren et al., 2013), and although originally designed for women, it has also been used with men (Manago et al., 2015). Additionally, the authors support the use of the Body Surveillance Subscale in clinical practice, prevention, and intervention efforts. Items are measured on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree) with a "not applicable". Appropriate items are reverse coded, and applicable item responses are averaged to compute subscale scores, with higher scores indicating higher levels of body surveillance (scored 0-49). In a study of women with breast cancer, the Body Surveillance subscale has good internal reliability (α = .77; Boquiren et al., 2013), which was replicated in the current study (α = .74).

4.5.2 Quality of life

The Functional Assessment of Cancer Treatment - **Breast (FACT-B**; Cella et al, 2017a) is a 37-item instrument designed to measure five domains of quality of life in breast cancer patients: physical, social, emotional, functional well-being as well as the breast cancer subscale. It is utilised with the core FACT–G (general) questions. FACT-B is designed for women with breast cancer and a license was granted to use the scale with men, with permission to amend the following item from "I am able to feel like a woman" to "I am able to feel like a man". Scored from 0-100, higher scores indicate a better quality of life. FACT-B has reported excellent internal reliability in women with breast cancer (α = .90; Cella et al., 2017). The current sample showed good internal consistency (α = .70).

4.5.3 Masculine self-esteem

The Masculine Self-Esteem Scale (MSES; Clark et al., 2003)

The MSES is a measure to assess the physical and mental components associated with negative self-appraisal to masculinity. It consists of 8 items (e.g., ‘No longer a whole man’). The measure was originally designed for men with prostate cancer, however, the wording is not specific to prostate cancer. As patients with prostate and breast cancer are treated similarly (e.g., with Tamoxifen), they may experience similar physical side effects (e.g., urinary and sexual dysfunction) (Pemmaraju et al., 2012), which may impact their sense of masculinity. Therefore, it was considered a suitable measure for men with breast cancer. The scale has been widely used with prostate cancer patients (Clark et al, 2003; Scandurra et al., 2022; Mcateer & Gillanders, 2019). Items are answered on a 5-point Likert scale ranging from 1 (not at all) to 5 (very much). As per the instructions for the measure, all items are reverse scored. Higher scores indicate higher masculine self-esteem. The normalised population men in men aged >50 years is 79.7, SD 20.6 (Clark et al., 2003). The measure has excellent internal reliability in men with prostate cancer (α = 91; Clark et al., 2003). The current sample showed high internal consistency (α = .88).

4.5.4 Self-esteem

The Single-item Self-Esteem scale (SISE; Robins et al., 2001) was used to measure self-esteem. The statement ‘I have high self-esteem' is rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Internal consistency reliability (Cronbach’s coefficient alpha) cannot be measured for a single item scale. However, a study comparing the SISE with the Rosenberg Self-Esteem Scale (RSE) 10-item scale reported a promising median correlation of .75

(Robins et al., 2001). The scale has been widely used, including with women with breast cancer and in male body image research (Hosking et al., 2017; Lewis-Smith et al., 2018). The SISE was chosen in preference to the Rosenberg Self-Esteem Scale (RSE) for this study to limit the number of items administered and participant burden.

4.6 Target sample

The target sample size for this study was *n* = 100. This was not based on a power analysis but guided by the sample of the only mixed methods study conducted to date with men with breast cancer (*n* = 100; Midding et al., 2019). This figure was deemed an appropriate size considering the rarity of the disease, concerns surrounding recruitment and the uncertainty surrounding Covid and how this may impact recruitment.

4.7 Eligibility criteria

Inclusion criteria:

- Men over the age of 18 years
- Have received a diagnosis of breast cancer, with or without treatment. There were no exclusion criteria for type of treatment or stage of disease
- There were no criteria concerning time since diagnosis
- Able to complete a questionnaire in English

Exclusion criteria:

- Men under the age of 18
- Men who have received a diagnosis for cancer other than breast cancer
- Not fluent English speakers

4.8 Recruitment strategy

Following ethical approval, prior to recruitment, initial email contact with breast cancer support organisations was made. These were followed up with phone calls, and where possible, either face-to-face meetings, SKYPE, or telephone conversations. Generic and breast cancer specific charities and support organisations were approached to share the study details. It took a considerable amount of time to form relationships with these organisations. Some voiced concerns about their prior experiences of being approached by researchers to help with recruitment. They spoke of the insensitive way their members had been positioned as merely numbers for previous research studies, and how researchers had failed to take into consideration that they were individuals living with cancer and undergoing treatment. However, over time and after many phone conversations and email correspondence, strong relationships with charities and support organisations were forged, and all agreed to support and help with recruitment. It was agreed the research findings would be shared with those organisations who helped with recruitment.

The study and link to the Qualtrics survey were advertised on the Centre for Appearance Research's social media channels, including Twitter, Facebook and Instagram (see Appendix 6 for a copy of the social media recruitment posts). Finally, snowballing sampling also occurred, whereby the study was shared online. Participants were provided with a simplified web link to access the survey. Table 5 shows charities, support groups and online forums who promoted the study on their social media channels.

Table 5.

Charities, support groups and online forums who promoted the study on their social media channels

Country	Organisation	Action taken
UK	Breast Cancer Now Maggie's Bust Walk the Walk One for the Boys Blue Ribbon Foundation #Bluegetittoo	Advertised the study on their social media platforms/forums
	Breast Cancer Haven	Displayed posters in their centres
	Penny Brohn UK	Tweeted and wrote a news story about the research on their website
US	Male Breast Cancer Coalition HIS Breast Cancer	Advertised the study on their social media platforms
	A Man's Pink	Dedicated a page on their website to the study
Australia	Breast Cancer Network Australia	Advertised the study on their social media platforms
The Netherlands	The Dutch Cancer Society	Advertised the study
Individuals	Breast cancer surgeon (Australia)	Promoted the study on social media
	Male with breast cancer (UK)	This individual is extremely active on social media and very motivated to raise the profile of BCiM at public events
	Patient advocate (UK)	Promoted the study

See Appendix 7 for a description of the charities, support groups and individuals involved in recruitment for study 1.

4.9 Analysis

4.9.1 Quantitative data analysis

The dataset was analysed using SPSS v.28. Preliminary examination of the raw data revealed that 200 men had accessed the survey, of which 113 consented to take part, and a further 24 withdrew without providing any data. One participant completed the survey twice, and one entry was only partially completed, and this was removed. One entry was from a PI providing feedback. This resulted in a data set of 87 men who completed the survey, and upon which this analysis was conducted. Preliminary checks revealed that the dataset conformed to assumptions of normality and there was very little missing data (<5%) of the total number of cases. This level of missing data is considered negligible and may be ignored during the analysis (Jakobsen et al., 2014).

4.9.2 Qualitative data analysis

Initial consideration was given to conducting a qualitative content analysis. This is a systematic coding and categorizing approach to evaluate patterns across responses and identify the frequency with which a topic is raised (Vaismoradi et al., 2013). However, participants gave detailed and rich responses to the open-ended questions in the survey which provided the researcher the opportunity to explore their experiences in more depth, and to gain a broader and deeper understanding of the issues facing men with breast cancer. Consequently, in line with the pragmatic approach to the PhD, consideration was given to the most suitable analytic approach and reflexive Thematic Analysis (reflexive TA; Braun & Clarke, 2022) was deemed a better match to both the dataset and the aims of the research (Braun & Clarke, 2022). Reflexive TA is particularly suited to health research and enables researchers to undertake robust and sophisticated analysis and to gain a deep insight into the experiences and perspectives of patients (Braun & Clarke, 2014).

Whilst both qualitative content analysis and reflexive TA are analytic approaches centered on the analysis of patterned meaning across the dataset, reflexive TA enabled the researcher to gain a deeper insight into the experiences of men with breast cancer (Braun & Clarke, 2022). Reflexive TA is theoretically flexible (Braun & Clarke, 2022) and the chosen approach to this study is outlined below;

An inductive approach was adopted to explore the experiences, meaning, and the subjective reality of participants (Braun & Clarke, 2013). This enabled themes to be formed by data content rather than pre-existing models and is in accordance with the exploratory nature of the PhD. Themes were identified semantically, examining explicit meanings of data and an experiential style aimed to capture participants' perspectives (Braun & Clarke, 2013).

In accordance with the central component of reflexive TA, the researcher's experiences, pre-existing knowledge, social position, and how these aspects influence and contribute to the research process and potential insights into the data (Braun & Clarke, 2022). Researcher subjectivity and awareness improves the trustworthiness of the research and further enhances the rigor and ethics of the findings (Bradbury-Jones, 2007). To provide transparency of the research process and to engage in reflexive thinking, the researcher kept a reflective journal of her position and how these may contribute to the research process and throughout the analysis (Braun & Clarke, 2022). Appendix 8 includes an extract of the reflexive log.

Analytic steps

Analysis followed the six phases of reflexive TA, conducted in a recursive process: (1) data familiarisation; (2) coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining, defining and naming themes; and (6) writing up (Braun & Clarke 2022).

Initial familiarisation of the dataset involved repeated readings of text to develop deeper insight. The analysis was conducted on paper, interesting features were noted, and preliminary codes were recorded by coding the responses, drawing comparisons across the dataset, identifying and developing themes (Appendix 9 includes an example of coding and an example of a thematic map). Themes were reviewed and confirmed as simultaneously unique, but integral to the broader story. Codes were organised into potential themes, which were reviewed several times. Titles, definitions and supporting evidence for each theme were collated. The themes are presented below, supported with illustrative quotes from participants. Participant number, age, treatment type and country are indicated next to each quote, to provide context. To ensure rigor and to enhance the validity of the findings (Thomas & Magilvy, 2011), the following steps were taken; the analysis was primarily conducted by the author, and example themes, titles, definitions, along with supporting evidence, were reviewed and confirmed by the supervisory team.

4.10 Results

4.10.1 Participant demographics

Participants were aged 25–89 years (mean = 61.43 years; *SD*:12.44). Most were married or in a civil partnership (86.2%). They had received treatment in 9 countries worldwide. Table 6 displays the sample's demographic characteristics.

Table 6.

Sample demographic characteristics

Characteristic		**n**	**%**
Age	Range 25 - 89 years		
(n= 87)	Mean 61.43 years (SD 12.44)		
Age			
(n= 87)	20-30	3	3.4
	31-40	5	5.7
	41-50	9	10..3
	51-60	23	26.4
	61-70	31	35.6
	71-80	14	16.1
	81-90	2	2.3
Ethnicity	White	85	97.7

(n=87)	Black/African/Caribbean/Black British	2	2.3
Relationship status	Single	4	4.6
(n=87)	Married/civil partnership	75	86.2
	In a relationship but not married or in a civil partnership	3	3.4
	Divorced	3	3.4
	Separated	1	1.1
	Prefer not to say	1	1.1
Sexuality	Heterosexual	81	93.1
(n= 87)	Gay	4	4.6
	Bisexual	1	1.1
	Other	1	1.1
Employment	Employed	34	39.1
(n=87)	Self-employed	7	8
	Retired	43	49.4
	Other (disabled)	3	3.4

Country of residence (n=87)	United States of America	57	65.5
	United Kingdom	9	10.3
	Australia	12	13.8
	Belgium	2	2.3
	Canada	3	3.4
	Germany	1	1.1
	New Zealand	1	1.1
	Czech Republic	1	1.1
	Austria	1	1.1

4.10.2 Breast cancer diagnosis and treatment information

Information regarding time since diagnosis and treatment(s) received is summarised in Table 7. Participants ranged from being diagnosed within one month to 48 years and 3 months (580 months), with a mean of 73.48 months (approx. 6 years 1 month), Std. Deviation of 87.85 months (approx. 7 years 3 months). Due to the complex and multifaceted treatments for BCiM, participants were able to select numerous options for treatment. Among the 87 participants, 81 had undergone radical surgery. Of these, 73 (90.1%) had undergone a single mastectomy, whilst 8 (9.9%) had undergone a double mastectomy. Only 6 (6.9%) of the total sample had not undergone surgery. Over half of the respondents (*n* = 55, 63.2%) were undergoing treatment at the time of completing the survey. See Table 7 for treatment characteristics.

Table 7.

Diagnosis and treatment characteristics

Characteristic		***n***	**%**
Time since diagnosis (months) (*N*=87)	Range 1-580 months		
	Mean 75.48 months		
	Std. Deviation 87.85		
Time since diagnosis (years)			
(*n*=87)	0 -2 years	29	33.3
	3 – 4 years	10	11.5
	5 – 6 years	17	19.5
	7 – 8 years	10	11.5
	9 – 10 years	6	6.9
	11 + years	15	17.2
Surgery (n=81)	Single Mastectomy	73	90.1
	Double Mastectomy	8	9.9
Treatment received (*n*=85)	Surgery	11	12.9
	Surgery + chemotherapy	10	11.8
	Surgery + Chemotherapy + hormonal	13	15.3
	Surgery + radiotherapy	2	2.4
	Surgery + radiotherapy + chemotherapy	5	5.9
	Surgery + radiotherapy + chemotherapy + hormonal	18	21.2

	Surgery + hormonal	12	14.1
	Surgery + hormonal + rehab	1	1.2
	Surgery + chemotherapy + hormonal + rehab	1	1.2
	Surgery + radiotherapy + hormonal	2	2.4
	Surgery + hormonal + radiotherapy + rehab	1	1.2
	Surgery + chemotherapy + radiotherapy + rehab	1	1.2
	Surgery + chemotherapy + radiotherapy + hormonal + rehab	4	4.7
	Chemotherapy + radiotherapy + hormonal	3	3.5
	Radiotherapy + hormonal	1	1.2
	None	2	2.4
Currently undergoing treatment (n=87)	Yes	55	63.2
	No	32	36.8
Type of treatment currently undergoing (*n*=55)	Hormonal (e.g., Tamoxifen)	38	48.7
	Chemotherapy	11	14.1
	Radiotherapy	2	2.6

	Other	27	34.6
Additional health concerns (*n*=80)	Yes	64	80.0
	No	16	20.0

Nb. The cumulative percentage may exceed 100, as participants were allowed to select more than one treatment, i.e., they received several treatments.

4.10.3 Psychosocial measures

The mean scores for the psychosocial variables are presented in Table 8.

Table 8.

Descriptive statistics on psychosocial variables

Psychosocial variable	Theoretical min-max	Mean (SD)
Functional Assessment of Cancer Treatment; Breast Cancer specific (FACT-B)	0-100	70.85 (16.04)
Body Image Scale (BIS)	0-30	9.05 (7.06)
The Multidimensional Body-Self Relations Questionnaire; Appearance Evaluation Subscale (MBSRQ-AE)	1-5	3.64 (1.09)
The Objectified Body Consciousness Scale; Body Surveillance Subscale (OBCS)	0-49	29.90 (5.70)
The Single-Item Self-Esteem Scale (SISE)	1-5	3.67 (1.08)
Masculine Self-Esteem Scale (MSES)	0-100	74.56 (21.24)

* Cronbach's coefficient alpha cannot be measured for a single item scale

4.10.4 Research questions and results

Is there a difference in body image scores for men currently undergoing treatment and men not currently undergoing treatment?

BIS: There was a non-significant difference for those undergoing treatment (M = 8.85, SD = 7.27) and those not currently undergoing treatment (M = 9.50, SD = 6.79), t = (83) = -.405, p = .69, two=tailed).

MBSRQ-AE: There was a non-statistical difference for those undergoing treatment (M = 3.35, SD = 0.80) and those not undergoing treatment, t = (84) = -1.58, p = .12, two=tailed).

OBCS: There was a non-statistical difference for those undergoing treatment (M = 31.73, SD = 6.76) and those not currently undergoing treatment (M = 34.45, SD = 8.08), t = (83) = -1.67, p = .10 two=tailed).

There was a non-statistical difference in all body image measures between men currently undergoing treatment and not currently undergoing treatment, and the magnitude of the effect was small for all measures.

Are men who undergo a greater number of treatments for breast cancer associated with lower body image scores than those who have fewer treatments?

There was a non-significant difference between those who had received 1-2 treatments and those who had received 3-5 treatments, F (0.6, 78, p = .61; Wilks' Lambda = .98; partial eta squared = .02. The number of treatments received for BCiM do not impact body image.

Are body image scores negatively associated with masculine self-esteem?

There was a strong, negative correlation between masculine self-esteem and body image (BIS), r = -.78, n = 84, p = <.001, with high levels of masculine self-esteem associated with lower levels of body image concerns. There was a strong positive correlation between masculine self-esteem and body image (MBSRQ-AE), r = .50, n = 85, p = <.001, with high levels of quality of life associated with higher levels of positivity and satisfaction with appearance. Finally, there was a positive correlation between masculine self-esteem and body image (OBCS), r = -.44, n = 85, p = <.001, with high levels of masculine self-esteem associated with higher levels of body surveillance and higher levels of distress. Table 9 shows correlations between Masculine self-esteem and body image scales.

Table 9.

Correlations between Masculine self-esteem and body image

	MSES	**BIS**	**MBSRQ-AE**	**OBCS**
MSES	*			
BIS	-.78**	*		
MBSRQ-AE	.50**	-.62**	*	
OBCS	.44**	-.53	.49**	*

**Correlation is significant at the .01 level (2-tailed)

Masculine self-esteem (MSES)

Body image (BIS)

The Multidimensional Body-Self Relations Questionnaire; Appearance Evaluation Subscale (MBSRQ-AE)
The Objectified Body Consciousness Scale; Body Surveillance Subscale (OBCS)

Is body image negatively associated with quality of life scores?

There was a strong, negative correlation between quality of life (FACT-B) and body image (BIS), r = -.61, n = 85, p = <.001, with high levels of quality of life associated with lower levels of body image concerns. There was a strong positive correlation between quality of life and body image (MBSRQ-AE), r = .62, n = 86, p = <.001, with high levels of quality of life associated with higher levels of positivity and satisfaction with appearance. Finally, there was a strong, positive correlation between quality of life (FACT-B) and body image (OBCS), r = .55, n = 85, p = <.001, with high levels of quality of life associated with higher levels of body surveillance and higher levels of distress. Figure 3 shows scatterplots displaying the direction of the relationship between quality of life (FACT-B) and the body image measures (BIS, MBSRQ-AE, OBCS) and quality of life (FACT-B) and masculine self-esteem (MSES). Table 10 shows correlations between quality of life and body image scales.

Table 10.

Correlations between Quality of life and body image scales

	FACT-B	BIS	MBSRQ-AE	OBCS
FACT-B	*			
BIS	-.61**	*		
MBSRQ-AE	.62**	-.62**	*	
OBCS	.55**	-.53	.49**	*

**Correlation is significant at the .01 level (2-tailed)

Masculine self-esteem (MSES)

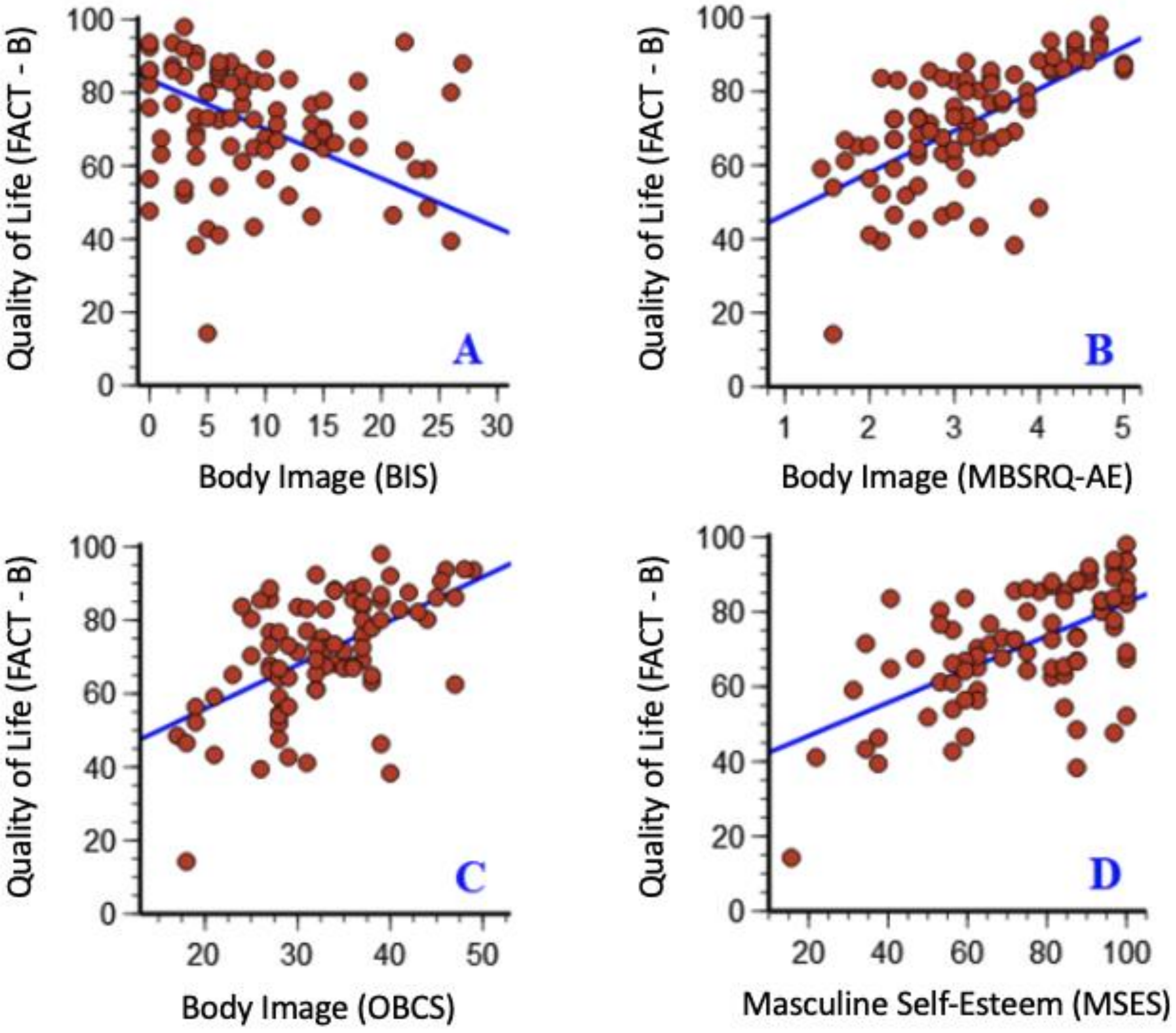
Body image (BIS)

The Multidimensional Body-Self Relations Questionnaire; Appearance Evaluation Subscale (MBSRQ-AE)

The Objectified Body Consciousness Scale; Body Surveillance Subscale (OBCS)

Figure 3.

Scatterplots displaying the direction of the relationship between quality of life (FACT-B) and the body image measures (BIS, MBSRQ-AE, OBCS) and quality of life (FACT-B) and masculine self-esteem (MSES).



How well do the measures of body image, quality of life, self-esteem and the demographic variables (time since diagnosis and age) predict Masculine Self-Esteem?

The model explains 63% of the variance in masculine self-esteem (MSES). Of these variables, the Body Image Scale (BIS) makes the largest unique contribution (beta = -.63), and quality of life (FACT–B) made a statistically significant contribution (beta = .25) as did time since diagnosis (beta = -.17).

Is there a difference in quality of life scores for men currently undergoing treatment and men not currently undergoing treatment?

The mean value of quality of life for those undergoing treatment (M = 67.94, SD 16.42) was significantly lower than those not currently undergoing treatment (M = 76.10, SD 14.15), t (-84) = -2.40, two-tailed, p = .02. The magnitude of the differences in the means (mean difference = -8.36, 95% CI -15.29 to – 1.43) was medium (d = 0.5).

How well do the measures of body image, self-esteem, and the demographic variables (time since diagnosis and age) predict quality of life? What is the best predictor of quality of life: body image, Masculine Self-Esteem, self-esteem, time since diagnosis, or age?

The model explains 47% of the variance in quality of life (FACT-B). Of the variables, The Multidimensional Body-Self Relations - Appearance Evaluation subscale (MBSRQ -AE) makes the largest unique contribution (beta = .317), although Masculine Self-Esteem (MSES) (beta = .316), time since diagnosis (beta = .19) and the Objectified Body Consciousness Scale (OBCS) (beta = .20) also made a statistically significant contribution.

4.10.5 Mediation analysis

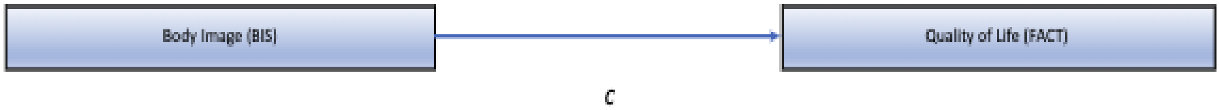
To further explore the mechanisms underlying the relationships identified in the research questions mediation analysis were performed using PROCESS (Hayes 2019). Mediation analysis is used primarily for two purposes: to understand how certain relationships occur, and to identify possible targets for future interventions research (Field, 2013). Mediator variables (M) lie along the causal pathway between an independent (X) and dependent variable (Y), explaining all or part of the effect of the independent variable on the dependent variable. A test of mediation examines whether the effect of the independent variable (X) on the dependent variable (Y) occurs via a third, intervening variable (M) (Field, 2013). PROCESS is based on regression-based path-analytic framework and estimates the indirect effect and bias-corrected confidence intervals (CI). An indirect effect is considered significant when the CI do not include zero (Field 2013). All analyses were based on 5000 bootstrapping samples. Bootstrapping is a nonparametric resampling procedure, and as such, it does not violate assumptions of normality. Bootstrapped confidence intervals were presented for all mediation effects (Field 2013). Analysis were conducted on each of the body image scales.

Model 1

A mediation analysis was conducted to examine the mechanisms underlying the relationship between body image (BIS) and quality of life (FACT-B) in men with breast cancer. More specifically, it examines whether masculine self-esteem (MSES) mediates the relationship between body image (BIS) and quality of life (Figure 4).

It was hypothesised that (1) body image (BIS) would be negatively associated with quality of life, and positively associated with masculine self-esteem; (2) masculine self-esteem be positively associated with quality of life; and (3) masculine self-esteem would mediate the association between body image and quality of life.

Simple linear relationship



Mediated relationship

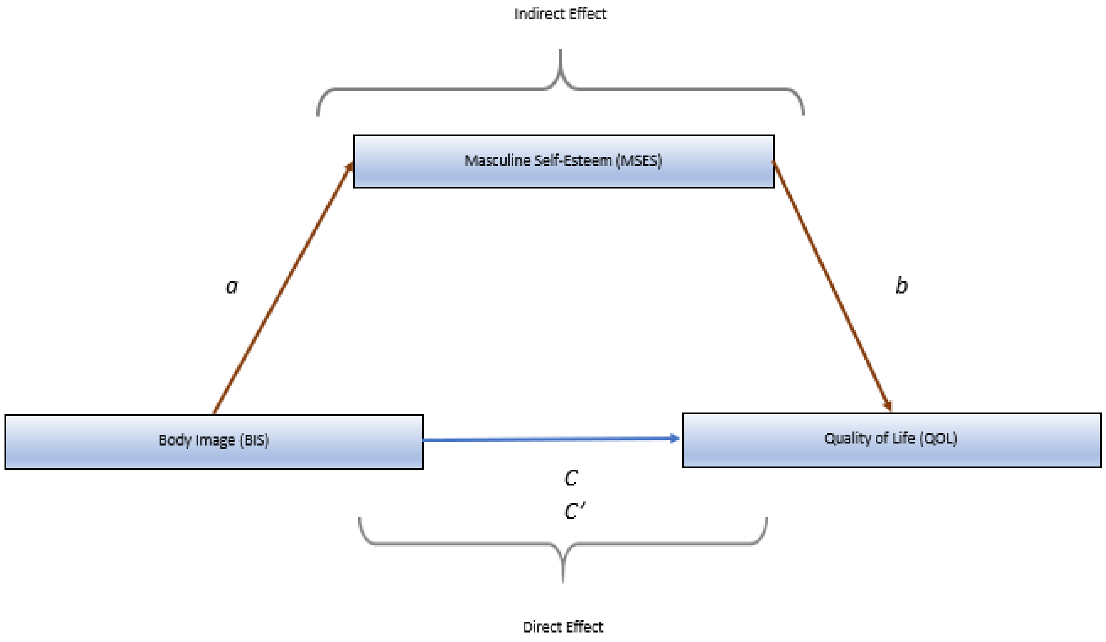


Figure 4. Model of body image (BIS) as a predictor of quality of life (QOL), mediated by masculine self-esteem (MSES). The confidence interval for the indirect effect is BCa bootstrapped CI based on 5000 samples.

a = effect of predictor on the mediator

b= effect of the mediator on the outcome

c = total effect of predictor on outcome without the mediator, total effect= direct + indirect effect

(c = c’ +a*b)

c’ = direct effect of predictor on the model, in the presence of the mediator

ab = indirect effect of predictor on outcome through mediator.

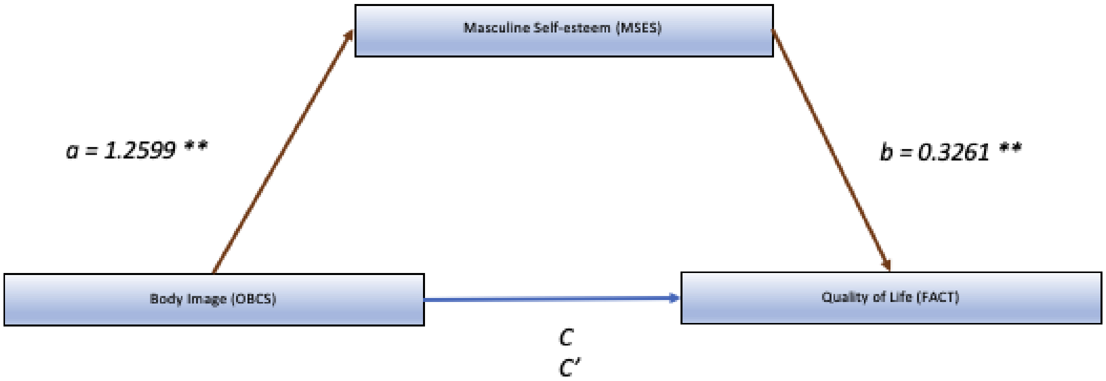
Results

The total effect = 0.0021, comprised of a direct effect of -0.6741 and an indirect effect = a (-2.327) * b (0.291) = - 0.6762. The indirect effect is significant 95% CI [-1.1401 to -.2094]; hence there is a significant mediation of the relationship between BI and QOL by MSES.

Coefficients for each regression pathway, including direct effects between body image and quality of life, are given. With quality of life as the outcome variable, body image (BIS) showed a significant indirect effect through MSES, *a*b* = -0.6762, 95% CI [-1.1401 to -.2094]. In the presence of the indirect effect (*ab*= -.6762) of body image (BIS) on quality of life through masculine self-esteem, the direct effect (c' = -0.6741) was statistically significant. This suggests partial mediation between body image (BIS) and quality of life.

Model 2

The second mediation analysis examined whether MSES mediated the relationship between body image (OBCS) and quality of life (QOL). It was hypothesised that (1) body image (OBCS) would be negatively associated with quality of life, and positively associated with masculine self-esteem; (2) masculine self-esteem be positively associated with quality of life; and (3) masculine self-esteem would mediate the association between body image and quality of life.



$c' = 0.7858^{**}$
$c = 1.1967$, 95% CI [0.1454 to 0.7825]

* = p < .05
** = p < .01

Figure 5. Model of body image (OBCS) as a predictor of quality of life (QOL), mediated by masculine self-esteem (MSES). The confidence interval for the indirect effect is BCa bootstrapped CI based on 5000 samples.

Results

The total effect = 1.1967 and this is comprised of a direct effect of 0.7858, and an indirect effect = a 1.2599) * b (0.3261) = 0.41085. The indirect effect is significant 95% CI [0.3960 to 1.1755]; hence there is a significant mediation of the relationship between OBCS and QOL by MSES.

Coefficients for each regression pathway, including direct effects between body image (OBCS) and quality of life, are given. With quality of life as the outcome variable, body image (OBCS) showed a significant indirect effect through MSES, *a*b* = 0.4109, 95% CI [0.1454 to 0.7825]. In the presence of the indirect effect (*ab*= -.0.4109) of body image (OBCS) on quality of life through masculine self-esteem, *the direct effect (c'* = 0.7858 was statistically significant. This suggests partial mediation between body image (OBCS) and quality of life.

Model 3

A third mediation analysis was conducted to examined whether MSES mediated the relationship between Body image (MBSRQ-AE) and quality of life (QOL). It was hypothesised that (1) body image (MBSRQ-AE) would be negatively associated with quality of life, and positively associated with masculine self-esteem; (2) masculine self-esteem be positively associated with quality of life; and (3) masculine self-esteem would mediate the association between body image (MBSRQ-AE) and quality of life.

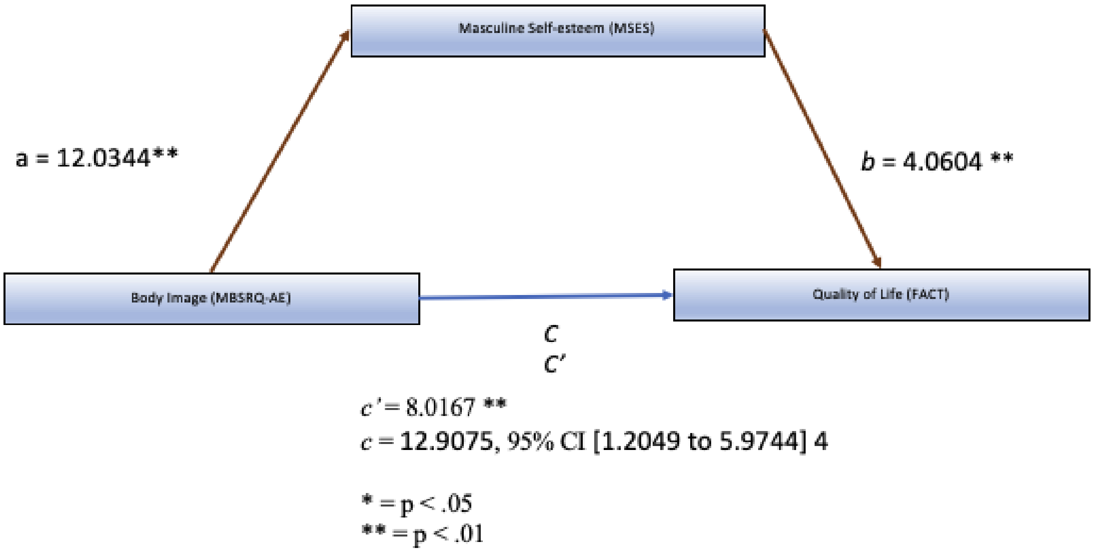


Figure 6. Model of body image (MBSRQ-AE) as a predictor of quality of life (QOL), mediated by masculine self-esteem (MSES). The confidence interval for the indirect effect is BCa bootstrapped CI based on 5000 samples.

Results

The total effect = 12.9075 and this is comprised of a direct effect of -0.6741, and an indirect effect = a (12.0344) * b (4.0604) = 4.8908. The indirect effect is significant 95% CI [1.2049 to 5.9744]; hence there is a significant mediation of the relationship between MBSRQ-AE and QOL by MSES.

Coefficients for each regression pathway, including direct effects between body image and quality of life, are given. With quality of life as the outcome variable, body image (MBSRQ-AE) showed a significant indirect effect through MSES, *a**b* = -0.6762, 95% CI [1.2049 to 5.9744]; In the presence of the indirect effect (*ab*= 4.8908) of body image (MBSRQ-AE) on quality of life through masculine self-esteem, the direct effect (c' = -8.0167) was statistically significant. This suggests partial mediation between body image (MBSRQ-AE) and quality of life.

4.11 Support preferences

Only seven (8%) of the total sample reported that they had sought support for appearance related changes. Of these, six provided further details on the type of support they sought; three sought the support of a counsellor/psychologist, one approached a breast cancer support group but was denied access as he was male, one contacted a large cancer society in the US but the organisation did not respond to his request, and one man successfully sought support from a female breast cancer support group. Only five (6%) of the total sample responded to the question of when support was sought. One man reported this was at diagnosis, another several years post diagnosis, one man during treatment and two men reported they were currently in the process of seeking support for appearance related changes.

Participants were asked about what format of support they would have preferred, options included group meeting, online support or peer support (it was not specified if peer support was online or in person). A total of 54 men responded, with the majority preferring peer support (*n* = 18; 33.3%) or group meetings (*n* = 15; 28%). Two participants provided suggestions for support, this included one-on-one support but did not stipulate if this was online or in person and one responded they would like support for their carer. Table 11 below displays support preferences for the sample.

Table 11.

Support preferences

Characteristic		*n*	%
Sought support for appearance related concerns (*n*= 85)	Yes	7	8.0
	No	78	89.7
Type of support sought (*n*=6)	Counsellor/Psychologist	3	3.4
	Female breast cancer support group	1	1.1
	Cancer support group denied/ not responded to request	2	2.3
When support was sought (*n*=5)	At diagnosis	1	1.1
	During treatment	1	1.1
	Within the past year	2	2.3

	Several years post diagnosis	1	1.1
Preferred sources of support	Peer support	18	33.3
(*n*=54)	Group meetings	15	27.8
	Online support	11	20.4
	Group and online support	2	3.7
	Group and peer support	1	1.9
	Peer and online	2	3.7
	Peer, online and group support	5	9.3
Preferred terminology to refer to breast cancer in men	Male breast cancer	65	74.7
(*n*= 85)	Breast cancer	16	18.4
	Chest cancer	4	4.6
Did the survey address your			
Appearance related concerns?	Yes	82	94.3
(n=84)	No	2	2.3

Nb. The cumulative percentage may exceed 100 as participants were allowed to select more than one support preference, i.e., they selected a number of different support preferences.

4.12 Terminology

The next section asked participants about the term they prefer to refer to BCiM. Whilst the majority (*n* = 65; 76.5%) thought it should be referred to as 'male breast cancer', 16 (18.8%) participants preferred 'breast cancer', with very few opting for 'chest cancer'.

4.13 Qualitative Findings

Reflexive TA was conducted on the open-ended questions included in the survey (Table 3). This provided the chance to gain a more detailed insight into men's experiences.

Of the 87 men who completed the survey, 64 (74%) provided responses to the open-ended questions. These varied in length considerably, with some men writing at length and others writing brief comments. Responses ranged from two to 350 words. The themes are presented below using exemplars from the survey responses to illustrate and support the findings. These are shown in italics, alongside the participant number, age, surgery type, and country of residence. Four key themes were identified: Isolation, Pink bias*,* Effects of treatment on appearance, and Advocate for BCiM. Each main theme had a number of sub-themes, as displayed in Figure 7.

Figure 7.

Four key themes and sub-themes

4.14 Isolation

Isolation was the key theme that resonated throughout the data. Many participants experienced feelings of loneliness, social isolation, and lack of psychosocial support. This was felt in different ways from diagnosis and throughout their cancer journey, and for some, continued for many years even when treatment had finished:

"Men are not heard of or seen, sadly suffering total isolation and secrecy from society…. cancer is a lonely disease…Male Breast Cancer is even lonelier"

(P55, age 64, mastectomy, US)

"It's bloody lonely being a man with breast cancer"

(P35, age 55, mastectomy, UK)

Lack of awareness

It was felt by some participants that the rarity of BCiM, as well as a lack of awareness that the disease can affect men, may contribute to social isolation:

"…. the initial shock of diagnosis is followed by the strangest reaction ever by friends, colleagues and family. Disbelief? Men don't get breast cancer"

(P35, age 55, mastectomy, UK)

Men also highlighted a lack of awareness and experience of treating male patients with breast cancer among healthcare professionals. They expressed the need for a better understanding of BCiM amongst medical staff:

"More education for GPs about diagnosis in male breast cancer"

(P12, age 68, mastectomy, Australia)

"Need more education for GPs and medical students about men's breast cancer"
(P60, age 62, mastectomy, UK)

"Faster diagnosis and more awareness by doctors that male breast cancer is a reality"
(P69, age 78, mastectomy, Australia)

As a result of this lack of awareness, one participant shared his experiences and stressed the importance of men needing to be proactive about their health concerns:

> *"I caught my cancer early…The other issue is advocating for yourself before, during and after treatment. My first doctor tried to dismiss my concern. People need to insist and tell their doctor what they want."*
> (P64, age 61, mastectomy, US)

Lack of social support

Sharing their breast cancer diagnosis was a cause of distress for many participants. The unpleasant reactions of others, in particular from family and friends, contributed to some men feeling isolated at a time when they needed support. One participant highlighted how a lack of awareness of BCiM can impact the behaviour of others as they do not know how to react to their diagnosis:

"Horror…. whereby people you know avoid you like the plague and yes even do cross the road to avoid a conversation with you."

(P35, age 55, mastectomy, UK)

"My male acquaintances just flatly refuse to converse about the subject and are happy to cut short any health-related conversation and walk away."

(P35, age 55, mastectomy, UK)

He further described his shock at the way he was treated and had expected to be supported especially from his female friends:

"…. the worst reaction is ambivalence, people either assume you will get over it, or frankly don't seem to register the term breast cancer with males, therefore that empathy trigger that I thought kicked in around this diagnosis only exists for women… I actually thought the ladies I knew in my life through work etc. would be supportive, yet the total opposite has happened."

(P35, age 55, mastectomy, UK)

For some, the lack of support and isolation was long-term and endured for many years after treatment has finished. One participant spoke of not having heard of another male patient with breast cancer for 15 years and continuing to feel isolated:

"I had no support or anyone who wanted to speak with me during my 2005-2006 ordeal…. At that time, I had never heard of men having breast cancer. I never have to this date."

(P78, age 66, mastectomy, US)

For some men, the impact of social isolation and loneliness was associated with severe consequences and a lack of self-esteem:

“I hate myself much of the time.”

(P74, age 62, mastectomy, US)

“There’s nothing positive to say about this insidious disease that destroys so many lives…my life will never be the same.”

(P67, age 65, mastectomy, Australia)

Whilst one participant stated how he found it to be so traumatic that he contemplated suicide:

“It was a terrible time in my life where I wanted to end my life.”

(P78, age 66, mastectomy, US)

A number of participants expressed how they did not feel they belonged to the breast cancer community and consequently, were unable to share their experiences or access suitable practical, physical or emotional support:

“… as a male with the disease, it leaves you stranded in a sort of limbo. It’s like you don’t actually fit anywhere, ladies prefer to discuss their condition with other ladies, men don’t have a recognised platform to do this.”

(P55, age 64, mastectomy, US)

A few men reported they had successfully reached out to cancer support groups, although they had experienced mixed reactions. Due to the low numbers of men with breast cancer, some found they were the only male in the group. Despite this, they felt a sense of solidarity from being with other breast cancer patients and benefitted from the mutual support and encouragement of being with others who understood their experiences and concerns. One man reported the positive effects of attending a support group:

"Joined a breast cancer survivor group I am the only male, but we all have the same issues."

(P77, age 63, mastectomy, US)

In contrast, one participant who actively sought and approached a breast cancer support group was refused access because he was male:

"Asked for support from major breast cancer groups. Was denied because I'm a man."

(P72, age 34, mastectomy, US)

Isolated within the healthcare setting

Some men expressed feeling isolated and excluded within the clinical setting. Hospital environments regarding breast cancer care tend to be typically designed for women and left some men feeling unwelcomed and excluded. A number of men made recommendations to improve the environment for BCiM patients:

"Make breast clinics less 'imposing' for men."

(P61, age 58, mastectomy, UK)

"Don't ostracise men in breast clinic waiting rooms."

(P55, age 64, mastectomy, US)

Others explained how they took measures to avoid potentially difficult situations from occurring in the healthcare setting:

"All too often the caregivers are unaware that men too get breast cancer or they feel they must isolate men in treatment settings or waiting rooms. To help avoid this I usually take the first appointment of the day."

(P13, age 71, mastectomy, US)

Furthermore, the impact of health professionals' behaviour also contributed to men feeling isolated within the medical setting. Medical staff may be more familiar with discussing breast cancer with female patients and may automatically address the accompanying female in the room. One participant described his anger at not being addressed directly whilst receiving his diagnosis:

"When telling a male they have breast cancer…tell the man…don't direct the conversation to the person accompanying them"

(P35, age 55, mastectomy, UK)

This theme has highlighted how men with breast cancer can experience considerable emotional and social isolation. Some participants felt excluded by friends, work colleagues, within the medical setting and by health professionals, and even ostracised from breast cancer support groups. As a result, men may endure the difficulties associated with breast cancer diagnosis, screening, and treatment on their own, and may be unlikely to seek or receive psychosocial support.

4.15 Pink Bias

The second theme focused on the feminisation of breast cancer and the gender disparities in the provision of care, support, and research between male and female patients.

Feminisation of breast cancer

Some men reported how breast cancer is predominately portrayed as a female disease and how the pink ribbon paraphernalia which surrounds much of the breast cancer advocacy had a negative impact on them. Although they clearly understood the disparity between the high number of women diagnosed compared to men, they felt excluded by the ‘pinkness’ of breast cancer campaigns and how provision of support is predominantly targeted towards women:

“My main thoughts are how PINK this disease is, and sadly by statistics I fully understand why the balance of support sways to the main group affected by breast cancer, but as a male with the disease, it leaves stranded in a sort of limbo.”

(P55, age 64, mastectomy, US)

“Be mindful all breast cancer information is in pink print.”

(P55, age 64, mastectomy, US)

Furthermore, there was often a lack of gender relevant information readily available to male patients. It was suggested by one participant:

“Have some male breast cancer leaflets available… they had to be ordered in!”

(P62, age 68, double mastectomy, US)

The feminisation of breast cancer had a substantial negative impact for some men, and caused them to challenge their own internalised gender stereotypes:

“The system is designed to feminise the disease which can, as a male, leave you questioning why you have it, when you are told it’s hormone based, and that hormone is oestrogen, the female hormone, your Cave-man brain kicks in…inventing the misconception are you more female than male….is this why I’m more sensitive, is this why I had man-boobs etc..”

(P55, age 64, mastectomy, US)

For some, their perceptions of masculinity were further tested by the inappropriate and insensitive hospital settings where they received treatment. One man reported being treated in a hospital typically focused on women’s health:

“In Germany men with breast cancer are usually treated by Gynaecologists in so called “Brustkrebszentren” which are part of gynaecological hospitals. This is not suitable for men.”

(P37, age 70, mastectomy, Germany)

As a result, men often felt marginalised by their experiences and suggested that the system should be improved to be more inclusive. Several men proposed how appropriate information for BCiM patients would help to improve access to services, promote social inclusion, and enable men to make more informed choices about their care. They proposed small, inexpensive changes to readdress the gender balance and render breast cancer services and information more accessible to all:

“The only real change should be getting rid of the pink bias. Get rid of pink gowns. Make treatment offices gender neutral. And provide two medical forms. The one for men leaving out the pregnancy and menstrual cycle question”

(P64, age 61, mastectomy, US)

Gender bias

Some participants felt they were not treated equally to female patients with breast cancer. Many drew comparisons and highlighted disparities in the provision of care, treatment, and support between male and female patients:

“Could have been given the same kind and tender care that women get.”
(P74, age 62, mastectomy, US)

In particular, some men felt there was a lack of importance placed on the appearance concerns for male patients compared with women with breast cancer. This was highlighted by the contrasting amount of support and treatment options provided for women:

“Reconstruction could have been offered to me as it is to women.”
(P9, age 69, mastectomy, Australia)

“Ladies are offered assistance to limit deformity, men seem not to be offered the same cosmetic correction.”

(P55, age 64, mastectomy, US)

"My scar and creases are not ideal. I wonder if there might have been better attention or options if I was female."

(P84, age 62, mastectomy, Australia)

A number of men voiced their concerns regarding the gender bias in breast cancer research and the impact this may have on them as male patients with the disease:

"Consistently aware that treatment of male breast cancer is sometimes affected by the lack of studies involving us."

(P20, age 64, mastectomy, US)

Many participants reported feeling concerned about the lack of research specifically conducted on the side-effects of the hormone therapy drug, Tamoxifen, which is commonly prescribed to BCiM patients:

"More research on men and the effects of Tamoxifen."

(P18, age 59, mastectomy, US*)*

"The fact that Tamoxifen has not been properly tested on men is a worry."

(P70, age 57, mastectomy, UK)

Consequently, the paucity of male specific breast cancer research resulted in some participants lacking confidence and having reservations about their healthcare. This often led them to question medical and treatment decisions:

"Lack of research into male breast cancer means consultants can only treat men consistent to how they treat women. If this involves hormonal treatment how can this be acceptable when we are different 'hormonally'?"

(P61, age 58, mastectomy, UK)

"I worry that there is no data to support that the treatment plan I am on (which has been designed around studies with women) is not the best solution for a man with the disease."
(P14, age 59, mastectomy, US)

"I am also dismayed that the treatments and advice from the medical fraternity appears to all be pretty much aimed at women. It makes me question whether men get the best treatment, as our physiology is different to women."
(P36, age 54, mastectomy, Australia)

One participant stressed how conformity to masculine traits may impact men's behaviour and may be implicated in the reluctance of men with breast cancer to seek support or discuss their condition with others:

"…. Most will never reach out and talk or share, because society and the male ego won't let them"

(P55, age 64, mastectomy, US)

"Men accept the diagnosis, then hide it from the world"

(P55, age 64, mastectomy, US)

This theme highlighted how the feminisation of breast cancer can negatively affect male patients. Furthermore, men often felt they were not treated equally to women and received substandard care and treatment options. This was often compounded by the lack of research conducted in men with breast cancer, which can cause uncertainty and result in men with breast cancer lacking confidence in their treatment.

4.16 Effects of Treatment

The third theme focused on the physical consequences of treatment and the psychosocial challenges often faced by men with breast cancer. There was considerable diversity in how men experienced and managed the impact of changes to their appearance due to cancer treatment.

Hidden wounds versus battle scars

A large number of men discussed how they struggled with the physical scarring resulting from their mastectomy. Some made a concerted effort to conceal scars with their clothing. Despite this, many still felt anxious and self-conscious, and were reluctant to expose their bodies. They took measures to hide their scars, especially when in public:

"My scar has healed well, though I don't go in public without a shirt, even at a pool."

(P6, age 57, mastectomy, US)

"I don't take my shirt off in public due to my mastectomy."

(P43, age 59, mastectomy, US)

"Not really. I think I hide it well."

(P52, age 77, mastectomy, US)

Concerns regarding changes to appearance associated with treatment were an ongoing and complex process. For some men, the passing of time helped them to overcome their initial concerns and accept their altered appearance:

"It was a little odd seeing myself with one less nipple at first, but I'm used to it now, and I'm not ashamed of my "battle scar."

(P50, age 43, mastectomy, US)

"Definitely I'm a lot flatter on my chest than my belly but I'm fine with it."

(P19, age 30, double mastectomy, US)

"As time goes by, my breast cancer experience is becoming less important."

(P23, age 89, mastectomy, Belgium)

However, for others, changes to their appearance were particularly traumatic. They struggled with how their altered appearance may be perceived by others close to them:

"I truly dislike my appearance when I shower or look at myself in the mirror after I shower. I am no longer a whole person and I no longer want my wife to look at me."

(P78, age 66, mastectomy, US)

However, this contrasted to the experiences of others who expressed a more upbeat and positive approach. These men wore their scars with pride and saw them as a sign of survivorship:

"No changes other than my mastectomy scar. And I am not afraid to take my shirt off. I want others to know that this is the face of Male Breast cancer."

(P7, age 61, mastectomy, US)

"My appearance is really not a concern to me. I spend time on the beach without a shirt and wear my scars as a badge of honour."

(P36, age 54, mastectomy, Australia)

"I have my mastectomy scar, but it is a badge of honour for me."

(P64, age 61, mastectomy, US)

Some participants managed to find relief in making light of a potentially life-threatening illness. The use of humour as a coping strategy amongst male friends served to reduce tension and hide embarrassment of the physical side-effects of treatment:

“My friends call me UniNip”

(P43, age 59, mastectomy, US)

Changes to appearance

A number of participants referred to both temporary and permanent changes to their appearance, which they considered harder to conceal than their mastectomy scars. Some men reported weight increase as a side-effect of medication, which they deemed as more of a concern than physical scarring:

“Obesity is main appearance issue, not scar issue.”

(P65, age 72, mastectomy, US)

The negative impact of treatment-related changes on their increased body weight and lifestyle was summarised by one man, who stated:

“*Easy weight gain and lack of mobility has been a disaster”*

(P55, age 64, mastectomy, US)

Other visible changes noted by participants included the hyperpigmentation of their skin after radiotherapy:

"After about the fourth week of radiation treatments, the skin got much darker where the radiation was directed"

(P58, age 68, lumpectomy, US)

Others detailed how they struggled with changes to their skin due to the side-effects of fatigue and exhaustion associated with breast cancer treatment:

"My appearance affects me when my face looks grey drawn with dark circles under my eyes"

(P35, age 55, mastectomy, UK)

A number of men developed lymphoedema following breast cancer treatment. The physical side-effects included the build-up of lymphatic fluid and swelling in the upper body, especially the arms, breast, and torso:

"I have developed lymphedema in my arm, and that bothers me more than the cancer scars."

(P36, age 54, mastectomy, Australia)

"*I have been left with chronic Lymphoedema. It is very bad. I sometimes gain as much as 30lbs in one day."*

(P74, age 62, mastectomy, US)

However, some men had a pragmatic approach when facing the challenges of their altered appearance. For example, rather than feeling distressed at losing their hair due to chemotherapy treatment, they managed to adopt a positive outlook:

"So, we lose our hair, so what? It will grow back and, in some instances, better than before."

(P75, age 77, mastectomy, US)

A large number of men reported distress associated with how the physical side-effects of the hormone therapy, Tamoxifen, caused erectile dysfunction and decreased libido:

"After Tamoxifen for five years still have low sexual function"

(P60, age 62, mastectomy, UK)

"The Tamoxifen seems to have destroyed my sex drive and capability."

(P17, age 74, mastectomy, US)

For some men, the side-effects of treatment were harder to manage than the cancer:

"The mastectomy was easy to deal with but the Tamoxifen ruined me."

(P18, age 59, mastectomy, US)

"Hormone therapy is the worst! It has changed my whole life more than having cancer or a mastectomy."

(P43, age 59, mastectomy, US)

This theme demonstrated how a large proportion of men experienced psychosocial distress associated with changes in their appearance due to breast cancer treatment. For the majority of participants, the temporary and permanent changes to their appearance had a negative impact on many aspects of their lives.

4.17 Advocate for BCiM

Some participants found meaning and purpose from their breast cancer experience. A number of men had the ability to turn the negative experiences of cancer into a positive, and used their personal journey and altered appearance to become an advocate for BCiM. These men were determined to educate others on how men, as well as women, can develop breast cancer, and to increase awareness of the disease.

Using scars as a tool and educating others

Some men reflected on their personal experiences and their own lack of knowledge of BCiM prior to their diagnosis. There was a sense of responsibility felt by some men to use their experiences to inform others:

"I've taken it upon myself to spread the word to men that we get breast cancer also. I was one of those men that was ignorant to that fact right up until the time I was informed that I had it."

(P58, age 66, mastectomy, US)

"I want to warn other men to make sure they know that men can get it as well."

(P19, age 30, mastectomy, US)

Some men engaged with the media to raise the profile of BCiM to a wider audience. Others took the opportunity to display their mastectomy scars to increase awareness and use their experiences of being a male with breast cancer:

"I have been out there educating people and men specifically that they can get breast cancer. I walked a 5K with my shirt off and my scar on display. I have been interviewed on television and written up online about my cancer…. I continue to educate others and going forward I will continue this."

(P64, age 61, mastectomy, US)

Others saw their role as an advocate for BCiM to publicise the disease, with the intention of reducing the stigma surrounding what is known typically as a female disease, as well as an opportunity to reduce the associated social isolation:

"Stigma and embarrassment men feel needs to be eradicated."

(P64, age 61, mastectomy, US)

"Highlight and raise awareness that males also get breast cancer at breast cancer events, or all the myths and ignorance will continue, and a good majority of males with the disease will continue to live in silence and isolation."

(P55, age 64, mastectomy, US)

Others described using their altered bodies as a potential conversation tool to engage with and to educate others. This was evident in situations such as swimming or at the beach, where they may expose their bodies, and consequently, their altered appearance to others. Men were particularly keen to raise awareness within the younger generation:

"I can advocate Male breast cancer when someone points out why I have one man boob but flat chest the other side.. I can educate kids about the mastectomy scar whilst at the swimming baths."

(P35, age 55, mastectomy, UK)

"*I spend time on the beach without a shirt, and wear my scars as a badge of honour and I am very pleased to share my story and spread awareness with the curios."*

(P36, age 54, mastectomy, Australia)

In summary, this theme captures the passion and the sense of meaning and purpose some men experienced due to their breast cancer journey. In their advocacy work, they often used their bodies and altered appearance as a tool to instigate conversations about BCiM and were able to use their experiences to educate others. In becoming an advocate for BCiM, they were able to raise awareness that men can also develop breast cancer and to champion the cause of raising the profile of BCiM to a wider audience.

4.18 Discussion

This section provides an integrated summary of the key findings of the study. As previously stated, the study was exploratory and aimed to gain a deeper understanding of men's experiences of receiving a diagnosis and treatment for breast cancer and the possible impact of appearance changes due to treatment. The main areas of concern which were highlighted in the literature review and formed the basis for the study were body image, masculine self-esteem, and quality of life. The results below illustrate the similarity of experiences of men with breast cancer in a range of countries. These will now be discussed in relation to the quantitative and qualitative results of the study, as well as the wider literature.

4.18.1 Body image

Breast cancer treatment in men can bring about multiple changes, causing distress and alteration to one's appearance (Quincey et al., 2016). There was considerable variation of men's experiences of body image concerns in both the quantitative and qualitative elements of the study. The quantitative results showed a broad range of scores, which is consistent with evidence documenting body image disturbances in both male and female patients who have undergone treatment for a wide variety of cancer types (Bahrami et al., 2017). Whilst some were adversely affected by changes to their appearance, others were relatively unaffected. The variation in men's experiences suggests that some individuals are more vulnerable than others.

There was no statistical difference in all the body image measures between those men who were currently undergoing treatment and those who were not. This is supported by findings of a study with men with prostate cancer, in which men did not experience worsening body image perception during treatment compared with post-treatment (van den Driessche et al., 2016).

Furthermore, the quantitative results in this study showed there was no significant difference in body image scores for men receiving more treatments for breast cancer than those receiving fewer treatments. Factors associated with body satisfaction may include the type of treatment rather than the number of treatments. Research which has studied predictors of body image in breast cancer patients are mostly restricted to women having breast reconstruction (Chen 2012; Teo et al., 2016). However, a literature review on the psychosocial consequences of prostate cancer treatments, showed how men may endure the side-effects of treatment (e.g., urinary and sexual dysfunction) for many years. Some of these side-effects can directly affect body image and may have negative long-term psychological and social implications (Mainwaring et al., 2021). This is important to consider as BCiM patients are also similarly prescribed Tamoxifen (Eggemann, 2020). Unfortunately, due to the uneven cell sizes within this study it was not possible to explore the impact of treatment type on body image in more depth.

The range of body image concerns were corroborated in the qualitative data, which similarly indicated a broad spectrum of appearance concerns due to breast cancer treatment. This was captured in the 'Effects of Treatment' theme, wherein many participants faced difficulties adjusting to the changes to their appearance after treatment. For some, this was traumatic, and they made concerted efforts to hide their scars whilst in public places, such as the beach or swimming pools. These findings align with existing qualitative research (France et al., 2000; Midding et al., 2018; Pituskin et al., 2007; Quincey et al., 2016; Williams et al., 2003). However, others wore their scars with pride and saw them as a symbol of breast cancer survivorship, supporting previous qualitative findings with this group (Levin-Dagan & Baum, 2022; Pituskin et al., 2007; Quincey et al., 2016; Rabbee & Grogan, 2016; Thompson & Haydock, 2020b).

As well as scarring, other physical and functional changes to their bodies caused concern among participants. These included hair loss, weight gain, lymphoedema, radiation-related skin changes, and the side-effects of fatigue and exhaustion associated with breast cancer treatment. This supports previous research among this group (da Silva, 2016; Rabbee & Grogan, 2016; Trusson & Quincey, 2019).

The qualitative findings illustrated that for some men, the passing of time helped them to adjust to their altered appearance. This is supported by the quantitative results which showed time since diagnosis is associated with improved body image scores. This is in accordance with research with female breast cancer patients, which indicates that body image satisfaction can improve over time (Bloom et al., 2004; Brederecke et al., 2021). However, it cannot be assumed that body image disturbance will improve over time; as research conducted with women with breast cancer indicated sustained body image difficulties among this group (Przezdziecki et al., 2013). Therefore, support needs for appearance related changes in men with breast cancer may be ongoing post-treatment and into survivorship.

Several participants voiced concerns regarding a lack of gender relevant information. The materials provided were written for women and did not represent men. Consequently, many did not feel prepared for the results of cancer treatment and faced difficulties with adjusting to their changed appearance. Similarly, the lack of gender appropriate support materials regarding possible changes to men's appearance following treatment for breast cancer has been raised in a number of studies (Donovan & Flynn, 2007; Egestad et al., 2019; Fentiman, 2018b; Iredale et al., 2005; Midding et al., 2017; Pituskin et al., 2007; Quincey et al., 2016; Sime, 2012; Trusson & Quincey, 2019), despite informational support being especially important for rare conditions (Midding et al., 2017).

There was considerable interplay between body image concerns and the themes of 'Isolation' and 'Effects of Treatment'. Some men were concerned about the visibility of their treatment-related hair loss, which impacted their identity. These findings are corroborated in a study conducted with both male and female breast cancer patients who have experienced hair loss post-treatment (Trusson & Quincey, 2019). As a result, some men may restrict their social activities and interactions to conceal their health status. Such social withdrawal and isolation may have a negative effect on quality of life, social and emotional support (Dua et al., 2017).

The low number of participants who sought support for appearance related concerns is supported by research highlighting how male patients receive less social and emotional support than female breast cancer patients (da Silva, 2016). Consequently, their emotional support needs are often unmet (Fentiman, 2018). Men are typically less likely to access information and health services and tend to rely on their partners for emotional and social support rather than formal support services (Thompson & Haydock, 2020a). This may lead to isolation as they experience the disease alone (Midding et al., 2019).

Finally, the disparity of body image concerns and experiences in this study highlights the diversity within this patient group. It emphasises the need for an individually tailored approach to BCiM, which would also enable those at risk of poor adjustment to be identified.

4.18.2 Quality of life

The quantitative results indicated men undergoing treatment for breast cancer have lower quality of life than those men not undergoing treatment. To the best of the researcher's knowledge these have not been measured previously with this population at the time of conducting this study. However, these results are substantiated in research conducted with men with prostate cancer (McCaughan et al., 2013).

Results of the multiple linear regression indicate that time since diagnosis and age explain 47% of variance in quality of life, with more time since diagnosis and being older age were associated with better quality of life. These findings are in accordance with a study conducted with *n* = 21 men with breast cancer in Morocco, which similarly showed quality of life generally improves after treatment (el Fouhi et al., 2022).

Furthermore, the present findings indicated there was a strong relationship between quality of life and body image scores (BIS, MBSRQ-AE), with higher levels of quality of life associated with satisfaction with appearance. This supports research conducted in *n* = 74 men with prostate cancer in the US (Taylor-Ford et al., 2013).

The qualitative element of the study casts further light on factors that negatively impacted the quality of life for men with breast cancer. The theme of 'Isolation' encompassed participants' feelings of loneliness, social isolation, and lack of psychosocial support, which adversely affected their quality of life, and for some, was long-lasting. Many participants also expressed feelings of isolation from friends, work colleagues and health professionals, due to a lack of awareness of BCiM. Similar results were identified in research with men with breast cancer (Egestad et al., 2019; Francis, 2018; Midding et al., 2017; Pituskin et al., 2007; Quincey et al., 2016; Sime, 2012; Sulik, 2012; Thompson & Haydock, 2020; Walker & Berry, 2019). The isolation experienced by many men, along with a lack of psychosocial support, may have a detrimental effect on their quality of life.

Finally, the theme of 'Effects of Treatment' focused on the distressing physical consequences of treatment (including venous thrombosis, lymphedema, tiredness, hot flushes, decreased libido and erectile dysfunction) for which some participants, had a negative impact on their quality of life. These posed significant challenges to their quality of life and well-being, and reflects previous findings among this group (Farrell et al., 2014; Nguyen et al., 2020; Pemmaraju et al., 2012; Ruddy & Winer, 2013; Sime, 2012; Visram et al., 2010). The effects of treatment on masculine self-esteem are discussed below (section 4.18.3).

4.18.3 Masculine self esteem

The quantitative results indicated higher levels of masculine self-esteem to be associated with lower levels of body image concerns. These findings are supported by the multiple linear regression, which indicated body image and the demographic variables (time since diagnosis and age) to explain 63% of the variance in masculine self-esteem. Length of time since diagnosis and older age are associated with higher masculine self-esteem. These results are further substantiated by the results of the mediation analysis, which suggest that masculine self-esteem partially mediates the relationship between body image and quality of life. These findings are in line with a qualitative meta-synthesis of studies published with men with prostate cancer concluded that body image, self-esteem and sense of masculinity are interconnected constructs (Bowie et al., 2022). Further qualitative research with men with breast cancer has shown that being diagnosed and treated with breast cancer can challenge men's masculine identity (Levin-Dagan & Baum, 2022; Quincey et al., 2016, 2021).

The qualitative findings further support the potential impact of BCiM on masculine self-esteem for some men. The Theme of 'Pink bias' focused on the feminisation of breast cancer and the consequent negative impact on their masculine self-esteem. The pinkness of breast cancer awareness campaigns often serves to reinforce gender misconceptions that breast cancer only affects women and marginalises men with the disease. Similar findings have been reported in other research with men with breast cancer (Francis, 2018; Pituskin et al., 2007; Quincey et al., 2016; Rabbee & Grogan, 2016; Sulik, 2012; Thompson & Haydock, 2020b).

A number of participants spoke of a lack of awareness of BCiM among hospital staff, and some reported being treated in gynecological hospitals. This had a substantial impact on their masculinity and caused some to challenge their own internalised gender stereotypes. Similar experiences have been explored in research which has shown how men often feel excluded in the medical setting. As a result, they often feel out of place, uncomfortable and isolated (Halbach et al., 2019; Sime, 2012; Skop et al., 2018; Walker & Berry, 2019)

The 'Effects of treatment' theme also interacts with men's threatened masculinity. Men reported contrasting experiences, for some the results of mastectomy surgery (scaring and asymmetry of the chest) challenged their masculine identity, whilst others were seemingly unconcerned. Similar experiences are reported in the male breast cancer literature (Pituskin et al., 2007; Quincey et al., 2016, 2021; Rayne et al., 2017; Thompson & Haydock, 2020b).

For some, the side-effects of the hormone therapy, Tamoxifen, which can cause erectile dysfunction and decreased libido, negatively impacted their sense of masculinity. Similar findings, which may be a result of male sexual potency being a central component to hegemonic masculinity, have been reported in the BCiM literature (Donovan & Flynn, 2007; Farrell et al., 2014; Nguyen et al., 2020; Quincey et al., 2021; Sime, 2012).

Conformity to masculine norms and isolation were interconnected. Some participants in the study were concerned about the reaction of others and the perceived stigma associated with being a man diagnosed with what is commonly perceived as a female disease. As a result, some chose to conceal their diagnosis which led to further isolation and the potential benefits of practical and emotional support from family and friends. These findings align with research conducted with men with breast cancer (Quincey et al., 2016; Donovan & Flynn, 2007; France et al., 2000; Iredale et al., 2005; Midding et al., 2018; Pituskin et al., 2007; Thompson & Haydock, 2020).

Very few men in the current study reached out to support groups, of these only one reported a positive experience. Consequently, they did not have the opportunity to share experiences, practical tips, and emotional support with other men in a similar position. These results align with other studies which similarly report how men with breast cancer may not feel comfortable accessing support groups (Iredale et al., 2005; Pituskin et al., 2007; Quincey et al., 2016; Sime, 2012). In accordance with other research, for some participants, the isolation was long-term and endured for many years after treatment had finished (Thompson & Haydock, 2020). For one participant in this study, the consequences of isolation were so severe for he contemplated suicide. A study conducted with men diagnosed with prostate cancer shows isolation and loneliness to be associated with higher risk of suicide (Smith et al., 2018) whilst social isolation is a significant risk factor for male suicide in the general population (Oliffe et al., 2019).

Conversely, others expressed a sense of responsibility to raise awareness of the disease. Some participants discussed using their scars as a tool to initiate conversation and used their experiences to inform others about BCiM, mirroring previous research among this group (Egestad et al., 2019; Naymark, 2006; Pituskin et al., 2007; Quincey et al., 2016; Sime, 2012).

Finally, the qualitative results add further insight into quantitative results of masculine self-esteem among men with breast cancer. The findings of the mediation analysis show the potential mediating role of high masculine self-esteem in protecting men struggling with body image concerns from experiencing poorer quality of life. To the best of the researcher's knowledge, this is a novel finding and the first research to test this relationship among men with breast cancer. Although not the focus of PhD, this is an important relationship which warrants further research and may be considered a target for psychological intervention, to help men with breast cancer to adjust to physical symptoms without experiencing reduced self-esteem.

The results of study 1 are further explored in relation to the findings of the PhD overall in the final general discussion (chapter 7).

4.19 Strengths and limitations

The following section will outline the strengths and limitations of the study and consider how this could be addressed in future research. First, the use of an online survey enabled a large sample of men from a broad geographic range to share their experiences and concerns. To the best of the researcher's knowledge, this is one of the largest psychosocial studies with men with breast cancer to be conducted to date.

However, there were also limitations inherent in the study. Firstly, there was not a comparison group, despite a considerable amount of time and thought being given to this methodological option. Other cancer groups were considered, including male head and neck patients, well as more prevalent male cancer groups, such as prostate cancer. Attention was also given to comparing the experiences of men with breast cancer with men who have had surgery for gynecomastia which similarly results in scaring of the chest (Ordaz & Thompson, 2015). However, the specific psychosocial challenges associated with being diagnosed and treated for what is commonly perceived as a female disease, are not apparent in other patient groups. These distinguish the experiences of men with breast cancer from that of other health conditions. Further thought was given to comparing the experiences of men in the general population with no prior history of cancer but similarly, this would not fit with the aims of the study.

The second limitation relates to the demographic homogeneity of the sample. The majority identified as White, so it is not known how far their responses would generalise to other ethnicities. This is especially important, as incidence of BCiM is higher in Black men than White men (Shin et al., 2014). Furthermore, appearance ideals and perceptions of masculinity may differ across racial and ethnic groups (Connor et al., 2021; Olson et al., 2020;) and the pressure to conform to cultural ideals may influence how men experience breast cancer and their bodies post treatment. Future research in this area should explore more appropriate ways of engaging participants from ethnically diverse populations. This is discussed in more detail in chapter 7 (section 7.13).

Thirdly, only participants who had undergone mastectomy provided details about changes to their appearance in the open-text responses. Men in this study who had a mastectomy constituted the majority of the sample (*n* = 81, 93%), and future research would benefit from exploring the impact of other treatments for BCiM, such as lumpectomy, in more depth.

4.20 Reflections on the methods

The use of both standardised quantitative measures and open-ended qualitative questions in the survey design gathered complementary data from respondents about their experiences. The qualitative element provided additional insights into the experiences of men with breast cancer and enhanced the quantitative results. The quantity and richness of the qualitative data was surprising, as it had not been anticipated that men would provide such in-depth responses. This may have been because men with breast cancer have not previously been given much consideration (e.g., the lack of male-specific information etc), and they appreciated the opportunity to be asked about their views and experiences. The use of an online survey perhaps provided anonymity and respondents were comfortable to share personal experiences more readily than in a face-to-face interview (Oates et al., 2022). Finally, the results from both the qualitative and quantitative data guided the second study and the direction of the PhD (chapter 3, section 3.4).

4.21 Reflections on the impact of Covid on study 1

Recruitment began for study 1 in September 2019, with an initial target of recruiting *n* = 100 participants. However, due to the Covid pandemic, the decision was made to stop recruitment at the end of February 2020. I felt it was unethical and insensitive to ask participants, who may be undergoing treatment for breast cancer, to complete a survey at a time when they may be experiencing heightened anxiety (Shah et al., 2023). Furthermore, participants may also have been left to cope with interruptions of clinical practice in oncology screening, diagnosis, treatment, surgery and follow-up care for breast cancer (Hilmi et al., 2020). As one of my patient advisors articulated, *"My cancer hasn't gone into isolation".*

Furthermore, I was concerned that anxiety resulting from the pandemic may influence participants' responses to the questionnaire. There was the potential of confounding effects, whereby the results may not have been representative of men's experiences in non-pandemic times.

At the time of making the decision, I had made considerable progress with recruitment, whereby 87 men had already completed the survey. Thus, this still placed the study as one of the largest psychosocial research studies in BCiM conducted in the UK to date.

4.22 Feedback to key stakeholders

A summary of findings was sent to all participants and charities who requested feedback. This included an invitation to be contacted regarding future research in the area. A summary of the study was posted on Instagram. A copy of the letters and social media post are presented in Appendix 10. Several charities and healthcare professionals who had promoted the study thanked me for ‘closing the loop on this research by forwarding the report’ and forwarded the results to their interested stakeholders. This facilitated dissemination of the results to a wider audience.

4.23 Reflection on the Biopsychosocial model and study 1

The Biopsychosocial model (chapter 3, section 3.11) emphasises that a person’s physical state is dependent on their social and mental state (Engel, 1977). The model has been a helpful way to conceptualise the results of study 1 which showed the interaction of psychological and social variables can impact body image, masculine self-esteem and quality of life in men with breast cancer. These can play an integral role in how men experience breast cancer and cope with the illness and its treatments. The isolation expressed by many participants highlights the social dimension of the model (e.g., social support, access to services) and illustrates how this may influence their experience of breast cancer.

4.24 Conclusion and direction of study 2

The exploratory nature of this study provided a deeper understanding into men's experiences of receiving a diagnosis and treatment for breast cancer, and the possible impact of body changes. Additional insight was provided into their preferences for support, as well as their preferred terminology to refer to BCiM. This study presents interesting results regarding body image, masculine self-esteem, and quality of life. However, there was an overarching concern throughout the themes relating to the pervasive sense of isolation and lack of psychosocial support. To address this key issues further, prominance is given to the qualitative findings, which drive the following study 2.

Although not the sole focus of research to date, a number of studies have explored the lack of support available to men with breast cancer (Bunkley et al., 2000; Quincey et al., 2016; Sime, 2012; Thompson & Haydock, 2020) and, at the time of planning the second study, a monthly, online peer support resource for men affected by breast cancer in the UK (The Men's Virtual Meet-up (VMU)) had recently been established. Therefore, rather than conducting a further study with BCiM patients which may merely serve to replicate existing research, it was deemed key to gain a holistic overview of the impact of BCiM. It was considered important to explore the experiences of individuals who provide practical and emotional support to men with breast cancer, and the impact of BCiM and caregiving on their lives. As no research to date has explored the experiences of their informal carers in the UK, it was vital to conduct research with this population. In accordance with the explanatory sequential design of the PhD, attention was given to the overall direction of the PhD. It was decided that exploring the needs of men with breast cancer (study 1) followed by the experiences of their informal carers (study 2) would further expand the field of research in this area and provide a broader understanding of the psychosocial impact of BCiM.

Therefore, the second study in this PhD was qualitative research to explore the experiences and psychosocial support needs of informal carers (wives, husbands, partners, family members or friends) of men with breast cancer.

Chapter 5. Study 2: Exploring the experiences and psychosocial support needs of informal carers (wives, husbands, partners, family members or friends) of men with breast cancer - A qualitative study.

5.1 Introduction

This chapter will firstly define the term 'Informal Carer (IC)' and outline their role. It will subsequently present the background and aims of the study.

The term, IC, is commonly used to refer to someone who actively participates in sharing the patient's illness experience on a practical and/or emotional level (Beaver & Witham, 2007). It does not include those who provide professional paid or voluntary care, such as healthcare professionals working in the community or charity volunteers providing support. Providing care is often a gradual process and carers do not immediately identify with being a 'carer' (Carduff et al., 2014). Furthermore, ICs frequently provide additional support, as BCiM patients often experience comorbid health conditions (Andrykowski, 2012). Research conducted with caregivers of people with advanced cancer has shown that their role is not well defined, and that their experiences are poorly understood (Ugalde et al., 2012). For the present study, ICs are defined as being a wife, husband, partner, family member or friend who currently support, or have supported, a man who has been diagnosed with breast cancer.

Not only does cancer affect the patient, but it also affects the lives of family members and close friends (Kim & Given, 2008). The role of supporting BCiM patients falls primarily on partners, close family members or female friends who have had breast cancer (Midding et al., 2019). There are currently around 10.58 million ICs in the UK (www.carersuk.org, 2022) who typically face caring responsibilities with little to no formal training or additional support (Kim & Given, 2008).

The physical, emotional, financial, and social impact of caring for an individual with cancer can be considerable. ICs of individuals with cancer (not specifically men with breast cancer), may experience anxiety and depression, concerns about the future and losing the patient, financial worries, and strain in family and marital relationships (Kim & Given, 2008). They may also experience poor physical health including sleep difficulties and fatigue, cardiovascular disease, poor immune functioning, and increased mortality (Beaver & Witham, 2007).

However, in addition to the negative outcomes associated with caring, positive psychological outcomes have also been identified. A systematic review identified personal resources, such as confidence and self-esteem, which facilitated positive aspects of caring for someone with a cancer diagnosis (no specific cancer type), as well as the ability to construct meaning from the experience of caring (Young & Snowden, 2017).

A thorough literature search was carried out to identify if any research to date specifically explores the experiences of ICs of men with breast cancer. This identified only one qualitative study with female partners of men with breast cancer in Denmark. Egestad et al., (2019) reported that carers often assume the role of patient advocate, face a lack of communication and experience stress, unmet information, and emotional support needs. However, due to the different healthcare and support systems in the UK, it is not known how these findings are transferable. To the best of the researcher's knowledge, no research has been carried out within this population in the UK.

A body of research has been conducted with the ICs of cancer in general (Li et al., 2013; Seal et al., 2013; Young & Snowden, 2017). Additional studies have been carried out with ICs of specific cancer patient groups, including women with breast cancer (Beaver & Witham, 2007; Lafferty et al., 2011; Regan et al., 2015), and cancers such as head and neck cancer (Balfe et al., 2016; Halkett et al., 2020) and cachexia (Wheelwright et al., 2016). Further areas that have been explored include ICs of male specific cancers, such as prostate (Sinfield et al., 2012) and testicular cancer (de Padova et al., 2019). Research has also been conducted with ICs of rare diseases (McMullan et al., 2022), which highlighted challenges including sub-optimal interactions with HCPs, insufficient (or absent) emotional, social and psychological support, as well as a lack of financial support or awareness of existing support services.

However, BCiM is unique given that men are diagnosed with what is commonly perceived as a 'female' illness (Midding et al., 2018). This is further supported in the theme "Pink Bias" in study 1 (chapter 4, section 4.15). This could potentially make the experiences of their ICs different to carers of other cancer groups or rare diseases. Consequently, given the potential consequences resulting from of a lack of understanding of psychosocial support needs for those caring for men with breast cancer, research in this area is crucial.

Therefore, study 2 posed the following research questions:

- What are the experiences and main psychosocial issues that face the ICs of men with breast cancer?
- What psychosocial support is currently provided for the ICs of men with breast cancer?
- What are the psychosocial support needs of the ICs of BCiM?

Study aims:

- To explore the experiences and psychosocial support needs of ICs of men with breast cancer
- To inform subsequent studies in the PhD.

5.2 Ethics approval

Ethical approval for the study granted from the Faculty of Health and Social Sciences Ethics committee at the University of the West of England, UWE REC REF No: HAS.20.12.059 (Appendix 24).

5.3 PPI in Study 2

Feedback on the study design and semi-structured interview schedule was sought from two ICs of men with breast cancer. These were introduced through PPI who provided feedback on the design of study 1. Neither took part in the current study. Due to the absence of research with this population, their involvement was key to ensuring that the questions were pertinent and addressed the matters which most affected their lives. They were provided with a draft of the interview schedule, and we discussed the acceptability and suitability on Teams calls. Interviews were piloted and the feedback was positive. Minor amendments were made to the interview questions and schedule order. For example, they recommended finishing the interview by asking a positive question and suggested asking: "What are your hopes for future support for carers of men with breast cancer?".

5.4 Method

5.4.1 Design rationale

Due to the lack of research in this field, a qualitative approach was deemed the most appropriate method to elicit participants' experiences and perspectives (Braun & Clarke, 2014). Different data collection methods were considered when designing the study, such as dyadic interviews. These involve two participants who interact in response to open-ended research questions, whereby the comments of one participant elicits responses from the other (Morgan et al., 2016). An advantage of dyadic interviews is that the method allows participants to stimulate ideas that might not have been either recognised or remembered (Morgan et al., 2013). Research conducted with female breast cancer patients and their partners demonstrates how a dyadic approach can allow unique relational insight into how individuals react and respond within the dyad, and how couples function and experience illness, by enabling participants to reveal both shared and individual interpretations, experiences, understandings and meanings (Keesing et al., 2016). Nonetheless, after consideration, this method was not deemed suitable for the present study. It was recognised that talking about sensitive issues, such as the experience of caring in the presence of the person being cared for, may restrict participants' ability to talk freely (Morgan et al., 2013). Furthermore, discussing personal issues and feelings in dyadic interviews may also have the potential to cause conflict in a relationship (Voltelen et al., 2018).

Consequently, semi-structured interviews were deemed the most suitable method of data collection for the study. These involve the researcher having a pre-designed list of interview questions with scope for reciprocity, which allows the interviewer to probe participants' responses for more depth, clarification, meaning and critical reflection (Galletta & Cross, 2013) . It also allows the participant to raise issues that the researcher may not have considered (Braun & Clarke, 2013).

Data collection took place between January and June 2021, during the Covid pandemic. Due to government restrictions, it was not possible to carry out face-to-face interviews. Consequently, participants were given the option of conducting the interview on Microsoft Teams or the telephone, rather than in-person. This method enabled the researcher to access participants from dispersed geographical locations, saving time and travel expenses, and reducing the carbon footprint of the researcher (Selvam et al., 2020). Reflections on this method are presented in section 5.11.

The ability of being able to see each other on screen enabled the researcher to build up trust and develop a rapport with the participant both before and during the interview. The benefit of establishing a rapport, based on respect between researcher and participant, is both essential to ethical practice, and to generate rich data (Guillemin & Heggen, 2009). Additionally, given the sensitive nature of the interview, it also enabled the researcher to recognise visual cues if the participant was becoming upset, and consequently manage the conversation in a professional and sensitive manner. Finally, the use of semi-structured interviews allowed the interviewer to probe and develop conversations, which helped to produce rich data for the study.

5.4.2 Interview schedule

The semi-structured interview schedule is presented in Appendix 11. Topics included the experience of caring for a man with breast cancer, the information and support received as an

IC, and how they felt BCiM had impacted their relationship. The topics were broad to allow participants to share their experiences.

5.4.3 Recruitment

Participant inclusion criteria

- Men or women living in the UK when they were caring for the man with breast cancer
- Aged 18 years or above
- Able to take part in an interview conducted in English without the need for an interpreter
- Currently supporting or have supported and cared for a man who has received a diagnosis for breast cancer
- Bereaved carers were eligible. Their experiences of caring for a man who has since died from breast cancer were deemed important, with their inclusion enabling a better understanding of the impact of death from breast cancer of a loved one and their ongoing support needs

Participant exclusion criteria

- Aged under 18 years old. Consideration was given to include those under 18 years old, but the experiences of young adult carers are very specific (Becker & Sempik, 2019) and would warrant a separate study.
- ICs of men with breast cancer who were not residents in the UK. As the health and social support systems differ between countries, the experiences of ICs may also differ. Consequently, it was decided to restrict participation to those providing care and support in the UK, which reflects the systems that this current body of research is trying to inform.

5.4.4 Number of participants

The concept of sample size and data saturation is embedded in a positivist-empiricist ontology (generally used in codebook or coding reliability types of TA) and is inconsistent with the realist values and assumptions of reflexive TA (Braun & Clarke, 2021). Saturation is defined as 'information redundancy' or the point at which no new themes or codes 'emerge' from the data (Braun & Clarke, 2021). In this study, data saturation is perceived as a reductionist term, that conceptualises the meaning of data to 'reside in' the data. It fails to acknowledge or embrace the interpretative role of the researcher in reflexive TA as "an active agent in the production of knowledge" (Trainor & Bundon, 2021, p. 707).

In accordance with reflexive TA used to guide this body of research, it was acknowledged during the design phase that *"it is nigh on impossible to define what will count as saturation in advance of analysis, because we do not know what our analysis will be until we do it"* (Braun & Clarke, 2021, p. 210). Consequently, the sample size was not determined during the planning stage (Malterud et al., 2016), but rather, during the process of data collection. This included reviewing the quality, depth, and breadth of the data (Braun & Clarke, 2021). For this study, the researcher reflected on the richness of the dataset collected from 12 participants and felt there was a broad representation of in terms of age, experiences of caring for men at varying stages of the illness, and relationships with the men with breast cancer (including seven wives, one husband, two widows, one child and a friend). It was also felt that the dataset was rich and diverse, and provided depth, understanding, and insight, into the lives of ICs of men with breast cancer, whilst meeting the aims of the study. The number of participants was also determined by barriers to recruitment. Due to the rarity of the illness, the channels of access to potential participants were limited. Despite readvertising the study on social media and asking participants at the end of the interviews to forward the study details to others they felt may be interested in participating, no new participants came forward. For these reasons, recruitment was halted at 12 participants.

5.4.5 Recruitment strategy

Participants from study 1 who requested to be informed of future research were contacted by email and asked to share the study information with their ICs. This resulted in four participants whose ICs took part in study 2.

The study details and webpage link were posted on the social media platforms of the researcher and her research centre (the Centre for Appearance Research), including Twitter, Facebook and Instagram (Appendix 12). Breast cancer charities and support organisations who had helped with recruitment for study 1 were approached to help with promoting the study (Appendix 13). Many of them posted the study details on their social media and online forums, as well as on their websites. In addition, the researcher was invited to join 'The Men's VMU' (Virtual Meet Up) to introduce the research and invite men to share the study information with their ICs. The Men's VMU is a dedicated safe space for men with breast cancer in the UK. The free monthly forum is hosted by BCiM 'thrivers' (i.e., peers). Also, snowball sampling occurred, whereby ICs forwarded details of the study to other ICs.

Study adverts directed potential participants to the secure on-line platform, Qualtrics, which was used to host the study information, obtain consent, and collect sociodemographic data. This included age, gender, ethnicity, relationship status, sexual orientation, relationship to the patient and employment status. Those who expressed an interest via the Qualtrics survey were contacted via email. The researcher's email was provided to address any questions from potential participants. Due to the Covid pandemic, hard copies of the participant information and consent forms for the study were not offered. A copy of the study information provided to potential participants, consent page and demographic information collected is included in Appendix 14.

5.4.6 Ethical consideration

Given the sensitive nature of the topic, several ethical issues were considered prior to data collection. It was recognised that talking about their experiences may be upsetting for some participants and this was highlighted on the participant information sheet. Contact details were therefore provided for a number of free support organisations (Breast Cancer Now, Macmillan and Carers UK), should anyone require support after participating.

Additionally, at the beginning of the interviews, the interviewer stressed that participants could stop the interview at any time and refrain from answering any questions should they feel uncomfortable. If a participant became upset, the recording was stopped, and the interviewer checked they were all right to continue, or if they would prefer to reschedule or terminate the interview. This happened on three occasions, and on each occasion, all chose to continue with the interview. Further, participants were reassured that the conversation was confidential and any identifying information would be removed. Finally, they were assured that no details would be shared with the person with breast cancer they were supporting.

At the end of the interviews, participants were reminded of the information sheet and sources of support, should they have any concerns. Following the interview, all participants were sent a 'thank you' email that reminded them once again of these support services (Appendix 15).

Consideration was also given to the impact of conducting sensitive and potentially emotional interviews on the well-being of the researcher (Mitchell, 2011). Consequently, consideration was given to the timing of the interviews. These were organised so that they were not conducted in close succession. Additionally, supervision sessions were available after each interview to debrief should the researcher find it psychologically challenging and wish to discuss any concerns.

During the data collection period, notes were recorded and the interview schedule consequently modified. For example, it became natural to briefly outline the first study in the PhD and to explain what had led to this study. This was found to be a more natural and useful introduction which eased the participants into the conversation. An additional question about awareness of BCiM prior to diagnosis was added to the interview schedule. Finally, each participant was asked at the end of each interview if they felt there were any other questions or areas which had not been covered in the interview. This was often the time when participants revealed extremely interesting experiences and discussed significant impacts of BCiM and caring on their lives which had not been covered in the previous interview questions.

Throughout the data collection process, reflective memos were recorded. These enabled the researcher to engage with their own subjectivity and emotion (Elliott et al., 2012). Notes were made after each interview and throughout the process of analysing the data. Reflective memos also add to the credibility and trustworthiness of qualitative research, aid the analysis (due to the researcher recording the meanings derived from the data; Mortari, 2015), and enhance the rigor and quality of qualitative research (Baillie, 2015). See Appendix 16 for an extract of a reflective memo.

5.4.7 Choice of method for qualitative analysis

During the design process, interpretative phenological analysis (IPA; Smith, 2004) was initially considered as an appropriate qualitative approach. IPA aims to produce a detailed insight of personal lived experience and how participants understand and make sense of their experiences (Smith, 2004). It is a suitable methodology for examining complex and emotionally laden topics such as health research (Smith, 2015). It is underpinned by three theoretical approaches; phenomenology (the study of experience), hermeneutics (the theory of interpretation) and idiographic (a particular person making sense of their experience) (Larkin, Flowers & Smith, 2021). In the analysis of the data the researcher engages in 'double hermeneutic', in that they are making sense of the participants making sense of their worlds (Smith, 2021).

It is acknowledged that IPA could have been suitable for the current study and the exploratory nature of this research. However, it was considered that reflexive Thematic Analysis was a better fit. The researcher acknowledges similarities between the two approaches, which are both centered on the exploration of participants' subjective experiences and sense-making (Braun & Clark, 2013) and researcher subjectivity (Smith, 2019). However, IPA is argued to produce depth and a broader unpicking of issues whereas Thematic Analysis is argued to produce breadth of analysis (Spiers & Riley, 2018). IPA and TA can 'work well together as methods' (Spiers & Riley, 2018, p. 287) however this can result in neither method reaching its potential (Braun & Clarke, 2020).

For this study, the researcher was keen to gain a broad and diverse understanding of the experiences of the ICs of men with breast cancer. The analytic focus of this research is on identifying themes across the data set as opposed to also identifying unique features of individual cases and therefore better suited to reflexive TA (Braun & Clarke, 2020). Finally, reflexive TA is considered better suited to larger samples (larger than *N* = 10) (Fassinger, 2005). In keeping with the pragmatic approach of the PhD, reflexive TA was deemed the most appropriate technique to address the research questions.

The analysis followed Braun and Clarke's (2020) six-phase process to explore patterns across datasets, and these were carried out in a recursive process (Braun & Clarke, 2019) (chapter 4, section 4.9.2).

5.5 Results

5.5.1 Participant demographics

Whilst the recruitment strategy generated 16 respondents, one lived in the USA and was not eligible to participate, and three did not reply to follow-up emails.

Twelve informal carers (11 female, 1 male; mean age = 54 years [range = 25–77 years]) participated. Interviews, lasting an average of 55 minutes (range = 28 – 71 minutes), were conducted via online video calls (Microsoft Teams n=8) or telephone (n=4). There was a broad range of experiences of ICs, including caring for men in the early stages of treatment, mid-treatment, and many years after diagnosis. One participant was caring for a man in palliative care and two were bereaved carers of men who had died of breast cancer.

The majority were married to the patient (n=9), whilst one IC was the daughter, one was an ex-partner who had been in a relationship with the patient at the time of diagnosis and treatment, and one was a close friend. Participant characteristics are presented in Table 12.

Table 12.

Participant characteristics

Characteristic		*n*	%
Age	Range 25 - 77 years		
(N= 12)	Mean 53.42 Std. Deviation 15.23		
Gender	Female	11	91.76
	Male	1	8.33
Ethnicity	White	12	100
Relationship status	Married	9	75
	Relationship or civil partnership	1	8.33
	Widowed	1	8.33
	Single	1	8.33

Sexual orientation	Heterosexual	10	83.33
	Bisexual	2	16.67
Relationship to patient	Wife	9	75
	Husband	1	8.33
	Ex-partner	1	8.33
	Daughter	1	8.33
Employment status	Employed	4	33.33
	Retired	4	33.33
	Self-employed	2	16.66
	Student	1	8.33
	Unable to work due to disability	1	8.33

5.5.2 Themes

The findings report four key themes: “The impact of caring,”, “The unmet needs of patients”, “Isolated and alone” and “Making a difference”. These are illustrated in Figure 8.

The themes are presented below using exemplars from the interviews, along with pseudonyms to illustrate and support the findings (Thorne, 2021). These are shown in italics, alongside the participant age, relationship to the man with breast cancer, year the man was diagnosed, and their stage of cancer. Identifying features of both the participant and associated man with breast cancer, where they live, or hospital attended, have been removed to maintain anonymity (Saunders et al., 2015). Table 13 provides participant details.

Table 13.

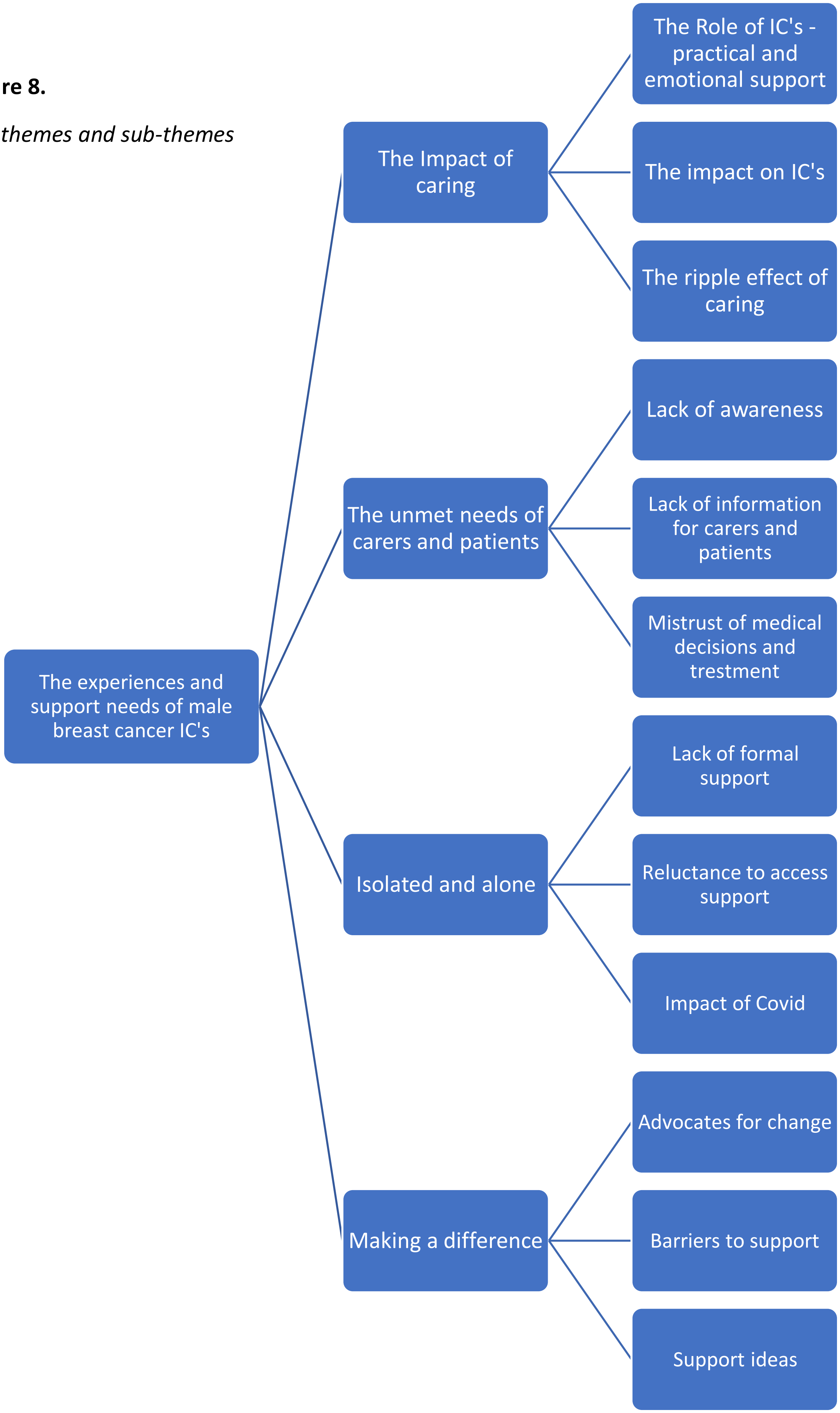
Participant information

Pseudonym	Age (years)	Gender	Relationship to BCiM patient	Year of diagnosis	Cancer stage at the time of the interview
Dee	52	Female	Wife	2004	Deceased
Anna	31	Female	Wife	2008	Palliative Care
Ambellina	25	Female	Daughter	2011	Deceased
Mia	52	Female	Wife	2007	Secondary
Andora	77	Female	Mother	2005	Secondary
Nico	51	Female	Wife	2012	Not given
Ragdoll	73	Female	Wife	2021	Not given
Bouquet	70	Female	Wife	2011	Not given

Becksbud	47	Female	Friend	2007	Secondary
Raine	48	Female	Ex-partner	2018	Secondary
Jeremiah	66	Male	Husband	2015	Not given
Freya	49	Female	Wife	2021	Secondary

Figure 8.

Key themes and sub-themes



5.5.3 The impact of caring

The role of informal carers

This theme resonated throughout the data and illustrated the role of the ICs and the impact of caring for a man with breast cancer. From the outset, the role of caring was often all-consuming and played a significant part in their lives:

"At the beginning you just kind of go into a bubble and you don't want to know about anything else, it just consumes you and just takes you over."

(Mia, age 52, wife, 2007, secondary cancer)

"It is living with cancer, you are literally living with cancer, and you are drawn into it day after day, and you can't get away from it."

(Raine, age 48, ex-partner, 2018, secondary cancer)

"You can't get off the bus can you…you've just got to go on the ride."

(Mia, age 52, wife, 2007, secondary cancer)

From the beginning of the cancer journey, the ICs played an integral role in supporting the patient. Initially, it was often the ICs who urged the patient to go to the GP and encouraged them to push for a referral for further tests and a diagnosis. Participants often portrayed themselves as a 'gatekeeper' to medical appointments, healthcare providers, and professionals:

"I said you've got to go to the doctors, you've just got to go."

(Mia, age 52, wife, 2007, secondary cancer)

"He found the lump when he was 11…. at no time during the times that he mentioned it over the years, it was nearly 30 years, at no time did anyone even take a look or touch it, they just literally looked at him as though he was mad, as if to say men don't get breast cancer so it's nothing to even worry about. ….. So, it was me who really spurred him on to go back to the GP again and I went with him so he wouldn't get fobbed off this time, because in the past they wouldn't even look and it was the first time the GP actually looked and touched it."

(Raine, age 48, ex-partner, 2018, secondary cancer)

Participants shared clear examples of practical and emotional support they provided, and described how they often endured the pressures and responsibilities of caring and support. They frequently felt responsible for the physical and emotional well-being of the patient, supporting them with the day-to-day practicalities of living with cancer, such as managing their medication, and driving them to medical appointments:

"I did all of his medication, tablets and things, it was just easier…popped them in the pill box and sorted them all out."

(Dee, age 52, widow, 2004)

"He was physically unable to do anything, we had aids put in the house to help him get up, I was helping him get up, helping him dress, I was making him food, everything and driving because he couldn't drive, I was helping him walk round the house, everything."

(Anna, age 31, wife, 2008, palliative care)

"He was the love of my life so whatever it took, you would do, so you would just want to make him as comfortable as possible…even if it was down to just running him a nice bath and making sure it was the right temperature."

(Dee, age 52, widow, 2004)

Several ICs felt it was important to accompany the patient to medical appointments. They expressed concerns regarding the patient's anxiety, which often resulted in a gulf between what the doctor said and what the patient heard. Furthermore, they spoke of the patient's memories being foggy during consultations, and how they found the situations overwhelming and struggled to remember the information they received:

"I was going in and because it's not directly affecting me, I was able to absorb the information because he would come out and say "what did he say?" and he's got to do this or go there…sometimes we would go in with a list of questions and he would go in to ask the Doctor and he would just forget some of the questions, because the pressure is on and the pressure of a Doctor."

(Jeremiah, age 66, husband, 2015, stage not given)

The demands placed on the ICs often increased during chemotherapy and radiotherapy as the patient experienced the side-effects of treatment:

"He was unable to function at all and he was like a dribbling mess in the bed, and I was having to spoon feed him soup just to get some nutrition into him…Making sure he was functioning, making sure he was eating and making sure he was drinking. The chemo had really awful effects on mouth ulcers and dry lips, so it was constant – like suck on this bit of pineapple or putting lip balm on him. It was kind of almost like looking after a baby."

(Nico, age 51, wife, 2012, stage not given)

"After he'd had radiotherapy he didn't want the shower on him because it was too forceful so he might want a bath, I remember asking him if he wanted some of that E45 cream, because he used that a lot of the time for washing and stuff rather than soap…so I rubbed that gently on his back, rubbing it on and leaving it there…you would only want your partner to do that, it's being in your safe space with somebody that you love and care for and you know they don't mind, they aren't repulsed by your body…you just want them healed."

(Dee, age 52, 2004, widow,)

The diagnosis and treatment of BCiM may result in long-term changes in a patient's functional and social abilities. Personality and behaviour changes caused by mental health issues, as well as the side-effects of treatment, were a concern for some ICs. For some, the personality changes rendered them unrecognisable:

"He was in a band, and he'd go out and be drinking and when I met him he was the absolute life and soul of the party, he was the loudest one in the room and you know he was incredibly gregarious and he is now an absolute shell of the person he once was. If someone who hadn't

seen him for 12 years was to see him now, they wouldn't recognise him."

(Nico, age 51, wife, 2012, stage not given)

Many BCiM patients also suffered with long-term comorbidities, such as anxiety, depression, and diabetes, which ICs often helped them to manage. This increased the tasks and responsibilities they undertook as their carer:

"He has mental health issues at the best of times, but this really bought it to the fore… My role as a carer was for his health and his mental health as well. So, from the day he was diagnosed he had to be put on beta-blockers, antidepressants and sedatives, so with the combination of all the medication he was on it meant that he couldn't function normally, he was completely out of it, he couldn't drive himself, he couldn't make himself food, he couldn't go about anything normally because he was basically on his back sedated. So, I would have to get him in the car and drive him to his appointments and in the first two weeks he was in hospital every day having biopsies or bold tests."

(Raine, age 48, ex-partner, 2018, secondary)

"There is a lot of emotional support because he does get quite depressed at times."

(Anna, age 31, wife, 2008, palliative care)

"If his fatigue is particularly bad or his mood swings, his mood swings kind of jump around as well. So if his fatigue is really bad, he goes through spells when he can't get out of bed for very long, for days and days on ends, so I make sure he gets up and has a meal…he's diabetic as well

which was diagnosed at the time of his diagnosis…. I make sure he eats a lot, I home cook everything, and we are vegetarian as well, so I make sure everything is very balanced diet of vegetables."

(Nico, age 51, wife, 2012, stage not given)

The responsibilities of caring also fell on younger members of the family. For the young carer who participated in the study, her father's diagnosis brought about a significant amount of change in her life and impacted her emotionally. At ten years old, she supported her family by assuming adult roles and responsibilities when her father was ill. These included performing grown up tasks, such as cooking, cleaning, and looking after her younger brother:

"I ended up kind of becoming a carer and having to look after my brother a lot as my mum would have to go to hospital with my dad all the time and I ended up becoming more of a parent role to my brother…I'd be left at home with him and I'd have to get his uniform ready for school, get food ready, generally staying at home and being the adult."

(Ambellina, age 25, daughter, 2004, deceased)

Her experiences resulted in a loss of childhood through having to care for her brother:

"I didn't resent him for being poorly but it kind of felt like I was missing out on a lot of childhood things."

(Ambellina, age 25, daughter, 2004, deceased)

She expressed feeling different from friends when growing up, who were enjoying different childhoods, and did not understand her experiences as a young carer:

"They didn't quite understand how grief works and they'd all say "Oh your dad would be so proud of you" ... but what I really needed was that's it's ok to feel sad things. That would have been more helpful than anything else."

(Ambellina, age 25, daughter, 2004, deceased)

For those participants who were supporting a man who had recently been diagnosed with breast cancer, the future was unknown. Changes to their life due to cancer and worry about what their life might be like in the future, caused uncertainty:

"Because he has only just started treatment, we haven't got the full impact of this."

(Ragdoll, age 73, wife, 2021, stage not given)

'There will be different things that crop up inevitably, but I don't know about them yet."

(Freya, age 49, wife, 2021, secondary cancer)

ICs who also had young children often felt responsible for helping to prepare them for future changes. They had conversations which helped them to understand the progression of the disease and what they may expect in the future:

"We have talked about how dad may well get depressed, dad may well get some quite dark

times, dad is going to be really tired, probably, but we don't know."

(Freya, age 49, wife, 2021, secondary cancer)

Concerns about the hereditary BRCA gene were raised and ICs supported their partners in deciding when, how, and what to say to their children, and prepared themselves for their reactions:

"If they come back and think that it is hereditary then we have to make a choice to tell him in fairly basic terms."

(Freya, age 49, wife, 2021, secondary cancer)

"They both (children) said that they didn't want to know…. But we made the decision we would tell them, because we felt that if you didn't say and something happened to them they would then turn round and say 'well, why didn't you tell me?" you can never win really."

(Bouquet, age 70, wife, 2011, stage not given)

The impact on ICs

For many ICs, their primary focus was on the patient, and they did not consider the effect of the situation on themselves. For some, the impact of providing emotional care and practical support was overwhelming. Often, they neglected their own needs, which eventually took a toll on their physical and mental health, and ultimately, affected their ability to care and support:

"It really impacted me, and I went through, like self-harm, and just feeling really low."

(Ambellina, age 25, daughter, 2004, deceased)

"I had a nervous breakdown."

(Mia, age 52, wife, 2007, secondary cancer)

"My health absolutely suffered as a result of all of this, it suffered physically because I spent all my time looking after my son and husband that I ended up eating really badly and I got to the point where I had gastric surgery because I had put on so much weight that I was physically unable to do very much, I had no concern for myself because all if my concern was looking after those two."

(Nico, age 51, wife, 2012, stage not given)

For the young carer who participated, the ramifications of caring were long-term and continued into adulthood:

"I missed out on being a child and I still found that is impacting me as an adult. Even though I am turning 26 I still like childish things, like cartoons and video games, and I find myself, if I am in a lower mood, going back to more like a childlike manner."

(Ambellina, age 25, daughter, 2004, deceased)

The impact of caring was often exacerbated by the lack of communication between the patient and their IC. Some felt unable to share their concerns or express their feelings with the patient, as they felt they were overwhelmed with the physical and emotional effects of the cancer itself:

"You can't say things to your husband because he's got enough on his plate."

(Nico, age 51, wife, 2012, stage not given)

"It's like the unspoken thing that's there."

(Mia, age 52, wife, 2007, secondary cancer)

The mother of the BCiM patient who participated felt she needed to be seen as a strong role model and had to be positive in front of her son. This prevented her from showing her emotions:

"The way you support is by not breaking down in front of them but having quite moments afterwards. Have a cry when you are on your own…we don't talk about concerns because I don't want to upset him."

(Andora, age 77, 2005, mother, secondary cancer)

Finally, the impact of caring was felt long after the patient had died. Providing emotional care and practical support had consumed the lives of their ICs and their death left a void:

"When he died, I thought "what shall I do with myself?" Because I had so many things to do beforehand, I was like, well I don't have to do that again…`It was a really difficult time."

(Dee, age 52, 2004, widow)

The ripple effect of caring

Findings indicated how cancer affected the patient's family and friends. For some, BCiM had a major impact on their marriages and long-term relationships:

"It (BCiM) doesn't just have an impact on the person whose got it, but it has an impact on their immediate family and the people who are living with them every day."

(Mia, age 51, wife, 2012, stage not given)

"Everyone is suffering from breast cancer that has anything to do with someone with it."

(Raine, age 48, ex-partner, 2018, secondary cancer)

"I mean friends are more detached aren't they, it sort of makes the circle bigger, because they are not living with it, but they are still dealing with it…it's like a ripple effect, which hopefully softens the wider you go but it's still there"

(Mia, age 52, wife, 2007, secondary cancer)

Cancer often affected established roles. Taking on the responsibilities of an IC changed roles within relationships and effect relationship dynamics. As a result, the BCiM patient struggled to accept having a more dependent role on the IC, and the IC had trouble assuming a more dominant role, providing physical care, and emotional support. Distress caused by cancer and the change in couple's relationship roles had an important impact on the quality of some relationships. Many felt their relationship changed as they became more of a carer than a wife or partner:

"I became his nurse…. This goes beyond wife duties, helping him on and off the loo and things like that…I was like this is not my job."

(Mia, age 52, wife, 2007, secondary cancer)

"I had to almost divide myself in two, so I had me as his girlfriend and carer, but it's actually very difficult when you are caring for someone at that level and you are their nurse basically, it's impossible to have a loving close, physical relationship, I mean all that stopped so you end up purely being a carer for that person."

(Raine, age 48, ex-partner, 2018, secondary cancer)

The change in relationships and the effect of BCiM had a major impact on some marriages and other long-term partnerships, however, these varied from couple to couple. For some, the illness and change in their roles had a positive effect on their relationship and they found how facing the challenges of cancer together strengthened their bond:

"It's made us both stronger definitely, you know, a deeper respect, for me in him in what he is

going through. You'd have thought he'd been told he had a cold and not cancer in that he does just get on with it. I think for him in me in that he appreciates what I am juggling as well…. we have a better understanding of each other I think... getting to do things like this for your partner has made us closer and better friends and I think it's just made our relationship better."

(Anna, age 31, wife, 2008, palliative care)

For the young carer interviewed, her experiences as a child influenced her university course and her career choice. She based her dissertation on BCiM, which further helped her gain a deeper insight and understanding of the illness and her father's experiences. This enabled her to comprehend and make sense of events of her childhood as an adult:

"It was the main reason that impacted me to study radiotherapy because I used to go to radiotherapy sessions with him…I kind of clung on to it and away I went and studied it, I'm really glad I did, it kind of made the puzzle complete because now I understand everything that went on, I was able to piece things back together in my memories."

(Ambellina, age 25, daughter, 2004, deceased)

Whilst for others, the stress of cancer created new problems and their relationship and other family relationships broke down under the strain of the illness:

"It's destroyed our relationship; it's destroyed his relationship with his children."

(Raine, age 48, ex-partner, 2018, secondary cancer)

As well as assuming the responsibility of caring for the patient, many participants were also having to support and care for their family and young children which added an additional layer of stress at an already difficult time:

“Our son was about one and a half at the time, so it was difficult because I was obviously raising him and having to care for (Husband) going through his treatment and diagnosis at the same time.”

(Nico, age 51, wife, 2012, stage not given)

“I was looking after him and also looking after the family … for most of the time I felt like a single parent because he was so poorly.”

(Dee, age 52, 2004, widow)

Whilst struggling themselves with the pressures of caring and uncertainty of the long-term outcome, many ICs felt they had to be strong and positive and to try and maintain a sense of life carrying on as usual for the sake of the children:

“What you try and do is keep all the balls up in the air, to keep normality for the children.”

(Dee, age 52, 2004, widow)

On top of the emotional burden, most ICs also took over running the household and doing all the domestic chores:

“I was bringing up the children and looking after their emotional needs and everything else that was going on with them, and of course I’m not going to say “oh by the way the bins need taking

out". So, you become a fulltime parent, I was working part-time, I was looking after my children, I was doing hospital visits, I was sorting out medications, sorting out appointments."

(Dee, age 52, 2004, widow)

In addition to the impact on their physical and mental health and relationships, other significant pressures included the stress on employment and finances. Some ICs were forced to reduce the number of hours they worked or took leave to care for the patient. This affected both their income and household finances and provided additional stress and anxiety:

"Financially it was really tough, I was foster caring, we had our foster son for three years and we had to stop fostering, I lost my job, (Husband) wasn't working so we nearly lost the house."

(Mia, age 52, wife, 2007, secondary cancer)

The same participant explained how it was not only the carers who were impacted, but the ripple effect filtered down to their children. She spoke of the negative consequences of the illness on their children:

"He was in the final year at Uni got depression over it, so he pulled out and didn't finish his course."

(Mia, age 52, wife, 2007, secondary cancer)

Finally, even when treatment had ended successfully, some ICs were concerned that the cancer would return and struggled with the fear of recurrence:

“I think it’s always at the back of your mind, will it come back?”

(Bouquet, age 70, wife, 2011, stage not given)

5.5.4 The unmet needs of ICs and patients

Lack of awareness

Although all were aware of female breast cancer, most interviewees did not know that the illness could impact men, and spoke of their disbelief and shock in reaction to the diagnosis:

“It was a shock at the time, I hadn’t thought that men could get it.”

(Bouquet, age 70, wife, 2011, stage not given)

“He always said isn’t it typical that I got a woman’s illness, he’d say things like that like ‘I’ve got bloody breast cancer’……. he thought it was a woman’s illness.”

(Dee, age 52, 2004, widow,)

“At the beginning obviously it was a shock, as a guy you tend to think that it is a female related issue…… Even the word breasts, men don’t have breasts they have chests so that was difficult.”

(Jeremiah, age 66, husband, 2015, stage not mentioned)

For some, this led to difficulties accepting the illness and uncertainty about how best to discuss and support a man diagnosed with what is commonly perceived as a female disease:

"Not even knowing how to speak to a man about it because, I hate to say it, us girls we'll talk about tits and other bits and pieces and we can be quite open with one another, but you talk about breasts with a man and at times it can become, not a sexual thing, but you don't normally talk about boobs with a man. So, there is that whole concept there as well as that, I am talking about boobs with my best mate but its disjointed…so you have to try and get over that and I found that quite difficult."

(Becksbud, age 47, friend, 2007, secondary cancer)

Similar to the views expressed by men with breast cancer that participated in study 1 (chapter 4, section 4.15), some ICs voiced disappointment with breast cancer charities and awareness campaigns that were dominated by the colour pink. The subsequent association with femininity and the perception of the illness being a female only disease left some participants feeling that charities and organisations excluded the men they care for and support:

"So much of the fundraising and things like that have become so big and almost like a sisterhood that the men really got pushed out of the conversation."

(Ambellina, age 25, daughter, 2004, deceased)

"It's very much still advertised as a female cancer because everything is pink."

(Raine, age 48, ex-partner, 2018, secondary cancer)

Participants described how the general lack of awareness of BCiM made disclosure of their illness to others more difficult:

"I think there's a massive disbelief in people, you know "My God, that's a man and he's got breast cancer, I didn't even know that was a thing" and when people find out that my husband has got cancer, they'll say, "where is it?" and when I say it's breast they'll be "what?!" they can't believe it."

(Anna, age 31, wife, 2008, palliative care)

For some, their concern about stigma and the negative reactions of others, made them conceal the diagnosis:

"Because it's got this feminine sort of undertone to it, cause blokes say 'oh are they a woman then' that sort of thing…you've got to say they've got another sort of cancer."

(Jeremiah, age 66, husband, 2015, stage not given)

Furthermore, due to the lack of awareness, some ICs described how they had to explain to others that men can develop breast cancer when informing them of the diagnosis. This made an already sensitive conversation even more difficult, and resulted in some ICs not sharing the cancer diagnosis. This increased the caregiver burden:

"It's not just telling people he's got cancer, we've got to go through this sort of conversation that 'yes, its breast cancer, men can catch that too', not 'catch it' - wrong phrase, but there was that added awkwardness."

(Freya, age 49, wife, 2021, secondary cancer)

Lack of information for carers and patients

Similar to the qualitative findings reported in study 1 (chapter 4, section 4.14) regarding the lack of male specific breast cancer information, all the ICs described how they also found it difficult to access information about breast cancer in men. Participants were shocked at the paucity of information aimed at men and expressed disappointment that the available breast cancer literature often portrayed the illness as a female disease, were written for women, and did not represent men. Materials provided for men by healthcare professionals and charities included non-relevant information, such as menstrual cycles, breast reconstruction, bra fittings and diagrams of female breasts:

"It was really hard cause it was a man whose got breast cancer and everything they talked about, all the pamphlets were bras and mastectomy bras and wigs and reconstruction."

(Mia, age 52, wife, 2007, secondary cancer)

"(Husband) has been slightly taken aback that all the literature is aimed at women and he has to answer questions online about whether he has experienced the menopause."

(Ragdoll, age 73, wife, 2021, stage not mentioned)

"You are an outlier, you are the wrong gender…. I'm sat beside a man who is two days' post-surgery for breast cancer and the literature he is reading (from a major breast cancer charity) is saying that it's not possible, he is completely excluded from it."

(Freya, age 49, wife, 2021, secondary cancer)

ICs felt that if men were mentioned, very little attention was afforded to them, and it was felt to be tokenistic:

"They tend to do a token effort towards men, so they'll have a booklet, and it will all be aimed at women and then they'll say "men can get breast cancer as well" that sort of thing. The you'll find there will be fifteen different leaflets for women and then one, which you've really got to hunt for, for men."

(Jeremiah, age 66, husband, 2015, stage not given)

Some healthcare providers were also perceived as lacking in understanding of how the illness can impact men, consequently failing to treat and provide suitable care and support for male patients. They were guilty of assuming the gender of the breast cancer patient as female, and thus expecting the female ICs accompanying the male patients to appointments to be the patient:

"When we went for appointments most people assumed it was me who had breast cancer, if you went for a clinic appointment, I was asked how I was and I was like 'well, I'm fine, but I'm not the patient'."

(Dee, age 52, 2004, widow)

One participant described her husband receiving a letter from a healthcare trust for a hospital appointment that was addressed to a woman and suggested suitable clothing to wear:

"The letters weren't adjusted to be for a man, for the mammogram it said it would be better to wear a blouse and skirt to the mammogram appointment."

(Bouquet, age 70, wife, 2011, stage not given)

Interestingly, rather than suggesting the provision of gender specific information for men, several participants recommended that the existing breast cancer literature avoid gender references, use gender-neutral terms, and include pictures of male mastectomy:

"Put it as 'largely women' in brackets if you want to emphasise that …but it's been quite staggering, not even how slanted or biased but how absolutely it is that it's about women and that I couldn't say the psychological impact that has on (husband) it's not going to be a positive one but for me I've been quite staggered by it because it's not rocket science… just don't say women, say people, it's that simple."

(Freya, age 49, wife, 2021, secondary)

"I don't think it is worth having an entirely separate leaflet, because it's an expense for a very small number of people."

(Ragdoll, age 73, wife, 2021, stage not given)

Mistrust of medical decisions and treatments

Some participants expressed how the BCiM patient they were supporting often felt excluded within the hospital setting. One IC described how the hospital did not appear to have a policy on how to look after a man with breast cancer, and thus treated his husband as an anomaly. The medical staff did not know what ward to put him in post-mastectomy as they felt they could not put him with female breast cancer patients. This caused significant upset and made him feel awkward and uncomfortable at an already a difficult time:

"Medically they were a bit of a shambles….He went into hospital and then of course then they didn't know where to put him so they put him in an orthopedic ward with overweight men that had knee issues and things like this and all these butch blokes, all builders and stuff were all like (makes grunting noise) lager, lager and all this sort of stuff and he's there thinking oh no…and of course he didn't want to say to them what he had, that he had breast cancer."

(Jeremiah, age 66, husband, 2015, stage not given)

This lack of compassion made his husband angry and upset with the disparities in female and male breast cancer care and support in hospitals:

"I've known a couple of women who've had breast cancer and they don't seem to have had those issues they were into a ward with other women who had had breast cancer. The whole package seems to be a lot tighter but for men you are a bit of an oddity."

(Jeremiah, age 66, husband, 2015, stage not given)

Other ICs expressed how both they and the person they supported struggled with feeling like an outsider in hospital and the breast cancer community:

"It makes you think how much support there is for females with breast cancer and their supporters."

(Mia, age 52, wife, 2007, secondary cancer)

The female focus of breast cancer and the lack of research conducted in male patients resulted in the mistrust and uncertainty of medical decisions for the men by their ICs:

"When he was diagnosed, they immediately said they were going to put him forward for a mastectomy because that's the first thing they do with men, whereas it's the last thing they do with women."

(Nico, age 51, wife, 2012, stage not provided)

"There isn't much research done into men's breast cancer, they treat it the same as women's breast cancer so its "this is what we give women so it's what we'll give men" and there doesn't seem to be any evidence that it actually works on men or if it's any good for men."

(Jeremiah, age 66, husband, 2015, stage not given)

There was a sense of unjustness at the disparities in treatment offered to male and female breast cancer patients. It was often felt that medical professionals made assumptions about the treatment preferences of male patients, and they were not provided with the same level of treatment options as their female counterparts:

"I asked if he could have reconstruction, and it hadn't even been thought about or talked about because he was a man and why would he want it?... He chose not to, but he should have the option."

(Mia, age 52, wife, 2007, secondary cancer)

Many participants were extremely concerned about the medical treatment prescribed for men, particularly the hormone therapy, Tamoxifen. They were worried about men being prescribed a female hormone drug as well as the changing parameters of how long it was prescribed. This resulted in uncertainty and lack of confidence in their medical treatment:

"They are using the same drug on men that they are using on women, assuming that's going to work, but they haven't really investigated what works best on men… I think there may be a difference in the drug that you give and there should be, I am sure there must be a difference."

(Jeremiah, age 66, husband, 2015, stage not given)

"He was told 'take it for two years', then 'oh no, you need to take it for five years' and then, 'oh no, you need to take it for ten years.' So, the goal posts kept changing and I said to him I felt that he was starting to feel like a guinea pig because there isn't any research on the effects of Tamoxifen on men because it is a female drug, for female hormones."

(Nico, age 51, wife, 2012, stage not given)

The adverse side-effects, sometimes long-term, associated with Tamoxifen, posed significant challenges to the quality of life and well-being of patients, and consequently, also impacted the lives of their ICs:

"He still has to take these tablets, and this is the worst thing…Tamoxifen, but it gives him pains and he gets a bad pain in his neck and he has to put a heated pad on it when he goes to bed and we now sleep in separate rooms because he was so conscious and he needs a good night's sleep but he's also tossing and turning all night"

(Jeremiah, age 66, husband, 2015, stage not given)

"Another effect of the Tamoxifen, is he will very often forget things, he will put things down and forget where he's put them… he would forget that he is cooking, which could be quite dangerous… his short-term memory is diabolical now"

(Nico, age 51, wife, 2012, stage not given)

Tamoxifen often induced an impairment in men's sexual functioning and ICs described how their partners struggled with loss of libido and erectile dysfunction. This consequently impacted their intimate relationships:

"In terms of physically, it's (Tamoxifen) affected his libido …in terms of a physical marital relationship, that doesn't happen."

(Nico, age 51, wife, 2012, stage not given)

"He's lost all of his sex drive for a start, which is a big thing."

(Jeremiah, age 66, husband, 2015, stage not given)

The lack of faith in medical knowledge and adverse side-effects of Tamoxifen resulted in some men deciding to stop taking the medication contrary to clinical advice. ICs described the role they played in supporting their partner to come to this decision, although they were concerned about taking medical decisions into their own hands:

"We talked about it and he came to the decision that he wanted to come off it because they did keep changing the goalposts and it was completely untrustworthy"

(Nico, age 51, wife, 2012, stage not given)

Several of the ICs felt unprepared for the long-term impact of cancer and its treatment on the physical and mental health of the patient. They described the daily emotional challenges that they faced:

“There were times when, I’ll be very honest, I had to dig deep for patience.”

(Raine, age 48, ex-partner, 2018, secondary cancer)

“We are now 9 years down the road from his diagnosis and the effects of the medications and perhaps the chemotherapy, because “chemo-brain” is a newish concept the effects are obviously much more long term than either one of us could possibly have anticipated. So, I can’t see the light at the end of the tunnel now for him and it sounds really kind of tragic…when people now ask how he is doing I don’t say he’s either having a good day or a bad day but he’s having a bad day or a worse day”.

(Nico, age 51, wife, 2012, stage not given)

Finally, due to the basic lack of support, some ICs expressed feeling ill-informed and uncertain about how the illness impacts men, and consequently, this affected how they should best support the patient:

“I felt as though I wasn’t able to support properly because of a lack of knowledge, a lack of everything.”

(Becksbud, age 47, friend, 2007, secondary cancer)

The same participant continued to explain how the lack of information undermined her confidence and her ability to provide support. This resulted in her stepping back from the friendship:

"I felt myself withdrawing because I didn't know how to be with him."

(Becksbud, age 47, friend, 2007, secondary cancer)

5.5.5 Isolated and alone

Lack of formal support

Almost all participants expressed a distinct lack of formal support offered to them. Consequently, most did not receive any practical information and support with helping to care for a man with breast cancer, nor emotional support. Furthermore, they did not have the opportunity to talk about their concerns with others in a similar situation and discuss things they may not feel able to talk about with family or friends. Most participants were dissatisfied by the lack of formal support offered to them, which resulted in them feeling alone and isolated:

'Throughout all of this I have never received any support at all, no support has ever been offered… Nothing from hospital, not from friends and family."

(Nico, age 51, wife, 2012, stage not given)

"Emotionally there is no support nor any support for the men with this. There was no help with this, I didn't feel there was any sort of support."

(Dee, age 52, 2004, widow,)

"There are no support groups at all."

(Jeremiah, age 66, husband, 2015, stage not mentioned)

"Not feeling alone is the biggest issue because I think you can feel isolated from everyone else."

(Ambellina, age 25, daughter, 2004, deceased)

The lack of formal provision of support resulted in most of the ICs being forced to search for support online. They found no support for the ICs of BCiM patients in the UK, and the only information found was written for American ICs, which was mostly irrelevant due to the different healthcare and support systems:

"There wasn't really support out there for people, I didn't find there were any support groups or help or anything like that… I looked and looked for male breast cancer support groups for partners, the partners support is just not there, it's just not there… We looked for support groups for partners and kids and things but there was just nothing…the answer was "well, sorry, but there isn't anything out there'."

(Dee, age 52, 2004, widow)

"The only place we can seem to get any information from is America."

(Freya, age 49, wife, 2021, secondary cancer)

Due to the lack of BCiM specific support groups, one IC described how she had joined a female group, but it was not suitable and did not meet her needs:

"We were on a mastectomy forum… but he did not have a mastectomy I didn't feel I could participate in conversations there."

(Raine, age 48, ex-partner, 2018, secondary cancer)

The perceived benefits of a support group for ICs were recognised by a number of participants who felt it would provide cohesion and help address loneliness and isolation:

"It would perhaps have been good to talk to people in similar positions….to know that there were other people out there dealing with it."

(Bouquet, age 70, wife, 2011, stage not mentioned)

However, for some, family and friends provided emotional support, which helped them to cope with the challenges they faced in supporting a man with breast cancer:

"My parents are very supportive and very supportive of him…Every day at least a half a dozen friends would message me 'how are you?" always asking how I was first which I found quite overwhelming."

(Raine, age 48, ex-partner, 2018, secondary cancer)

"They'll pick the kids up from school and have us over for a meal."

(Anna, age 31, wife,2008, palliative care)

For most ICs, providing emotional care and support often impacted their social life and relationships outside the house. Although the support of friends and family was often initially present, this frequently dwindled, and they were left as the sole carer. This increased the amount of support they provided the patient and intensified their caregiving role:

"Initially when he was first diagnosed people were more supportive but as time has gone on people are much less supportive."

(Nico, age 51, wife, 2012, stage not given)

"A lot of his friends actually disappeared"

(Raine, age 48, ex-partner, 2018, secondary cancer)

"Obviously people were concerned and at the beginning I think everyone thought 'uh oh, this is it.. he's a gonna' sort of thing, but no, people were just supportive and sent cards and get well soon stuff and a lot of people now it never comes up, no-one brings it up, it never gets mentioned really, it did at the beginning."

(Jeremiah, age 66, husband, 2015, stage not mentioned)

“I don’t think he has had any support as such. He notified the family in February and got a few sympathetic emails, but they haven’t followed up. I am a bit surprised at them actually…nobody has bothered to follow up and see how he is and how he is getting on which surprised me a bit because they are quite a close family but apart from the initial sympathetic response no one has come back.

(Ragdoll, age 73, wife, 2021, stage not mentioned)

The sense of isolation was, for some, compounded by tensions in relationships with other family members, who had less understanding of the illness and its consequences for the carer. As a result, this resulted in the IC feeling more socially isolated and left with the pressures of providing care and support alone:

“My relationship with the majority of my family is non-existent now because they don’t like (husband) and they think I could have done better and whether that is partly because they think I am in this situation and it’s not living my best life as it were, so I don’t have that at all anymore so that has been quite a big impact. In terms of friends, it’s been quite a similar situation with a lot of my friends to be honest, you know they just don’t get it, they don’t get it, they just don’t understand it because they don’t kind of live it, so I think it’s very difficult for people who have no kind of comprehension or experience or knowledge of living with someone with a chronic illness to understand it, so they don’t so in some situations my friendships have ceased as a result.”

(Nico, age 51, wife, 2012, stage not mentioned)

It appeared that formal support was only provided to ICs whose husbands were receiving palliative care at home. Those ICs in this position spoke highly of the benefit of the services and support they received at this time:

"He had a nurse who was so good she used to phone me, and I'd go in and see her. She went above and beyond…she delivered medication to the house for us, just these little things that's made a massive difference…she's reached out to charities who work with families who are dealing with a terminal illness."

(Anna, age 31, wife, 2008, palliative care)

The breast care nurses were able to put them in touch with charities that organised trips and experiences for families living with life-limiting illnesses. They also helped with household chores:

"They did our washing for about four months, washing, drying and ironing…they would come on a Friday and take the boys' uniforms, I'd just fill one bin bag up and they'd bring it back on the Sunday evening washed, dried, ironed, it was just the best thing ever."

(Anna, age 31, wife, 2008, palliative care)

She explained how the centre where her husband was treated provided additional support services:

"We had six weeks of counselling which was really helpful…they also offered complimentary therapies like Reiki, reflexology, things like that."

(Anna, age 31, wife, 2008, palliative care)

"It was literally when Macmillan got involved, literally in those last couple of weeks did I get the help and the information. Because half of it is just having the information, people telling you what your rights are, any allowances, if you are entitled to things, because you just don't know where to get this information, it just doesn't seem to be out there."

(Dee, age 52, 2004, widow)

As well as practical support, they also provided emotional support and helped ICs to prepare and help cope with the death of a loved one:

"It was practical support as well as what to expect, and what happens when somebody dies and what to expect."

(Dee, age 52, 2004, widow)

Although the benefits of the formal support were clear, it was apparent that they would be of more benefit if provided earlier in the cancer journey:

"I would have liked the practical help earlier, financial information so we could have dealt with things sooner."

(Dee, age 52, 2004, widow)

Impact of Covid

Isolation was further impacted during the Covid pandemic, when many cancer patients were told to shield (stay at home at all times) and government restrictions prevented households from meeting. Due to these protective measures, many ICs were unable to see their family and friends and faced unique challenges. Some stayed connected with family by texting, Facetime, and Zoom calls, which they found to be supportive, and let them know they were not alone:

"Unfortunately, because of this pandemic we haven't seen them so much because they can't come round. We have communicated with text and that sort of thing, stood on the doorstep."

(Andora, age 77, mother, 2005, secondary cancer)

Several participants discussed how they supported the patient in dealing with the additional challenges posed by the Covid pandemic. Some experienced disruption in their treatment during this time, which exacerbated anxiety. However, some continued with their treatment seamlessly. During this time, hospital restrictions meant that ICs were not allowed to accompany the patient to in-person medical appointments, with most appointments being on the phone. These were not as satisfactory as face-to-face consultations:

"The last few meetings have been difficult with Covid, and we've been talking to someone on the phone and normally we would go up there."

(Jeremiah, age 66, husband, 2015, stage not mentioned)

"It has been quite hard with Covid, because he goes to all his appointments alone and I am not able to hear directly what he is hearing."

(Ragdoll, age 73, wife, 2021, stage not mentioned)

As well as caring for the patient during Covid, some ICs had the additional burden of home-schooling their children during this time. However, some ICs did receive support from the school which helped:

"During Covid it was horrible, the worst... …. school actually reached out and said they'd take the kids …. that was a massive help because they had been off for such a long time."

(Anna, age 31, wife, 2008, palliative care)

The restrictions on social interaction impacted their lives and exacerbated their isolation. However, some ICs who were shielding received support from family members, who went further to provide practical support during these times. One participant explained how her sister helped with shopping, which enabled her to stay at home and protect her family. Consequently, this helped to ease the additional stress she was experiencing due to Covid:

"Although she lives quite far away, about an hour and a half, through the first lockdown because we were shielding, she came every Thursday with shopping and left it on the grass at the front, it just became routine, she did it for about twelve weeks… it's all these little things that make a massive difference."

(Anna, age 31, wife, 2008, palliative care)

5.5.6 Making a difference

Advocate for change

Due to a lack of awareness and subsequent negative outcomes experienced by many ICs, some became advocates and often acted themselves to raise awareness of BCiM. For example, they challenged the discriminatory provision of care of male and female breast cancer patients by an insurance company, held meetings with the director of hospitals, and were vocal on radio shows:

"I was quite angry at the beginning because he needed Herceptin…but because he was a man, they (insurance company) said he couldn't have it. So, I just hit the papers, I went to MP's and everybody… we took on the insurance company."

(Mia, age 52, wife, 2007, secondary cancer)

This sentiment was echoed by the friend who supported him:

"Are you telling me that if I was a woman in this position, I would be getting it but because I am a man I am not? I mean that is straightforward discrimination."

(Becksbud, age 47, friend, 2007, secondary)

"When he was first diagnosed there was no pictures of a man's mastectomy to show men, it was all women…so along the way we've made changes… we did Race for Life and we had keyrings made, you know like the ribbon and they were acrylic and they had male breast cancer on them and me and my mum went round to every man there, there was thousands of them and we just handed them out"

(Mia, age 52, wife, 2007, secondary cancer)

For some ICs, helping to raise the awareness and educate others about BCiM was a positive and rewarding experience. This gave them a sense of purpose and helped them to face the challenges of breast cancer:

"We gave out leaflets at the local Asda to promote male breast cancer…. a lot of people just took them or ignored them and then one lady came back and said "my husband is going to do something about it, having seen your leaflet and he thinks he might have a problem"…so if you've got one on that day."

(Bouquet, age 70, wife, 2011, stage not given)

ICs spoke passionately about the need to raise awareness of the illness in men, to share their story, educate others, and to improve the support for future patients and others in their situation:

"It was really important to me because I don't want other families to go through this"

(Raine, age 48, ex-partner, 2018, secondary)

"We are changing it for others behind us, you know so that it is easier for them."

(Mia, age 52, wife, 2007, secondary cancer)

One participant went a step further and described how she felt compelled to set up an awareness campaign for BCiM. She expressed that raising awareness of the disease gave meaning to their experiences and a purpose to his life:

"Because there isn't much awareness about male breast cancer, I wanted to be the one to do it, I wanted there to be a purpose behind his diagnosis, because for him it's too late because it's incurable, I didn't want it to be a waste of a life and to make other people aware that this is something that men need to check for….I wanted people to realise that breast cancer is for everybody, it's for teenagers, it's for men, it's for women, it doesn't discriminate."

(Raine, age 48, ex-partner, 2018, secondary)

Barriers to support

Potential barriers to ICs accessing support were identified. Firstly, a number of participants felt guilty and reluctant asking for support and respite care. They felt a sense of responsibility to look after and care for the patient who they felt was more deserving of support than themselves:

"I don't like saying this because I am not the one living with what he is living with, so for me to say 'well actually I need a break from it' is kind of ridiculous."

(Nico, age 51, wife, 2012, stage not given)

"I didn't really go looking for support because I thought well why should I be looking for it, it should be him looking for it, he's the one who's sick and needs the support."

(Dee, age 52, 2004, widow)

Secondly, for some, they felt that asking for help could be a challenge, and they were resistant to seeking support in fear that they may be perceived as not coping. The young carer felt her mum did not ask for support as she was concerned how others may view her:

"She didn't seek any help because she might have looked at that negatively and not coping."

(Ambellina, age 25, daughter, 2004, deceased)

Lastly, several participants were reluctant to identify themselves as carers, and instead saw themselves as supporting the patient in terms of their relationship:

"This is what I promised to do, I'm his wife…it doesn't feel like a carer's role so to speak."

(Anna, age 31, wife, 2008, palliative care)

"I don't class myself as his carer…You just get on don't you, you just get on with life and looking after your partner and for me I would expect the same, treat others how you want to be treated yourself…I *am his partner and I support him, that's the end of it really."*

(Jeremiah, age 66, husband, 2015, stage not given)

Whilst not all ICs felt they needed support; they did recognise the benefits for others:

"I think it might be good for other people, but I don't think so for me because I don't think there is anything I could gain from a support group to be honest, I am quite independent anyway…. Obviously if I was struggling with the whole thing then yes I would love it but I am not struggling, I am pretty chilled with it all."

(Jeremiah, age 66, husband, 2015, stage not given)

Suggested support provision for ICs

Most participants felt strongly that they needed more support. Participants suggested several methods of support for future ICs of men with breast cancer. These included online forums and Facebook support groups, specifically for the ICs of men with breast cancer. Some had experience of using such support groups in the past for other issues and had found them useful. They particularly found the anonymity of online forums and the ability to access and read other people's posts to be beneficial. Furthermore, they found online groups fostered the sense of a community. A number spoke of the potential benefits of an online peer support group.

There was a consensus that due to the rarity of the illness in men, an in-person group meeting would not be feasible, and participants felt comfortable with platforms such as Microsoft Teams and Zoom following their use during the Covid pandemic.

Perceived benefits of support for ICs for men with breast cancer were expressed and these included: emotional support and practical tips for caring, sharing information and advice on medical and treatment experiences, managing side-effects and sharing information on the advice and support available.

It was largely felt that a support group could also improve confidence, increase ability to cope, and help learn how best to support and provide care for the patient:

> *"It would be invaluable just to speak to someone going through the same… I would love that, I would love to be a part of something like that."*
>
> (Anna, age 31, wife, 2008, palliative care)

> *"Just having people who are going through the same stuff as you are, so you could discuss it and maybe even talk through different treatments people are going through, the side-effects of some of the medications… their mood swings, your own mood swings, because you are on this emotional roller-coaster."*
>
> (Dee, age 52, 2004, widow)

> *"I think I would benefit from some group support, kind of just giving me a break."*
>
> (Nico, age 51, wife, 2012, stage not given)

The specific support needs of young carers were also recognised. The young IC in the study was never offered support and felt she would have benefitted from having other young carers to share her concerns with:

> *"It would be good to have other young carers to talk to and know that that's ok…what I really needed was that its ok to feel sad things."*
>
> (Ambellina, age 25, daughter, 2004, deceased)

Other therapies, such as counselling, were suggested as a potential support to ICs, as well as support for children impacted by BCiM. Support ideas, such as child play therapy, were suggested to help explain the illness and treatment side-effects. It was believed that support was able to also provide emotional support and enable children to understand more about their own feelings and thoughts:

> *"Explaining through toys and things like that would have been really helpful because there is nothing there for the children whose parents are going through treatment."*
>
> (Ambellina, age 25, daughter, 2004, deceased)

In turn, it was recognised how support for ICs would not only help themselves, but also the government and the NHS:

> *"The idea of support for carers should be fundamental, because without carers in this country, not just for breast cancer, the costs to the NHS would be astronomical and unmanageable. So, I think its long-term benefits, if you look at short-term help for some people will be long term benefits for the greater good."*
>
> (Nico, age 51, wife, 2012, stage not given)

5.6 Discussion

The participants in this study provided clear insight into the experiences and psychosocial support needs of the ICs of men with breast cancer. The broad range of participants in terms of age, gender and the related patient's cancer stage, illustrated how BCiM impacts a range of people. The ICs faced numerous challenges as they attempted to balance the provision of care and support with their family responsibilities, work commitments, and personal life. The findings reveal how their roles often changed as the illness progressed and how ICs navigated how best to provide care and support for the patient. Furthermore, the impact on their own emotions and well-being, as well the ripple effect of cancer and how they often supported others, particularly their children is illustrated.

The results highlight the practical tasks and emotional support ICs provided to the patient. This is in line with previous findings from carers for patients with other cancers (cancer type not specified) who also experienced substantial caregiving workloads (Zavagli, 2019). The impact of caring differed depending on the stage of the illness, thus replicating findings from a meta-synthesis of qualitative research conducted with the ICs of a person with cancer (although not specifically BCiM). The authors reported how the needs of patients and care tasks of ICs evolve, develop, and become increasingly difficult as the illness progresses (Seal et al., 2013).

For some, being an IC impacted on their own physical and emotional health. Several participants reported neglecting their own needs, and the toll impacting upon their well-being. This relates to a previous review that identified significant consequences for the health and well-being of caregivers of people diagnosed with cancer (type not specified) (Girgis et al., 2012). ICs in the present study often felt that they had to be strong for others, especially children, which mirrors the care-giving experience of ICs of cancer patients (breast, colorectal, lung and lymphoma) in the UK (Thomas et al., 2002).

In general, ICs often experience multidimensional unmet needs such as poor interaction with HCPs, (e.g., lack of communication and informational support), practical support (e.g., lack of care and assistance with daily tasks) and psychosocial support (e.g., lack of help with worries, fear of suffering and death, providing emotional support to the patients and unpredictability of the future) (Zavagli, 2019). These were extremely apparent with the ICs of men with breast cancer and were exacerbated by a lack of general lack public awareness of BCiM.

Some ICs raised concerns about the feminisation of breast cancer which they felt reinforced gender misconceptions that breast cancer only affects women and contributes to a lack of awareness. These findings are similar to those men included in a qualitative synthesis (Quincey et al., 2016) which reported how men's experiences of breast cancer are inconsistent with hegemonic masculinity. In the current study, the feminisation of breast cancer subsequently impacted ICs and they often had to explain the diagnosis to others about how men can also get breast cancer, which at times led to them not disclosing the diagnosis and therefore leading to isolation. Some also discussed the lack of awareness of BCiM by clinical staff and had experienced staff presuming appointments were for them as opposed to the male patient they were accompanying. This echoes the subtheme "Isolated within the healthcare setting" in study 1. The findings are also mirrored in a study by Walker and Berry (2019), who reported male patients experienced stigma and felt unwelcome in breast health centers. Due to the association of breast cancer with women, this may result in a difference in experiences between the ICs of men with breast cancer and the ICs of other cancer patients.

The majority of ICs were concerned with the lack of gender specific information for men with breast cancer. They described how the information provided to them lacked relevance to men and often included irrelevant content and details which affect only women, such as menstrual functioning and vaginal dryness. This is similar to the "Pink Bias" theme in study 1 wherein men with breast cancer raised concerns about the lack of gender relevant information. This is also evident in other research with BCiM patients (Bootsma et al., 2020; Egestad et al., 2020; Farrell et al., 2014; Quincey et al., 2016).

ICs in this study were not provided with support materials relevant to their role as carers. The information needs of ICs in general have been assessed extensively in the literature. A study of ICs of cancer patients (cancer type not specified) highlighted that although ICs need access to timely information to help them effectively support and manage patients' needs, access to relevant information is often not provided (Heynsbergh et al., 2018).

For some ICs in this study, the paucity of research with BCiM patients resulted in a mistrust of medical decisions and treatment. This, coupled with the adverse side-effects of treatment such as Tamoxifen, including sexual dysfunction and loss of libido, led some ICs to support the patients' decision to discontinue with the medication. Similar experiences were voiced by participants in study 1 and captured in the "Effects of treatment" theme (chapter 4, section 4.16). It also supports research conducted with men with breast cancer which showed the discontinuation of medication may lead to serious consequences, and ultimately, can cost lives (Pemmaraju et al., 2012; Visram et al., 2010).

For a number of participants in this study here was a lack of support services which had a significant impact on their ability to work and for some, resulted in additional financial pressures. This supports the findings of a scoping review of literature which highlights the financial costs experienced by caregivers of cancer patients (different cancer types but not including BCiM) due to the impact of care time on their ability to work (Coumoundouros et al., 2019).

The ICs of male patients with breast cancer may face additional challenges to those encountered by ICs in general. The unique burden of rare cancer caregiving experienced by the ICs of men with breast cancer align with reports of other rare cancers such as Scleroderma (a range of autoimmune conditions). These include poor interactions with healthcare professionals, insufficient (or absent) emotional, psychological and social support, lack of financial support and lack of awareness of existing support services (Applebaum et al., 2020; McMullan et al., 2022)

A fundamental challenge for the majority of participants in this study was the lack of support which rendered them isolated, unsupported and vulnerable to marginalisation. As in the theme "Isolation" in study 1 (chapter 4, section 4.14), most participants raised concerns about a lack of social support and feeling isolated. Unlike common conditions and more prevalent cancers, ICs of someone with a rare illness (such as BCIM) often have not met another person caring for someone with the same disease, which frequently results in isolation. Similar findings are reported with ICs of patients with rare conditions such as Scleroderma and Erdheim-Chester disease (an ultra-rare neoplasm) (Applebaum et al., 2020; Rice et al., 2020). Whilst a systematic review of the experiences of ICs of patients with glioblastoma (a rare brain tumour) also highlighted isolation as a key factor of the caregiving experience (Applebaum et al., 2016).

Due to the isolation and lack of awareness, a number of participants in this study became advocates to raise awareness of BCiM. Similar findings were reported in the theme "Advocate" in study 1. Patients and caregivers in rare diseases (disease type not defined) have increasingly become involved in creating disease-specific advocacy groups to share experiences, knowledge and to raise awareness (Nori et al., 2022).

The inclusion of bereaved caregivers in this study highlights the need for emotional and practical support both towards the end of life and after the death of a loved one. Participants detailed the uncertainty they faced and how they would have benefitted from support in understanding what to expect and knowing how to prepare for the death of a loved one. A study of spouse/partner cancer caregivers (*n* = 226; cancer type not specified) similarly reported participants were not emotionally prepared or prepared for the practical challenges associated with loss (Caserta et al., 2019). Furthermore, a systematic review of pre-loss grief and preparedness for death among ICs of terminally ill cancer patients (cancer type not specified) highlighted how high levels of preparedness for death predict more favourable bereavement outcomes (Treml et al, 2021). The sentiments of participants in this study highlighted how the void left from the death of the care recipient was long-term and showed that there may be lasting effects of caregiving that persist well beyond post-caregiving.

Interestingly, none of the ICs discussed the appearance related concerns or the impact the masculine self-esteem of those they supported. This may be due to men with breast cancer being reluctant to share their concerns with their ICs. Research has shown how patients of chronic conditions (such as cancer, stroke and pain) often experience the sense that they are a burden, also referred to as a "self-perceived burden" to those caring for them and do not share their concerns. This often results in ICs being unaware and affects their ability to provide support to care-recipients (Kuharic et al., 2023). In this study, the semi-structured interview questions were based on their role as an IC and the impact the illness had on their lives and relationships. Although not the focus of this research, future studies may benefit from exploring the awareness of ICs on these areas. If ICs are not aware of such concerns, they are not able to provide the practical and/or emotional support to meet their needs.

One participant in this study had been a young carer who cast light on her role providing emotional and practical support to her father. Her experiences of taking on similar responsibilities to those of adult carers, such as cooking, cleaning and looking after her siblings, resulted in the loss of her childhood. Similar findings are reported in a systematic review of young carers growing up with chronic illness in the family whereby children and adolescent ICs provide regular caring tasks and responsibilities. These can have a negative impact on their lives and can result in social isolation as young carers are unable to participate in activities with their peers (Chikradze, Knecht & Metzing, 2017).

The participant detailed the long-term negative impact of caring on her mental health which included self-harming. Similar findings have been shown in a cross-national study of adolescent young carers in six European studies which reported high percentages of young carers who are at significant risk of mental distress including self-harm due to their caring role (Lewis et al., 2023). A systematic review revealed how young carers (not specifically cancer carers) have poorer physical and mental health on average than their non-caregiving peers (Lacey, Xue & McMunn, 2022).

The participant in this study who had been a young IC also detailed the distressing loss of her father to breast cancer. Although there is little research with young caregivers who experience their parent dying, the impact can result in them not only losing a loved one but also a loss of role and identity which can leave them feeling isolated and alone (Barry, 2011).

In conclusion, the ICs of men with breast cancer often walk a parallel path to ICs of other cancer and rare patient groups. For the ICs of men with breast cancer many of these challenges are exacerbated, due to a lack of awareness, perceived femininity of breast cancer, and the subsequent lack of support. Good mental and physical health for the IC is vital to sustain the essential role they play in providing care and support. Neglecting their own needs can have devastating consequences, as when a carer’s quality of life declines, the same is likely to occur for the patient (Segrin & Badger, 2014).

Finally, much of the current data substantiates the findings of the first study in this PhD; whereby the sense of isolation, lack of support, paucity of information, and general lack of awareness of what is typically considered a “female” disease, were major concerns for many of the ICs. These findings show that the themes and challenges evident in men with breast cancer, are also often present with their ICs. Finally, to the best of the researcher’s knowledge, this is the first study to be conducted with the ICs of men with breast cancer in the UK, consequently, the findings are novel and add to the BCiM literature, further they extend existing knowledge of the impact of being a carer.

Finally, a summary of the findings were sent to the charities who promoted the study and those participants who requested feedback (Appendix 17).

5.7 Strengths and limitations

The following section will outline the strengths and limitations of the study. First, to the best of the researchers' knowledge this is the first study in the UK to explore the experiences of ICs of men with breast cancer and adds to the literature. Second, the breadth of participants' demographics (age, gender, and sexual orientation) and their relationships with the men with breast cancer (e.g., wife, husband, daughter, friend) provided a broad insight into the experiences of ICs from a variety of perspectives. Third, the inclusion of participants who had cared for and supported a man with breast cancer who has since died provided an additional perspective and identified how ICs needs may be ongoing long after the death of the man they cared for.

However, limitations of the study include the lack of diversity. All participants identified as white, and the study would have benefitted from encompassing a more diverse population. This is important as specific demographic groups of carers are known to be less likely to receive support (Phillipson et al., 2014), such as those from Black and minority ethnic populations (Greenwood et al., 2015). Future research in this area should explore more appropriate ways of engaging participants from ethnically diverse populations. There is a need for more research to focus specifically on individuals from diverse backgrounds. This is discussed in detail in chapter 7.

5.8 Reflection on the Analytic process

I found the first 'familiarisation' stage of to be an integral part of the analysis for this study. I transcribed each of the interviews verbatim, shortly after they took place and were still fresh in my mind. I could still envisage the participant talking to me as I typed up the dialogue. Although this was a lengthy and time-consuming task, I found this was an invaluable way to start the analytic process and I quickly became immersed in the data. During this time, I also kept a reflexive log. I was surprised by the impact some of the participants had on me, and I often found I continued to reflect on certain interviews, sometimes for many months after it had taken place. At times I struggled with how, as a researcher, one can build such a fast, intense rapport with someone they had previously never met, who shares such deeply personal memories and experiences, and then they never encounter each other again. This part of research feels cold and detached, and it was surprising what an intense and emotional journey conducting qualitative research can be.

I made familiarisation notes in relation to each interview and the whole dataset. These outlined initial, loose ideas about potential patterning of meaning in the data. The research questions had intentionally been designed to gain a broad, understanding of ICs' experiences. Consequently, my initial analytic observations and interpretations were conducted in a bottom-up, latent approach to the data.

The qualitative data analysis computer software package, NVIVO, was used. Throughout phases 2-5 (coding the data, generating initial codes, developing and reviewing themes, and refining, defining and naming themes), I was acutely aware of my position as a researcher to accurately portray the experiences of the participants. I was determined to capture the complexities of their experiences and to give voice to this previously unheard group. Additionally, I aimed to publish this study in a journal and thereby raise awareness of both BCiM and the experiences of their ICs.

During these stages, I often thought about the participants I had interviewed. I intentionally took time away from the analysis to go on long walks with my dog. I found this enabled me to get a distance and literally take a step back, clear my thoughts, and consider the analysis. I found this was effective, as it was often during these walks that I found I could better process the information, as well as taking time to reflect on my emotions. I ensured that I took a notebook with me whenever I left the house! I also talked through the data by talking to my PhD peers as well as my supervisory team. Throughout the process I also kept a reflexive journal, whereby I kept note of how I was making sense of the data as well as my emotional responses. The final stage of the analysis includes writing the report.

5.9 Conclusion

The provision of emotional and practical support for a man who has received a diagnosis of breast cancer falls primarily on family and friends. Providing emotional care and support can be demanding and enduring and impacts virtually every aspect of their lives. This study has provided an insight into the experiences and psychosocial support needs of ICs of men with breast cancer. ICs often are supporting others in their families, such as their children, as well as the man with breast cancer. The impact of providing care and support can result in ICs neglecting their own health, which may have serious implications. The rarity and associated lack of awareness of the disease, and its perception as a “female” disease, can compound the challenges around support and isolation of ICs in general. This is a novel area of research and the findings highlight the necessity to address and meet the information and support needs of all ICs of men with breast cancer throughout the cancer journey.

Appendix 25 shows the published article of this study. In accordance with the doctoral descriptors, this demonstrates the researcher has conducted enquiry leading to the interpretation of new knowledge through original research.

5.10 Reflection on the Biopsychosocial model and study 2

The Biopsychosocial model provides a holistic account of health and illness whist focusing on the person and their contexts (Wade & Halligan, 2017). It is therefore relevant for this study which provides an insight into the experiences and impact of providing care and support to men with breast cancer on their ICs. The results show ICs play an important role in providing practical and emotional support and are often isolated. There is a need to further understand and address the physical, psychological and social factors of caring for men with breast cancer. The model could be considered when designing an intervention to provide ICs with the education and practical tools needed to adjust to the physical, psychological and emotional stresses that they may experience when caring for a man with breast cancer. This will be explored in more depth in the final discussion chapter 7.

5.11 Reflections on the methods

I thoroughly enjoyed conducting study 1 and found the online survey method to be a solid basis to start the PhD. However, I was somewhat frustrated by the restrictions of an online survey and not being able to 'probe' participants on their responses, to gain a deeper and more informed insight. Although I felt I managed to garner a good understanding of the issues facing men with breast cancer, I was keen to gain more in-sight and a deeper understanding of the experiences of their ICs in this study. I was hoping this would be possible through using semi-structured interviews to conduct this study.

With a mixture of excitement and trepidation, I started conducting the interviews. From the outset, I was surprised by how honest and open participants were during our conversations. I felt that my being a similar age to many of the participants may have helped put them at ease and further enabled me to build a rapport early in the interview.

I felt extremely honoured and privileged that they chose to share so many deeply personal and emotional memories. At times, I had to fight back tears and remain professional, as their stories were often so sad and traumatic, but told with such love and affection. There were certain participants who really had a lasting effect on me, and I found myself thinking of them and wondering how they were for many days, weeks, and months after the interview. To this day, I would love to know how they are managing. I felt humbled by the sacrifices they made in providing care and support and the impact the disease had on so many aspects of their lives. I also felt honoured that they had managed to find the time to talk to me when their lives were so busy and they had little spare time.

As well as contributing to this body of research, I was extremely pleased that so many of them commented on how they had inadvertently benefitted from taking part and had found it to be a positive and enjoyable experience:

> *"I feel good now, I don't feel down about it at all because I am helping you and that means the world to me, so thank you."*
>
> (P10, age 48, ex-partner, 2018, secondary)

"Just doing this this morning has been really beneficial to me, just being listened to from the point of view of just being able to be really open about it without the concern that (Husband) is going to get upset about it, or I am saying things that make me sound like a bad person. It's just been really, really beneficial so thank you."

(P6, age 51, wife, stage not given)

Finally, I have thoroughly enjoyed conducting this piece of research. I have grown in confidence as a researcher and found the participants to be a source of inspiration. I feel a profound responsibility to do them justice and to give them voice by publishing the study in a journal.

5.12 Reflections on the impact of Covid on study 2

This study was conducted between January and June 2021 and Covid restrictions were constantly changing throughout. In January 2021, the government announced a national lockdown and instructed people to stay at home 'to control the virus, save lives and protect the NHS'. Restrictions meant all non-essential shops, cafes, restaurants and pubs were closed. We were only allowed to leave home to shop for basic necessities and travel was restricted. We were only allowed outside to exercise (once per day), seek medical assistance or to meet our support bubble and schools were closed with children taught online (GOV.UK, 2021).

No-one could predict the ever-changing landscape of the Covid pandemic and what possible restrictions may entail. Consequently, it made sense to conduct the interviews either on the telephone or on the Microsoft Teams platform. As we had been living under restrictions and were unable to meet up with friends or family for some months, as a society we had become increasingly used to such platforms. This became our new way of communicating with family, conducting work meetings, and a way to socialise. Social events such as meeting online with friends for a coffee or quiz nights now take place on such online platforms. Participants commented how they had become used to using online platforms due to the pandemic and appeared at ease with the technology.

When designing the study, it was deemed preferable to allow potential participants to choose whether they would prefer the interview to be conducted either via voice audio and/or video recording. This was to help counter the power dynamic which may exist when conducting qualitative interviews and is in keeping with the principles of actively including the participant in research (Dejonckheere & Vaughn, 2019). Most participants chose to conduct the interview on Microsoft Teams. Although only the audio was recorded, I found being able to see the participants when conducting the interview beneficial. It also enabled me to build a better rapport with participants than when having only the audio of the telephone. I also found it useful to be able to see the non-verbal cues, such as body language and gestures (DeJonckheere & Vaughn, 2019). This enabled me to check that the participant was ok to continue and to steer the conversation if necessary.

There was not a specific question in the interview schedule about Covid as I did not want this to be a specifically about how Covid affected their experiences of caregiving, but rather exploring the wider context of caring for a man with breast cancer. However, most participants discussed the impact of the pandemic, with those whose partners had died hypothetically discussing the impact of Covid if their partner were still alive. These factors formed the subtheme ‘Impact of Covid’ within the Isolation theme.

5.13 Next step

The first study in this PhD examined the experiences of the men with breast cancer, whilst this second study has explored the experiences of their ICs. In line with the multi-phase explanatory sequential design of the PhD (Figure 1, chapter 3, section 3.4), it was deemed important to also explore the inter-relationships between HCPs and men with breast cancer and their ICs. Together with studies 1 and 2, the next study aims to provide a holistic understanding and comprehensive overview of those who may be affected by or involved with men with breast cancer. The following chapter will present the third and final study in the PhD.

Chapter 6. Study 3: Exploring healthcare professionals' experiences and perceptions of the support needs of men with breast cancer and their informal carers. A mixed methods study.

6.1 Introduction

Within the UK healthcare system, initial concerns regarding potential symptoms of breast cancer in both men and women (e.g., an unusual lump or change in appearance, feel, or shape) are normally raised with the patient's General Practitioner (GP). If the GP is concerned, patients are referred to a specialist breast cancer clinic for further tests. If a diagnosis of breast cancer is confirmed, patients are cared for by a multidisciplinary team (MDT) of healthcare professionals, each with their own specialist expertise. MDTs often include breast cancer surgeons, specialist breast cancer nurses, oncologists, radiologists and radiographers. Other HCPs involved in the support of breast cancer patients may also include social workers, psychologists, counsellors, and GPs. In the UK, the NHS Breast Screening Programme invites all women from the age of 50 to 70 for screening every three years due to the increased risk of developing breast cancer (NHS.UK). However, men are not included in this programme, despite the average age of diagnosis being between 60 and 70 (Cancer Research UK, 2020).

As highlighted throughout, due to the rarity of BCiM, there is often a lack of awareness of the disease amongst men, which leads to delays in seeking medical attention (Bootsma et al., 2020; Co et al., 2020; Reis Abdalla et al., 2021). Furthermore, HCPs infrequently treat male patients with breast cancer, and are often unaware of the risks associated with the condition in men

(Bootsma et al., 2020). Together, these factors frequently result in delayed diagnosis, advanced stage diagnosis and poorer outcomes (Iredale et al., 2005; Pituskin et al., 2007; Younas, 2020).

Increasing evidence in the literature (chapter 2), plus the present research, shows both a clear lack of gender appropriate support materials and minimal psychosocial support provided to both male patients with breast cancer and their ICs. Studies 1 and 2 in this PhD and in the published literature indicate that men with breast cancer frequently feel stigmatised within the healthcare setting and along with their ICs, often feel isolated (Herring et al., 2022; Midding et al., 2018; Quincey et al., 2016, 2021; Sime, 2012; Walker & Berry, 2019). This supports a recent referral of the treatment and experiences of men with breast cancer in the healthcare setting as an 'epistemic injustice' (Younas, 2020). In contrast, female breast cancer patients are routinely provided with information regarding treatment and support in different formats, in addition to the frequent provision of decision aids to help inform shared decision making (Gao et al., 2021); which is largely lacking for male patients.

Within their professional roles, HCPs in breast cancer care are responsible for providing information, advice, and support, for patients and their ICs, during their illness. Their role is also to ensure those affected by breast cancer receive the optimal and most appropriate treatment and care (NICE, 2018). From the time of diagnosis and throughout treatment, cancer patients look to their HCPs for both medical guidance and emotional support (Bonito et al., 2013). Given the potential importance of this relationship, the increase in the incidence of this disease in men, and the fact that HCPs are likely to work with male patients with breast cancer at some point in their career, it is vital to explore the views and experiences of HCPs working in this field. Furthermore, meeting the needs of BCiM patients and their ICs may facilitate informed decision making. To the best of the researcher’s knowledge, only one study in the Netherlands has assessed the unmet information needs of HCPs involved in the care of male patients with breast cancer (Bootsma et al., 2020). However, no prior studies have been conducted with this population in the UK. Finally, in order to improve support for HCPs, patients and their ICs effectively, it is necessary to gain insight into the experiences and views of HCPs. For these reasons, it was deemed necessary to undertake a study in this area to gain further insight.

Consequently, Study 3 posed the following research questions:

- What are HCPs’ experiences, understandings, and perceptions, of the support needs of BCiM patients and their ICs?
- What resources or sources of support do they currently provide to BCiM patients and their ICs?
- What do they think are the resources that would facilitate and enhance support provision for individuals and ICs affected by BCiM?

Study aims:

- To explore the experiences of HCPs working with people with breast cancer and their ICs.
- To elicit HCPs’ perceptions of the resources/support services that would be beneficial for BCiM patients and their ICs.

6.2 Ethics approval

Ethical approval for the study was granted from the Faculty of Health and Applied Sciences Ethics Committee at The University of the West of England, Bristol, UWE REC REF No: HAS.21.11.037 (Appendix 24).

6.3 PI involvement in Study 3

Feedback on the survey was sought from representatives of HCPs involved in the care and support of men with breast cancer and their ICs. This included two from each of the following professions: breast cancer surgeons, GPs, BCNs, radiologists and social workers. These contacts were established and cultivated throughout the PhD.

Each PI was emailed the draft survey and asked to provide general feedback and to specifically comment on the length, appropriateness of the language, and the suitability of terms used within their professions to refer to BCiM. Despite follow-up contact with all those who had been sent the draft survey, feedback was only received from one breast cancer surgeon, one radiologist, and one BCN did not respond to the request to provide feedback.

Of those who did respond, most feedback regarded concerns about the feasibility of recruiting HCPs, due to their heavy workloads following the Covid pandemic. The majority agreed the survey should be kept as brief as possible so that busy HCPs would be more willing and able to take part. Due to the low numbers of BCiM, it was also suggested the recruitment criteria was widened to include HCPs who work with both men and women with breast cancer. Regarding feedback on language, one GP suggested using the more appropriate medical term of 'Patient Information Leaflets (PILs)' instead of 'Patient information booklets" and The British Medical Association was recommended as a relevant professional support organisation, should participants require support following taking part in the study. These were included.

PI supported an online survey as the most convenient, time-efficient, and accessible way for busy professionals to participate in the research project. They also recognised that potential participants would be familiar with using technology in their professional lives. Their feedback estimated that the survey would take less than five minutes to complete, which they deemed to be an acceptable length.

Due to the level of concern from PI advisors regarding potential problems with recruitment, a backup study was planned. If necessary, this would involve recruiting trainee health professionals studying at the researcher's university, rather than qualified health professionals. Conversations were held with members of staff at the researcher's university regarding this option and discussions held about how, if required, this could be conducted. Fortunately, the original avenue of recruitment was successful, and it was not necessary to use this backup plan. However, it was a useful exercise to have an alternative option and in accordance with the doctoral descriptors, this demonstrates the researcher has the capacity to adjust the project design in the light of emergent issues.

6.4 Method

6.4.1 Study Design

As with study 1, the online survey was hosted securely via the platform Qualtrics, (Qualtrics, 2019). Questions were formatted for a mobile device to enable participants to respond at their convenience. This sustainable method enabled access to participants from dispersed geographical locations, saving time, cost, and convenience, for both the participants and the researcher (Evans & Mathur, 2018).

As the study was interested in exploring the experiences and perceptions of participants, it was not deemed appropriate to use standardised measures that contained pre-determined items.

These can lack flexibility, relevance, and potential depth (Alves et al., 2020), and would not be suitable to answer the specific research questions of this study. Consequently, a 22-item online survey was developed and tailored to the specific research questions (Appendix 18).

6.4.2 Demographic information

The following data were collected: profession, gender, number of years in profession, and the number of BCiM patients and/or ICs each participant has provided care for in their career. This information was sought to provide an overview of the participants and their professional experience with this population.

6.4.3 Survey questions

The survey was designed to expand on the findings of the previous two studies in this PhD, that identified isolation, lack of support, lack of awareness, and associations with a female disease, as key issues for both patients and ICs. In accordance with the multi-phase explanatory sequential design of the PhD, qualitative data from studies 1 and 2 were used to build quantitative survey items in this study (Fetters et al., 2013). Figure 9 shows the convergence of themes from studies 1 and 2, and how the quotations from these preceding studies were transformed into ten statements for the present survey, Table 14. A statement on masculinity and body image was also included due to their prevalence in the findings of study 1. Participants were asked to indicate on a 5-point Likert scale from 1 ("strongly disagree") to 5 ("strongly agree") to what extent they agreed or disagreed with the statements. In the analysis, these categories were collapsed to indicate "agreement" or "disagreement", and those who indicated a 3 were categorised as neutral.

Figure 9.

Key findings of studies 1 and 2 and convergence of findings

Patient key findings (study 1)

Isolation

Lack of awareness

Impact on body image

Impact on masculinity

Lack of gender specific information

Lack of psychosocial support

Unmet needs of BCiM patients

Treatment concerns

IC key findings (study 2)

Isolation

Lack of awareness

Impact of caring on informal Carers

Lack of gender specific information

Lack of psychosocial support

Unmet needs of patients and their Informal carers

Treatment concerns

Convergence of findings

Isolation

Lack of awareness

Lack of gender specific information

Lack of psychosocial support

Unmet needs of BCiM patients and their ICs

Treatment concerns

Table 14

Illustrates quotes and corresponding ten statements included in Study 3.

Theme	**Quotes from studies 1 and 2**	**Statement included in study 3**
Isolation	"Men are not heard of or seen, sadly suffering total isolation and secrecy from society…. cancer is a lonely disease…Male Breast Cancer is even lonelier." (BCiM patient, study 1, age 55, mastectomy)	Men with breast cancer feel isolated.
	"Not feeling alone is the biggest issue because I think you can feel isolated from everyone else." (Ambellina, IC, study2)	
Lack of awareness	"Disbelief? Men don't get breast cancer." (BCiM patient, study 1, age 55, mastectomy)	There is little public awareness about male breast cancer.
	"I hadn't thought that men could get it (BCiM)." (Bouquet, IC, study 2)	Receiving a diagnosis of breast cancer is a shock as men tend to think it is a female disease.

Lack of gender specific information	"Have some male breast cancer leaflets available…they had to be ordered in!" (BCiM patient, study 1, double mastectomy) "All the literature is aimed at women…. the pamphlets included bras and mastectomy bras and wigs and reconstruction." (Mia, IC, study 2)	There is not enough literature specifically for men with breast cancer.
Masculinity	"Your Cave-man brain kicks in…inventing the misconception are you more female than male?" (BCiM patient, age 55, mastectomy)	Men with breast cancer feel less masculine.
Body image	"I truly dislike my appearance when I shower or look at myself in the mirror after I shower. I am no longer a whole person." (BCiM patient, age 66, mastectomy)	Men with breast cancer have concerns about their appearance and body image after mastectomy.
Lack of psychosocial support for men with breast cancer	"I had no support or anyone who wanted to speak with me during my 2005-2006 ordeal….	There is little support for men with breast cancer.

	At that time I had never heard of men having breast cancer. I never have to this date” (BCiM patient, age 66, mastectomy) “Emotionally there is no support for the men with this.” (Dee, IC, study2)	
Lack of psychosocial support for the ICs of men with breast cancer	“There are no support groups (for ICs) at all.” (Mia, IC, study 2)	There is little support for the informal carers of men with breast cancer.
Femininity of breast cancer	“My main thoughts are how PINK this disease (BCiM) is.” (BCiM patient, study 1, age 55, mastectomy) “It’s very much still advertised as a female cancer because everything is pink.” (Raine, IC, study 2)	Awareness campaigns portray breast cancer as a female disease.
Concerns about treatment	“The fact that Tamoxifen has not been properly tested on men is a worry.” (BCiM patient, age 57, mastectomy	Men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men.

> “There isn’t much research
> done into men’s breast cancer,
> they treat it the same as
> women’s breast cancer…. there
> doesn’t seem to be any
> evidence that it actually works
> on men.”
> (Jeremiah, IC, study 2)

The survey also comprised a mixture of closed and open questions. The closed questions were scored on Likert-type scales. Text-free response boxes were provided to allow participants to provide more detail to their answers, if they so wished. Two open-ended questions asked:

- What do you consider to be the main issues for men who have received a diagnosis of breast cancer?
- What do you consider to be the main issues for the informal carers of men who have received a diagnosis of breast cancer?

A text-free response box was provided at the end of the survey, should participants wish to add any additional comments.

6.4.4 Target Sample

The target sample was UK HCPs involved in the face-to-face treatment, care, and support of people who have received a diagnosis of breast cancer and their ICs. Due to the rarity of the disease and concerns of recruiting HCPs post- Covid, the criteria were purposely broad. Potential participants needed to have had experience working with breast cancer patients, but this did not have to be with male patients. It was not considered appropriate to include those professionals who have little in person or face-to-face patient contact, such as pathologists. Potential participants included: breast cancer surgeons, oncologists, general practitioners (GPs), breast cancer nurses (BCNs), radiologists, oncology nurses, psychologists, social workers and counsellors. Their main roles, duties, and responsibilities of working with breast cancer patients are outlined in the Glossary of Terms (Appendix 2).

As with study 2, recruitment was aimed at UK participants only. This was deemed important due to the potential differences in diagnosis, treatment protocols, care and support systems in the UK and other countries. It was also considered important to recruit a broad representation of HCPs to gain a wide range of experiences and perceptions of the support needs of men with breast cancer and their ICs.

As the study was exploratory, a small sample size was considered acceptable (Daniel, 2012). This was in line with other research wherein the surveys were developed by the authors to explore UK HCPs views and experiences with women with breast cancer (e.g., Williams et al. 2020; *n* = 58; Lafferty et al., 2011; *n* = 44). A target sample of 40 was chosen which was considered a feasible number to present a broad range of experiences and opinions. It was also deemed important to attempt to gather a spread of responses of HCPs from across the UK rather than just a small number of services. The proposed figure is slightly lower than previous studies and considers the rarity of BCiM compared to female breast cancer, as well as the potential challenges of recruitment of HCPs post-Covid.

6.4.5 Recruitment strategy

Recruitment took place between June and July 2022. The professional bodies of relevant HCPs were approached to ask if they would be willing to share the study details with their members. Table 15 shows the professional bodies and how they shared the study information.

Table 15.

Professional bodies and method of sharing the study information

Professional bodies	Method of sharing the study
The Association of Breast Surgery at the British Association of Surgical Oncology (BASO)	Added study details to website and circulated details in their members regular online newsletter
The Association of Breast Surgery (ABS)	Added survey information to ABS website and circulated details in members online newsletter
The British Psychological Oncology Society (BPOS)	Sent study details to their members
Breastcancernow.org	Shared the study details on their website
British Association of Social Workers (BASW)	Included in newsletter in Scotland and sent study details to BASW UK to share in their newsletter
Macmillan	Sent study details to staff

Note: Information was not available on how many potential participants the study information was shared with by the professional bodies.

HCPs who were known by the researcher and her supervisory team were emailed with details of the study, asking if they would be willing to participate and to share the study details with their colleagues. The adverts and study details are provided in Appendix 19. The study details and webpage link were posted on the social media platforms of the researcher and the Centre for Appearance Research, including Twitter, Facebook, and Instagram. The study was also included on the show-notes of episode 2, July 2022 of the Appearance Matters Podcast Summer Shorts Series, recorded by the researcher during the recruitment phase (Appendix 22). The Podcast is hosted by members of the Centre for Appearance Research. Link to the podcast:

https://soundcloud.com/appearance-matters/su2mmer-short-series-male-breast-cancer-and-informal-carers?utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing.

Snowball sampling was also employed, whereby professionals passed study details onto their colleagues.

6.4.6 Data analysis

Threats of Robots ('Bots') and measures taken to reduce these

Recruitment of research participants through social media platforms is often viewed favourably as a cost-effective, fast, and efficient way to reach a wide audience and target eligible participants (Arigo et al., 2018). However, since the development of study 1, online research methods are increasingly vulnerable to Bots, also known as automatic survey takers or fraudsters, which are a threat to sample validity and data integrity (Pozzar et al., 2020). Bots are increasingly prevalent in research and particularly evident when researchers offer financial compensation or incentives for completing the study (Teitcher et al., 2015).

In this study, the practical guidelines offered by Storozuk et al., (2020) were followed to mitigate threats and attempt to preserve data integrity:

- A CAPCHCHA (Completely Automated Public Turing test to tell Computers and Humans Apart) was embedded into the survey.
- The recruitment was carried out in stages; as outlined above, first it was distributed to professional bodies and contacts of the researcher and her supervisory team. Second, the study details and webpage link were posted on the social media platforms of the researcher and the Centre for Appearance Research, including Twitter, Facebook, and Instagram.
- The Qualtrics responses were manually checked daily for suspicious responses (e.g., all responses being the same). The researcher kept a record of any suspicious entries, and if found, these were deleted.
- No cash incentives or other prizes were offered.

In total, only three suspected suspicious responses were recorded. These were all identical and only answered the first four questions in the survey, whilst the remaining questions were left unanswered. These entries were deleted and not included in the analysis.

6.4.7 Statistical analyses

The dataset was analysed on SPSS v.28 using descriptive statistics. Not all responses have been compared according to profession, this is due to the uneven cell sizes in the sample as well as the different roles performed by the HCPs included in this study.

A qualitative content analysis was performed on the data derived from the two open-text questions. A number of health studies have used content analysis to explore similar topics as this study; including the informational needs of patients with cancer (Khoshnood et al., 2019; Wang, 2021), HCPs' views of the unmet needs of patients receiving cancer treatment (Ayvat & Ozbas, 2022) as well as other health conditions, including multiple sclerosis (Golla et al., 2012).

Three different approaches to content analysis were initially considered, namely; directed, summative and conventional. Directed content analysis is theory driven and is appropriate to use when the purpose of the content analysis is to validate or extend that framework. Summative content analysis involves identifying and counting essential keywords and is used to explore the contextual use of specific language. Whilst conventional content analysis involves coding categories to come directly from the text data, rather than imposing preconceived categories or theoretical perspectives. This is considered an appropriate design when existing theory or research on a topic is limited, such as BCiM, and therefore deemed the best fit for the purpose of this study (Hsieh & Shannon, 2005).

To ensure methodological rigour, the following systematic steps were taken based on the guidance set out by Erlingsson & Brysiewicz (2017); Firstly, the data were read and re-read several times by the researcher to become immersed in the data and to gain a sense of the text as a whole. Secondly, the data were organised, this included open coding, creating categories and abstraction. During the initial open coding process, notes were written as the data were read to describe all aspects of the data content. These were sorted into categories based on how different codes were related and linked into meaningful clusters, under higher-order headings. The third phase, abstraction, included formulating a general description of the topic through generating categories. These steps were conducted in a flexible, non-linear process. To enhance rigour, member checking was undertaken, whereby categories were discussed with the researchers' principal supervisor and any discrepancies were discussed until full agreement was reached. For the final phase, frequency counts were calculated, and exemplar quotes were selected to illustrate each category. The findings of the study are presented below.

6.5 Results

6.5.1 Participants

Overall, 62 UK based healthcare professionals participated, the majority of whom were female (*n* = 52, 84%). The largest proportion were surgeons (*n* = 20; 32%) and BCNs (*n* =13; 21%), and the average time in their respective professions was 9.79 years (range, 2 – 36 years). The vast majority (74%) worked in the NHS only, with 20% in both the NHS and private practice, 2% in private practice only, and 5% at a community hospice. All the respondents had treated, cared for, or provided support to women with breast cancer, 90% (n=56) of participants had worked with men with breast cancer, whilst less (*n* =23; 37%) had provided support to the ICs of men with breast cancer. Demographic details of sample by profession are presented in Table 16.

Table 16

Demographics of sample (N=62)

Profession	Gender M/F	Years in profession (mean)	No. who have treated/supported a man with breast cancer	No. who have supported ICs
Surgeon (*n*= 20)	9M/11F	14	20 (100%)	6 (30%)
Oncologist (*n* =6)	1M/5 F	13	6 (100%)	2 (33%)
General Practitioner (*n* =2)	2F	18	2 (100%)	1 (50%)
Breast Cancer Nurse (*n* =13)	13F	17	13 (100%)	9 (69%)

Radiographer (*n* =8)	8F	20	8 (100%)	2 (25%)
Psychologist (*n* =8)	8F	16	2 (25%)	0 (0%)
Physiotherapist (*n* =4)	4F	16	4 (100%)	3 (75%)
Occupational therapist (*n* =1)	1F	15	1 (100%)	0 (0%)
Total (N=62)	**62**	**13**	**56 (90%)**	**23 (37%)**

6.5.2 Healthcare professionals' views and experiences of working with men with breast cancer

Explaining a diagnosis to men with breast cancer

Regarding their experiences and perceptions of the support needs of men with breast cancer, 44 respondents (71%) reported that their role included explaining diagnoses to men with breast cancer (surgeons *n*=19, BCN *n*=10, oncologist *n*=6, GP *n*=2, radiographer *n* = 6 and physiotherapist *n* =1). Seven (11%) of the 44 respondents reported finding it harder to explain a diagnosis of breast cancer to male patients than female patients whilst the majority of the 44 respondents (*n* = 37; 60%) reported there was no difference, and only 2 (3%) had found it easier to explain a breast cancer diagnosis to a male patient.

As surgeons and BCNs were most frequently involved in explaining a diagnosis and treatment of breast cancer to male patients, it was decided to look at these two groups specifically. The majority of these groups collapsed together (74%) indicated that it was equally difficult to explain a breast cancer diagnosis to male and female patients (see Table 17).

Table 17.

*How difficult is it explaining a **diagnosis** to men with breast cancer compared to women with breast cancer?*			
Profession	It is easier	It is the same	It is harder
Surgeon (*n* =19)	2 (11%)	16 (84%)	1 (5%)
Breast cancer nurse (*n* =12)	0	7 (58%)	4 (33%)
Total (*n* =31)	2 (6%)	23 (74%)	5 (16%)

Explaining treatment to men with breast cancer

Regarding how difficult they found explaining treatment of breast cancer to male and female patients, the majority of surgeons and breast care nurses (80%) responded that it was equally difficult, 13% found it harder explaining to male patients and only 7% said it was easier than explaining to women (see Table 18). These findings indicate that explaining diagnosis and treatment to male patients is equally as easy or difficult for surgeons and BCNs.

Table 18.

*How difficult is it explaining **treatments** of breast cancer to men with breast cancer compared to women with breast cancer?*			
Profession	It is easier	It is the same	It is harder
Surgeon (*n* =19)	2 (11%)	16 (84%)	1 (5%)
Breast cancer nurse (*n* =11)	0	8 (73%)	3 (27%)
Overall (*n* =30)	2 (7%)	24 (80%)	4 (13%)

Support provided to men with breast cancer

In response to the research question, *'What resources or sources of support are currently provided to men with breast cancer?'*, the majority (n= 37; 60%) provided generic breast cancer information (e.g., leaflets, websites not specific to male breast cancer). Twenty-two (35%) reported signposting patients to a local support group/organisation/charity. Table 19 shows sources of support provided to men with breast cancer, by profession.

In the text-free boxes, six respondents provided additional details of support they provide in their professional role. These included: referral to social workers and counsellors, referral to genetic counselling, providing practical support with the side-effects of treatment e.g., lymphoedema management and weight fluctuations, and offering information on financial support. Table 19 shows support provided to men with breast cancer, by profession.

Table 19. *Support provided to men with breast cancer, by profession*

Profession	Generic breast cancer info	Specific male breast cancer info	Signpost to generic breast cancer support org.	Signpost to male specific breast cancer org.	Signpost to local support org.	Peer support	Psycho-logical therapies	Comple-mentary therapies	Refer to clinical psychologist/counsellor
Surgeon (*n* = 20)	15 (75%)	3 (15%)	11 (55%)	2 (10%)	7 (35%)	1 (5%)	0	2 (10%)	7 (35%)
Oncologist (*n* =6)	5 (83%)	2 (33%)	4 (67%)	0	2 (33%)	0	1 (17%)	1 (17%)	3 (50%)
General Practitioner (*n* =2)	2 (100%)	1 (50%0	0	0	1 (50%)	0	0	0	0
Breast Cancer Nurse (*n* =13)	10 (77%)	11 (85%)	11 (85%)	5 (38%)	6 (46%)	4 (31%)	5 (38%)	7 (54%)	10 (77%)
Radiographer (*n* =8)	3 (38%)	1 (13%)	3 (38%)	0	3 (38%)	0	2 (25%)	1 (13%)	3 (38%)
Psychologist (*n* =8)	0	0	0	1 (13%)	0	0	1 (13%)	0	1 (13%)
Physiotherapist (*n* =4)	2 (50%)	1 (25%)	2 (50%)	1 (25%)	2 (50%)	0	1 (25%)	2 (50%)	2 (50%)
Occupational therapist (*n* =1)	0	0	1 (100%)	0	1 (100%)	0	1 (100%)	1 (100%)	1 (100%)
Total (*n* =62)	**37 (60%)**	**19 (31%)**	**32 (52%)**	**9 (15%)**	**22 (35%)**	**5 (8%)**	**11 (18%)**	**14 (23%)**	**27 (44%)**

% > 100 as participants were allowed to choose more than one response

Suitability of current resources for men with breast cancer

The majority (*n*=33; 61%) felt resources were not appropriate whilst only 6% felt the resources were suitable for men with breast cancer. See more detailed results in Table 20.

Table 20.

HCPs' perceptions of the suitability of resources for men with breast cancer, by profession

Profession	Extremely unsuitable	Somewhat unsuitable	Neither suitable nor unsuitable	Suitable	Extremely suitable
Surgeon (n= 14)	1 (7%)	1 (7%)	9 (64%)	3 (21%)	0
Oncologist (n=6)	0	3 (50%)	3 (50%)	0	0
General Practitioner (n=2)	0	1 (50%)	0	1 (50%)	0
Breast Cancer Nurse (n=13)	0	10 (77%)	2 (15%)	1 (8%)	0
Radiographer (n=7)	1 (14%)	5 (71%)	1 (14%)	0	0
Psychologist (n=7)	4 (57%)	2 (29%)	0	1 (14%)	0
Physiotherapist (n=4)	0	4 (100%)	0	0	0
Occupational therapist (n=1)	1 (100%)	0	0	0	0
Total (n= 54)	**7 (13%)**	**26 (48%)**	**15 (28%)**	**6 (11%)**	**0**

BCiM-specific training

Only one participant (a surgeon) reported having received specific training on supporting men with breast cancer. They stipulated that this was provided as part of their registrar training before their consultant post, and that they had also conducted research in BCiM. However, nearly half of the 62 professionals who responded to the question (42%) felt that training on supporting men with breast cancer would be useful.

Out of the total number of participants, 17 (27%) provided suggestions for specific training, including: provision of specific communication tools for delivering diagnosis and discussing breast cancer with male patients; evidence-based information on treatment effects, including endocrine treatments; learning about psychological and emotional aspects of the disease, including male patients' perceptions of stigma; body image and the psychosexual implications of diagnosis and treatment; and finally, information regarding gender specific support and peer support services.

6.5.3 Healthcare professionals' views and experiences of working with the informal carers of men with breast cancer

Support for ICs of men with breast cancer

Regarding HCPs' experiences, understanding, and perceptions, of the support needs of the ICs of men with breast cancer, 23 participants (37%) responded that their role included providing support for the ICs of men with breast cancer (Table 21).

Table 21.

The number of HCPs in each profession who reported supporting the ICs of men with breast cancer

Profession	Number (%) who reported supporting ICs
Surgeon (*n*= 20)	6 (30%)
Oncologist (*n*=6)	2 (33%)
General Practitioner (*n*=2)	1 (50%)
Breast Cancer Nurse (*n*=13)	9 (69%)
Radiographer (*n*=8)	2 (25%)
Psychologist (*n*=8)	0 (0%)
Physiotherapist (*n*=4)	3 (75%)
Occupational therapist (*n*=1)	0 (0%)
Total (N=62)	**23 (37%)**

Support provided to ICs

Regarding the support they provide, 18 (78%) reported signposting ICs to male-specific breast cancer organisations, whilst a similar proportion reported providing generic breast cancer information (e.g., leaflets, websites not specific to male breast cancer) or signposting to a local support organization (as opposed to larger national breast cancer support charities). Less than half (48%) provide male specific breast cancer information. See Table 22 for type of support provided to the ICs of men with breast cancer by profession.

Table 22. *Sources of support reported to be provided to the ICs of men with breast cancer*

Profession	Generic breast cancer info	Specific male breast cancer info	Signpost to generic breast cancer support org.	Signpost to male specific breast cancer org.	Signpost to local support org.	Peer support	Psycho-logical therapies	Comple-mentary therapies	Refer to clinical psychologist/ counsellor
Surgeon (*n*= 6)	4 (67%)	1 (17%)	5 (83%)	1 (17%)	3 (50%)	1 (17%)	0	1 (17%)	0
Oncologist (*n* =2)	2 (100%)	0	2 (100%)	0	1 (50%)	0	0	0	0
General Practitioner (*n* =1)	1 (100%)	1 (100%)	0	0	1 (100%)	0	0	0	0
Breast Cancer Nurse (*n* =9)	7 (78%)	8 (89%)	8 (89%)	4 (44%)	6 (67%)	3 (33%)	2 (22%)	3 (33%)	4 (44%)
Radiographer (*n* =2)	2 (100%)	0	2 (100%)	0	2 (100%)	0	2 (100%)	1 (50%)	2 (100%)
Physiotherapist (*n* =3)	1 (33%)	1 (33%)	1 (33%)	1 (33%)	3 (100%)	1 (33%)	1 (33%)	1 (33%)	1 (33%)
Total (*n*=23)	**17 (74%)**	**11 (48%)**	**18 (78%)**	**6 (26%)**	**16 (70%)**	**6 (26%)**	**5 (22%)**	**6 (26%)**	**7 (30%)**

Suitability of resources for ICs of men with breast cancer

Fifty-eight participants provided their opinions on the suitability of current resources for the ICs of men with breast cancer. More than half (59%) feel that they were appropriate and only 12% feel they were suitable. See more detailed results in Table 23.

Table 23.

Suitability of resources for the ICs of men with breast cancer by profession.

Profession	**Extremely unsuitable**	**Somewhat unsuitable**	**Neither suitable nor unsuitable**	**Suitable**	**Extremely suitable**
Surgeon (*n*= 18)	0	9 (50%)	5 (28%)	4 (22%)	0
Oncologist (*n* =6)	0	1 (17%)	5 (83%)	0	0
General Practitioner (*n* =2)	0	1 (50%)	0	1 (50%)	0
Breast Cancer Nurse (*n* =13)	0	8 (62%)	5 (38%)	0	0
Radiographer (*n* =7)	1 (14%)	4 (57%)	0	2 (29%)	0
Psychologist (*n* =7)	3 (43%)	3 (43%)	1 (14%)	0	0
Physiotherapist (*n* =4)	0	4 (100%)	0	0	0
Occupational therapist (*n* =1)	1 (100%)	0	0	0	0
Total (*n* = 58)	**5 (9%)**	**30 (52%)**	**16 (28%)**	**7 (12%)**	**0**

Specific training on supporting ICs of men with breast cancer

None of the HCPs reported that they had received training on supporting the ICs of men with breast cancer. Twenty-two participants responded to the question ‘Do you think it would be useful to receive specific training on supporting ICs of men with breast cancer?’ of whom, only 8 (36%) thought it would be useful. Training suggestions included learning about signposting of ICs to sources of information and support (including psychological support) and the provision of more information for ICs regarding the common side-effects of treatment.

Specific resources for men with breast cancer and/or their ICS

When asked if they were aware of any resources specifically available for men with breast cancer and/or their ICs, 24 participants responded. Nearly half of these (38%) were aware of the Breast Cancer Now website and booklet, whilst 8% mentioned the Macmillan information booklet "Understanding breast cancer in men" and 4% mentioned each of the following: the NHS website, forums/Facebook groups (not specified), cancer research (not specified) breast cancer charities (not specified) and "Men Get Breast Cancer Too" posters (Walk the Walk).

6.5.3 Summary of results from statements

The following section provides a summary of the findings from the statements drawn from the findings of the previous studies in this programme of research (Table 14).

The vast majority (88%) agreed that men with breast cancer feel isolated, whilst a larger proportion (93%) agreed that there is little public awareness about BCiM. A similarly large proportion (87%) felt that receiving a diagnosis of breast cancer is a shock to men as they think it is a female disease, whilst a further 81% agreed that there is not enough information specifically for men with breast cancer. Interestingly, fewer participants (51%) agreed that men with breast cancer feel less masculine.

Most (79%) of the participants agreed that men with breast cancer have concerns about their appearance and body after mastectomy. Regarding support, most respondents (67%) agreed there is little support for men with breast cancer. A further 66% agreed that there is little support for the informal carers of men with breast cancer. The vast majority (96%) agreed with the statement that awareness campaigns portray breast cancer as a female disease. Finally, 49% agreed men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men, whereas 18% disagreed with this statement.

Table 24 below shows responses to statements. Comparisons of the data by profession was not carried out due to the uneven sample sizes. For a more detailed breakdown of each response by profession see appendix 21.

Table 24

Responses to the statements taken from the findings of studies 1 and 2 in this PhD

Statement	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Men with breast cancer feel isolated (*n*=61)	1 (2%)	1 (2%)	5 (8%)	32 (52%)	22 (36%)
There is little public awareness about male breast cancer (*n* =62)	1 (2%)	3 (5%)	0	23 (37%)	35 (56%)
Receiving a diagnosis of breast cancer is a shock to men as they think it is a female disease (*n* =61)	1 (2%)	1 (2%)	5 (8%)	25 (40%)	29 (47%)
There is not enough information specifically for men with breast cancer (*n* =61)	1 (2%)	2 (3%)	8 (13%)	22 (35%)	28 (46%)
Men with breast cancer feel less masculine (*n* =61)	1 (2%)	8 (13%)	20 (32%)	25 (40%)	7 (11%)
Men with breast cancer have concerns about their appearance and body image after mastectomy (*n* =62)	2 (3%)	3 (5%)	8 (13%)	34 (55%)	15 (24%)

There is little support for men with breast cancer (*n* =61)	1 (2%)	9 (15%)	9 (15%)	25 (40%)	17 (27%)
There is little support for the informal carers of men with breast cancer(*n* =61)	1 (2%)	8 (13%)	11 (18%)	25 (40%)	16 (26%)
Awareness campaigns portray breast cancer as a female disease (*n*=62)	2 (3%)	1 (2%)	0	19 (31%)	40 (65%)
Men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men (*n*=61)	3 (5%)	8 (13%)	20 (32%)	24 (39%)	6 (10%)

6.6 Content analysis

A content analysis was conducted on the two open-ended questions which asked:

- What do you consider to be the main issues for men who have received a diagnosis of breast cancer?
- What do you consider to be the main issues for the informal carers of men who have received a diagnosis of breast cancer?

6.6.1 HCPs' perceptions of the main psychosocial issues for men with breast cancer

Fifty-eight respondents (94%) answered the open-ended question regarding what they believed to be the main psychosocial issues for men with breast cancer. The results of a qualitative content analysis are displayed in Table 23. Responses ranged in length from one to 141 words. There were three main categories in the content analysis: (1) stigma; (2) health concerns; and (3) isolation and lack of support.

The ‘stigma’ category encapsulated HCPs’ perceptions of the challenges faced by men with breast cancer. The category included emasculation, body image concerns, the perception of breast cancer as a female disease, the subsequent difficulties sharing their diagnosis and shame. The second category, ‘health concerns’ related to the perceived health concerns of men with breast cancer and included worries about the side-effects of treatment, prognosis, hereditary risk and lack of research conducted in male patients with breast cancer. The final category of ‘Isolation and lack of support’ related to the perceived lack of male specific support and materials as well as the inappropriate medical environments for men with breast cancer. The frequencies and example quotes are illustrated in Table 25.

Table 25.

Results of the qualitative content analysis

Category	Sub-category	Frequency	Example
Stigma	Impact on masculinity	11 (17%)	“Feeing emasculated”
	Body image	8 (14%)	"Physical appearance, loss of nipple being noticeable. on a beach"
	Perceived as a female cancer	15 (26%)	"Societal perception that this is a female disease”
	Difficulty telling others	3 (5%)	"Difficulty sharing the news"
	Embarrassment	7 (12%)	“Embarrassment”
Health concerns	Treatment side-effects	11 (19%)	"Side-effects of hormonal-based therapies'
	Prognosis	7 (12%)	"Worry about prognosis"
	Paucity of medical research	8(14%)	"Lack of trial evidence to base decisions on"
	Hereditary risk	5 (9%)	"Guilt re genetics"

Isolation and lack of support	Lack of male specific support	9 (16%)	"Lack of male specific support networks"
	Inappropriate healthcare setting	3 (5%)	"Pinkness of breast cancer units"
	Lack of gender specific materials	10 (17%)	"Lack of supporting literature"

6.6.2 HCPs' perceptions of the main psychosocial concerns for ICs of men with breast cancer

The second open-ended question addressed the research question, 'What do HCPs believe to be the main psychosocial issues that face individuals ICs affected by BCiM?' There were three categories in the content analysis: (1) practical concerns; (2) health concerns for the patient; and (3) isolation and lack of support.

The category 'practical concerns' captured how HCPs perceived the impact of BCiM on their ICs and included how ICs provide support to the patient, how the disease may impact the IC/patient relationship as well as the financial implications of BCiM. It also covered difficulties in sharing the diagnosis with others. The second category 'health concerns for the patient' included the likely outcome or course of the disease, the side-effects of treatment and the inherited cancer risk for their children. Finally, the 'isolation and lack of support' category included the poor levels of awareness of BCiM and the lack of male specific breast cancer information. It also encompassed the lack of support for ICs of men with breast cancer and the subsequent isolation. The frequencies and example quotes are illustrated in Table 26.

Table 26.

Results of the qualitative content analysis

Category	Sub-category	Frequency	Example
Practical concerns	How to support a man with breast cancer	14 (24%)	"Not knowing how best to support"
	Impact on relationship	3 (5%)	"Impact on relationship"
	Financial concerns	2 (3%)	"Financial concerns due to loss of earnings"
	Sharing diagnosis with others	3 (5%)	"Difficulty explaining diagnosis to friends and family"
Health concerns for the patient	Prognosis	4 (7%)	"Is their cancer going to come back and will they die"
	Treatment side-effects	4 (7%)	"Likely that treatment will affect sexual function"
	Hereditary risk	5 (9%)	"Increased risk of disease to female offspring"
Isolation and lack of support	Lack of awareness	7 (12%)	"Insufficient knowledge about male breast cancer"
	Lack of gender specific information	12 (21%)	“Carer information and leaflets mostly have images of women with breast cancer…material geared towards women with breast cancer”
	Lack of support	8 (14%)	"Lack of support specific to men"
	Social isolation	3 (5%)	"Isolation from their peers as breast cancer is predominantly a female disease"

6.7 Terminology

Regarding what term HCPs use to describe men with breast cancer, the majority (61%) indicated using ‘male breast cancer’, followed by ‘breast cancer’ (56%), ‘breast cancer in men’ (45%), ‘men with breast cancer’ (32%), ‘chest cancer’ (2%), and 6% indicated ‘other’, but did not provide details. Table 27 shows likelihood of usage of terms to describe BCiM in professional practice, by profession.

Table 27.

Likelihood of usage of terms to describe BCiM in professional practice, by profession

Profession	**Breast cancer**	**Male breast cancer**	**Breast cancer in men**	**Men with breast cancer**	**Chest cancer**	**Other**
Surgeon (*n*= 20)	11	17	7	6	0	0
Oncologist (*n* =6)	4	3	2	1	0	0
General Practitioner (*n* =2)	2	1	1	0	0	0
Breast Cancer Nurse (*n* =13)	8	6	6	4	0	1
Radiographer (*n* =8)	5	5	5	4	0	1
Psychologist (*n* =8)	3	3	4	4	0	2
Physiotherapist (*n* =4)	2	2	2	0	1	0
Occupational therapist (*n* =1)	0	1	1	1	0	0
Total (*n* = 62)	**35 (56%)**	**38 (61%)**	**28 (45%)**	**20 (32%)**	**1 (2%)**	**4 (6%)**

**Participants were able to choose more than one term*

6.8 Discussion

The findings provide an insight into the perspectives of a wide variety of HCPs on the resources and support services currently available to men with breast cancer and their ICs. Additionally, suggestions for support services which may be beneficial to this population are provided. Their perceptions on the impact of BCiM on patients' perceptions of their masculinity and body image were also collected.

6.8.1 HCPs' views and experiences of working with men with breast cancer

Most HCPs who participated in this study had treated men with breast cancer. They reported providing men with breast cancer a wide variety of resources and support. The majority provided generic information (e.g., leaflets, websites not specific to male breast cancer) or signposted men to generic breast cancer organisations (not specific to men). Although generic support may improve quality of life for some men with breast cancer, they are often female-centric and inappropriate for a male audience (Nguyen et al., 2020).

Few HCPs reported signposting patients to male specific breast cancer support groups. The results of a scoping review showed support groups to be an important resource and benefit to patients with rare diseases, such as BCiM. These can provide a community, and the opportunity to share practical information and advice about the disease and its treatment. They also enable participants to provide and receive emotional support which can decrease isolation (Delise et al., 2016).

A small number of HCPs in this study signpost men with breast cancer to peer support. A systematic review of the benefits of cancer peer support groups (mixed cancer types, not BCiM) includes informational support, shared experiences, learning from and helping others (Jablotschkin et al., 2022). A study of peer support in men with prostate cancer showed that the sharing of experiential knowledge and emotional exchange with peers improves iquality of life (Huber et al., 2018),

Most HCPs felt there is not enough information or support specifically for men with breast cancer, and over half of the HCPs felt resources currently available in the UK for men with breast cancer were unsuitable. These concerns were further re-iterated by the 'Isolation and lack of support' category in the content analysis. This supports the findings of studies 1 and 2 in this PhD. These results are further reinforced by the existing literature that illustrates how materials provided to men with breast cancer often lack relevance and do not meet their information needs (Nguyen et al., 2020; Quincey et al., 2016). Materials are predominantly designed for women and often include content and details that are irrelevant to men, such as menstrual functioning and vaginal dryness (Egestad et al., 2019). Furthermore, resources often lack male specific information and do not include pictures of male bodies post-mastectomy (Skop et al., 2018). The under-representation of men in patient information resources can lead to men with breast cancer feeling ill-informed and marginalised (Quincey et al., 2016). The convergence of findings from the three studies in this PhD (Figure 10, chapter 7, section 7.1) will be discussed further in the following general discussion chapter.

When HCPs were asked how they find explaining a diagnosis of breast cancer to a male patient compared to a female patient, the vast majority reported it to be the same, with only few reporting finding it harder and very few finding it easier. This is contradicted by existing research, which found that some HCPs felt discomforted by male patients (Naymark, 2006). However, this study was conducted nearly 17 years ago and may not reflect current society. Further studies have suggested that HCPs may be more objective with male patients with breast cancer and more sensitive with female breast cancer patients (Williams et al., 2003). A more recent literature review on gender-bias in healthcare and gendered norms towards patients with chronic pain reported the depiction among HCPs of 'brave men' and 'emotional women' which may influence how they treat patients (Samulowitz et al., 2018). Furthermore, the vast majority (84%) of the sample in the current study were female, and research has shown that female physicians show more patient-centered communication and are better at explaining than their male counterparts (Mast & Kadji, 2018).

The majority of HCPs (51%) considered that men with breast cancer would feel less masculine. This was reiterated in the 'Stigma' theme in the content analysis (section 6.6.1) and supports the Pink Bias theme of study 1 (chapter 4, section 4.25) and the literature (chapter 2, section 2.4). However, the quantitative results in study 1 showed men reported a wide variety of masculine self-esteem scores, with the majority reporting high self-esteem however there was a wide variation in scores. Similarly, the vast majority of respondents (79%) perceived that men with breast cancer would have concerns about their appearance. This was further evident in the 'stigma' theme in the content analysis (chapter 6, section 6.6.1). The quantitative results in study 1 showed men reported a wide variety of body image scores, with some being concerned about their appearance whist others less concerned and is supported in the literature (chapter 2, section 2.3.2).

Many HCPs felt that the provision of training regarding BCiM would be beneficial. Due to the time constraints of HCPs, this could be achieved by providing online educational training programmes, as well as including these topics in core training. Online education and training programs to raise awareness and create knowledge have been integrated into routine medical education practice for students in the US (Menon et al., 2017). In New Zealand, online courses developed for HCPs have proved to be a practical, sustainable, flexible, accessible, low cost and provides reach a broad spectrum of HCPs (Maloney et al., 2012). Whilst in the UK, there has been a shift towards incorporating online teaching methods within traditional medical education post the Covid pandemic (Dost et al., 2020). This is discussed in more detail in the final general discussion chapter 7.

6.8.2 HCPs' views and experiences working with the ICs of men with breast cancer

Fewer HCPs responded that their role included providing support for the ICs of men with breast cancer. Those who did respond reported providing them with a variety of resources and support. The vast majority signposted to generic and/or male specific breast cancer organisations, local support organisations (information not provided as to whether these were general support organisations, i.e., not specifically cancer), or peer support.

More than half of respondents felt that the currently available resources in the UK were unsuitable for this population and that there is little support for the ICs of men with breast cancer. These results corroborate the findings of a qualitative study (study 2 in the thesis; Herring et al., 2022, Appendix 25) which showed how the ICs of men with breast cancer receive little emotional or practical support. As a result, they may experience significant levels of distress and often feel isolated. These findings are also consistent with a meta-synthesis of literature on more common cancers in men (Seal et al., 2013). The results of the content analysis in this study provided further insight into what HCPs perceive to be the main concerns for the ICs of men with breast cancer. The category ‘Practical concerns’ included challenges such as ‘How to support the patient’, whilst the category ‘Isolation and lack of support’ illustrated concerns regarding the lack of gender specific materials, lack of awareness, lack of support and isolation.

None of the HCPs who responded had received training on supporting the ICs of men with breast cancer. Future research would benefit from exploring the provision of training and education of HCPs on the support needs of ICs.

Finally, there was a lack of consensus regarding the term HCPs use to refer to men with breast cancer in their professional practice. The majority of participants in this study use the term ‘Male Breast Cancer.’ This variation may lead to confusion and uncertainty among other HCPs, patients, and their ICs. Research has shown how the use of different terminology by HCPs when explaining Ductal carcinoma in situ (i.e., the earliest form of breast cancer) can cause uncertainty surrounding the condition (Kennedy et al., 2009). The PPI input for this PhD outlined in chapter 1 (section 1.4.1) strongly recommended the need to move away from the use of this term and towards a more appropriate terminology of BCiM.

6.9 Strengths and limitations of the study

To the best of the researcher’s knowledge, this is the first study exploring healthcare professionals’ experiences and perceptions of the support needs of men with breast cancer and their informal carers in the UK. Despite recruitment for the study taking place post Covid, when the workload of HCPs was extremely high, recruitment was successful; the final number *(N*=62) was higher than the original target sample (*N*=40). Additionally, the broad range of professions presented an interesting insight into a variety of experiences.

Nonetheless, this study has limitations. Initial consideration was given to also exploring the experiences and perceptions of people who work for charities who may support men with breast cancer and/or their ICs. However, during PPI feedback from charities who had supported studies 1 and 2 it was evident many charities had either closed or had laid off staff members due to Covid. Consequently, this raised serious concerns regarding participation. The survey was sent to these bodies in the recruitment phase but there were no respondents, and it was therefore decided to focus on the experiences of HCPs. This is an interesting area for future research.

Further limitations include the demographic information regarding participant location could have been collected to explore variations in experiences of HCPs in different parts of the UK. However, following PI feedback, it was deemed crucially important to keep the survey as brief as possible to ensure maximum participation.

Second, although the number of participants was higher than initially expected, the uneven representation and small cell size of certain professions (General Practitioners (*n*=2) and Occupational therapists (*n*=1)) provided a limited representation of various HCPs. Future research could benefit from exploring the views and experiences of charities and support organisations in this field.

6.10 Reflections on the methods

The use of an online survey proved to be an effective and fast method to reach a broad range of participants. I feel that the mixed methods design of the survey proved successful in collecting data from a range of different professions. Although some participants did take the time to add more detailed responses, the brevity of answers provided by many were disappointing, and more detail may have provided deeper and newer insights. Upon reflection, the shortness of responses may have been due to the time constraints of participants. Future research including semi-structured interviews with HCPs may provide more rich and in-depth data.

To avoid bias when conducting the content analysis, I was mindful of the need to set to one side my experience, knowledge, and insight, gained from conducting the previous studies in the PhD and from the wider literature. I felt it was extremely important to try and maintain a neutral approach and remain open to finding new perspectives evident in the present data. At times during the analysis, I found that this was difficult, and I consciously had to remind myself not to be influenced by my work to date, my reading around the topic and to focus solely on the content of the present data. Having my Director of Studies member check the analysis further helped reduce the likelihood of this happening.

6.11 Reflection on the impact of Covid on study 3

Surprisingly, it was the aftermath of Covid which most affected this study in the PhD. In 2021 (when this final study was conducted), life for the most part had returned to a semblance of normality. However, the impact of the pandemic was keenly apparent in the UK healthcare system. Breast cancer services had been seriously impacted, which resulted in disruptions due to appointments being cancelled or postponed, barriers imposed by transport closures, and stay at home orders which prevented many patients from attending appointments. This resulted in a large backlog of services and the system was overwhelmed and under extreme pressure (Schneider et al., 2021). The workload of the HCPs I was aiming to recruit for this study was at unprecedented levels. The feedback I received from PI advisors regarding study 3 voiced serious concerns regarding the challenges facing HCPs, their extremely heavy workloads and serious doubts that they would have the time to complete the survey. Accordingly, I designed a backup study, which although was not needed I felt was a worthwhile exercise and something I will endeavour to do in the future. However, following my concerns about recruitment, I was surprised that the sample size exceeded the target number, and I am extremely grateful for their participation. This may indicate that HCPs recognise the importance of research in this area and that their contribution to research may potentially improve the future care and support for this patient population and their ICS.

6.12 Feeding back to key stakeholders

A summary of findings was sent to all participants who requested feedback (Appendix 20).

6.13 Reflection on the Biopsychosocial model and study 3

The range of HCPs in this study represent members of the multidisciplinary cancer care team who aim to provide comprehensive care to cancer patients and their ICs (Wang & Feng, 2022). The biopsychosocial model may help to understand the interactions between the biological and psychosocial components of the disease that can affect patient and ICs health and well-being and enable HCPs to adopt a holistic approach to providing support to this population.

6.14 Conclusion

HCPs provide a variety of resources to these groups, although most feel these are somewhat unsuitable for this population. There are overlapping concerns for both BCiM and their ICs among HCPs, regarding health concerns, isolation, and lack of support, which need to be addressed. There is a recognised need for appropriate, male-specific materials, and sources of support to be provided to both patients and their ICs. Finally, training on how best to support men with breast cancer and their ICs may be beneficial to HCPs. The findings of this study will be discussed in relation to the PhD overall, and the experiences of patients (study 1) and their ICs (study 2) in the following final general discussion chapter.

Chapter 7. General discussion, implications for care, future research and conclusions

7.1 Introduction

The overall aim of this PhD was to gain a deeper understanding of the psychosocial impact of BCiM. This was achieved by using an explanatory sequential design to explore the experiences of men with breast cancer and their ICs, as well as the experiences and perceptions of their support needs from UK based HCPs. The studies in this thesis have revealed a number of interesting and complimentary findings. This final chapter will demonstrate the researcher has met the final doctoral descriptors, in that she has developed independent judgment of issues and ideas in the field of research and can critically reflect and evaluate the research conducted in this PhD.

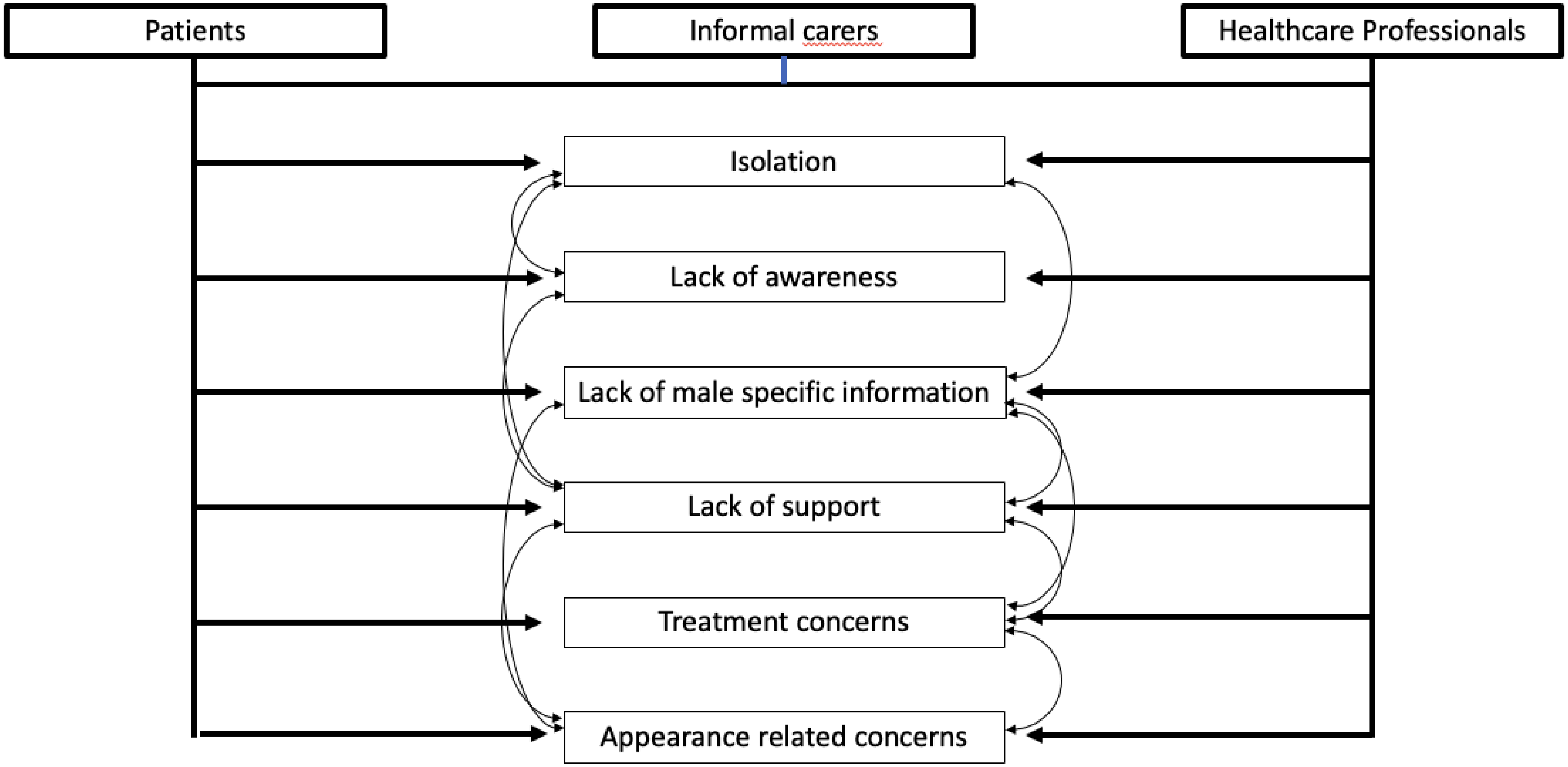
To date, there has been limited psychosocial research conducted in BCiM. Most studies have been qualitative in their approach, and to the best of the researcher's knowledge, the studies in this PhD are the first to be conducted with both the ICs of men with breast cancer and HCPs involved in their care and support in the UK, thereby adding an original contribution to knowledge. The three studies in this thesis have presented novel findings in previously under researched areas, and together, have started to address the gaps in the literature and provide a more holistic understanding of the impact of the BCiM. Study 1 was conducted with 87 men with breast cancer in nine countries. In accordance with the explanatory sequential design, this informed study 2, which interviewed 12 ICs of men with breast cancer, and study 3, an online survey with 62 UK-based HCPs. Recruitment for Studies 2 and 3 were limited to participants from the UK only as it was deemed important that the findings represented the healthcare system the research aimed to inform. However, there is a recognised ongoing need for more research to be conducted in other countries to potentially compare experiences and support systems around the world. Although each study adopted different research methods and samples, there is significant overlap in many of the key findings.

The findings of each study are presented in the corresponding chapters (Chapter 4, 5 and 6). This final chapter provides an integrated summary of the key findings across the thesis. These are set out in the following central themes: isolation, lack of awareness, lack of male specific information, lack of support, treatment concerns and appearance related concerns. Many of these themes are inter-related (Figure 10). To avoid repetition, these will be briefly discussed in relation to the wider literature, whilst a more detailed discussion is provided in each study chapter.

The implication of findings in relation to the future provision of care, support, and information are presented, along with recommendations for areas for future research and support. Limitations of the research are outlined ahead of a reflective section on the impact of Covid, methods used, the role of PPI, and the PhD as a whole. An overview of the key findings of the PhD are presented in Figure 10.

Figure 10.

The psychosocial impact of BCiM experienced by patients and their ICs, and the perceptions of HCPs. An overview of the key findings and interrelationships.



7.2 Isolation

Isolation is a thread throughout the thesis and is experienced by both men with breast cancer and their ICs. This was clear in study 1 (chapter 3) where a main theme in the qualitative element of the study was 'Isolation'. The theme encompassed feelings of loneliness, social isolation and feeling isolated within the healthcare setting.

Many of the experiences of isolation voiced by men with breast cancer were echoed by the ICs interviewed in study 2 (chapter 4). The theme, 'Isolated and alone' clearly demonstrated the negative impact of isolation experienced by the vast majority the ICs of men with breast cancer. This was encompassed by a distinct lack of formal support and the additional impact on loneliness and social isolation experienced during the Covid pandemic.

The findings of studies 1 and 2 are further supported by HCPs in study 3 (chapter 5), wherein the vast majority (88%) agreed (either "somewhat" or "strongly") that men with breast cancer feel isolated. Such convergence in findings across the three studies highlights its prominence.

The overwhelming sense of isolation expressed by many men with breast cancer and their ICs in this research is a result of numerous interacting factors and is related to the themes 'Lack of awareness', 'Lack of male specific information' and 'Lack of support.' The consequences of isolation in both men with breast cancer and their ICs has been discussed in detail in chapter 4 (section 4.14) and chapter 5 (section 5.5.5) and are summarised below.

Due to the general lack of awareness of BCiM, concerns about the reaction of others and perceived stigma associated with being a man diagnosed with what is commonly seen as a female disease, many men with breast cancer chose to conceal their diagnosis which may lead to further isolation. As a result, many men and their ICs are often left to cope without social, emotional or practical support, often for many years after treatment has finished. These findings align with research conducted with men with breast cancer (Quincey et al., 2016; Donovan & Flynn, 2007; France et al., 2000; Iredale et al., 2005; Midding et al., 2018; Pituskin et al., 2007; Thompson & Haydock, 2020,).

The perception of breast cancer as a gendered disease and the concern of adverse reactions when disclosing their diagnosis resulted in some participants referring to the illness as another form of cancer. This mirrors the behaviour of men who choose to refer to their “chest cancer” when disclosing their diagnosis of breast cancer (Walker & Berry, 2019) . The concealment of diagnosis for men with breast cancer may negatively impact and potentially isolate them from the practical and emotional support of friends and family, leaving them to cope with the disease alone.

A number of participants spoke of a lack of psychosocial support which rendered them isolated and raised concerns about gender disparities in the provision of breast cancer support. The lack of social support received by male patients with breast cancer compared to female patients with breast cancer is similarly reported in several studies (Bootsma, 2020; da silva, 2016; Donovan & Flynn, 2007; Iredale et al., 2005; Midding et al., 2019; Trusson & Quincey 2019).

Several participants in study 1 also expressed feeling isolated from the breast cancer community. Only one man reported the benefits of attending a breast cancer survivor group, although he still felt isolated as he was the only male in the group. In contrast, a number of men (study 1) and ICs (study 2) did not feel welcome in generic breast cancer support groups because of their gender.

ICs reported they felt uncomfortable as they did not share similar experiences with the other members. Although participants recognised the benefits of support groups, they were aware they did not have the same space as female patients or carers to share experiences, practical tips and emotional support. These experiences are closely interrelated with the 'Lack of social support' theme (chapter 4, section 4.14).

As well as experiencing social isolation, men with breast cancer in study 1 also felt isolated within healthcare settings. Some expressed feeling uncomfortable and unwelcome in the predominantly female setting of hospital breast cancer units. These experiences mirror the accounts of men with breast cancer reported in other research studies (Brett et al., 2005; Halbach et al., 2019; Trusson & Quincey 2019; Sime, 2012; Skop et al., 2018; Walker & Berry, 2019). One participant reported being treated in a gynecological hospital which was wholly unsuitable and made him feel extremely awkward, out of place and isolated. Similar experiences of men being treated in gynecological wards were captured by men with breast cancer in research conducted by Sime (2012) as well as a study in Germany (Halbach et al., 2019) which indicates how men in different countries experience similar treatment.

These results clearly illustrate how men with breast cancer can experience considerable emotional and social isolation. This is due primarily to the lack of awareness of BCiM and can lead to men feeling excluded by friends, work colleagues, health professionals and even breast cancer support groups. The majority of those affected by BCiM are unlikely to receive psychosocial support and endure the difficulties associated with breast cancer diagnosis, screening and treatment isolated and alone.

Isolation and ICs

Due to the paucity of services available for the ICs of men with breast cancer, many feel isolated. Their experiences of caregiving care are often similar to the ICs of other patient groups. ICs of people with rare blood cancer (Abblebaum et al., 2020) and other rare diseases (not specified; McMullan, et al., 2022) also showed poor interactions with HCPs, insufficient (or absent) emotional, psychological, and social support, lack of financial support, and lack of awareness of support services. Moreover, the association of BCiM with a 'female' disease may result in their ICs facing additional challenges to those encountered by ICs in general.

The sense of isolation experienced by the ICs in study 2 was exacerbated by the Covid pandemic. This increased social isolation and stress, reduced support networks, and added challenges to daily care activities by increasing practical and logistical concerns. These findings are supported in a scoping review of the impact of the Covid pandemic on family carers (generic carers due to illness and frailty, not specifically BCiM) in the community (Muldrew et al., 2022). ICs who experience isolation may also encounter difficulties which negatively affect their quality of life, mental and physical health (Vasileiou et al., 2017). Furthermore, isolation is associated with an elevated risk of mortality, due to a lack of access to care and the benefits from caregiving from friends, relatives, and adult children (Pristavec & Luth, 2020). Finally, it is fundamental to consider the impact of isolation on ICs, as research has shown that when the carer's quality of life declines, the same is likely to occur for the patient (Segrin & Badger, 2014).

None of the ICs interviewed in study 2 were aware of general or cancer specific support groups for carers. Whilst most ICs were open to accessing support, many expressed barriers to seeking help. These included guilt and reluctance to ask for support, fear of being perceived as not coping and prioritising the patient's needs above their own. Although no research has specifically explored the barriers and facilitators of ICs of men with breast cancer accessing support, similar results have been expressed in qualitative research conducted with the ICs of men with prostate cancer (Sinfield et al., 2012). Results showed similar barriers to those voiced by the ICs in study 2 and included a lack of awareness of sources of help, lack information, reluctance to ask for help, and prioritising the patient's needs. Similar findings are reported a study of ICs of cancer patients (type not specified), who described prevalence of a lack of support which impacted their ability to effectively support and manage patients' needs (Heynsbergh et al., 2018). Whilst the wider carer support literature shows how dementia family caregivers often struggle to find information about appropriate services or supports (Macleod et al., 2017). A qualitative study exploring the information and support needs of family carers at the end of life (condition not stipulated) similarly found barriers to support included a reluctance to ask for help (Harrop, Byrne & Nelson, 2014). Whilst a study of older women providing care to their husbands (condition not reported) showed how carers prioritised the patient's needs above their own needs (DiGiacomo et al., 2013). These findings show that ICs providing care and support across various conditions and at various stages, often face similar challenges.

In conclusion, men with breast cancer and their ICs are often isolated and experience the disease alone. It is vital that HCPs and those who provide support such as breast cancer support organisations, charities and carer support organisations understand the psychosocial consequences of BCiM for patients and their ICs. There is a need to increase awareness of the likelihood and potentially serious ramifications of isolation in this population. There is a need to raise awareness of the current support resources available to men with breast cancer, such as the online peer support group ‘The Men’s VMU’ (Virtual Meet-Up) and the Breast Cancer Now peer telephone and email support service.

There is a further need to identify, develop, and provide support for those at risk of isolation and to tailor support according to individual needs. Implications for research and practice are outlined and explored in more depth below.

Implications for future research in this area

- Aim to further investigate the relationships among factors associated with isolation in this population. Existing research in other rare cancer groups could be drawn on and areas to consider may include social support, barriers to support and cognitive beliefs.
- Potentially explore acceptable and accessible ways to facilitate the early recognition of social isolation and other support needs in both men with breast cancer and their ICs.
- Plan to explore potential barriers and enablers to accessing support for men with breast cancer and their ICs, including to existing support.
- To evaluate current psychosocial support interventions specifically for men with breast cancer

Implications for practice

These findings indicate an urgent need for the provision of effective psychosocial support specifically for men with breast cancer globally (study 1) and their ICs (in the UK) to help alleviate isolation. Due to the stigma often associated with men being diagnosed with what is commonly perceived as a female disease, many men may not feel comfortable accessing generic breast cancer support groups. Therefore, potential modes of practical and emotional support may include male specific breast cancer online peer support groups to bring together men with similar experiences, to share their concerns, fears, and frustrations of breast cancer. As discussed previously (chapter 5, section 5.4.5), 'The Men's VMU' (Virtual Meet-Up), an online peer support group for men with breast cancer, has been established since study 1 was conducted. A similar online peer support group specifically for the ICs of men with breast cancer as well as a specific website to provide information and support for men with breast cancer and their ICs could further benefit this population. These recommendations are considered in more detail in section 7.10. Finally, there is a need to raise awareness and provide training to HCPs so they are aware of, and able to signpost patients and their ICs towards current, reputable, detailed information and support.

7. 3 Lack of awareness

Participants across the three studies raised concerns about the lack of awareness of BCiM. These included the lack of awareness among the public, the perception of breast cancer as a female disease, and difficulties in disclosing diagnosis due to lack of awareness. The theme is closely linked to the 'Isolation' and 'Lack of support' themes. In study 1, several participants expressed concerns about the lack of awareness of BCiM, thereby indicating this is a global issue. These findings were supported in study 2, whereby 'Lack of awareness' is a subtheme of the theme 'Unmet needs of carers and patients.' Several ICs who took part in the study had been unaware themselves that men could develop breast cancer. The findings of studies 1 and 2 are further corroborated by the HCPs in the final study. In study 3, nearly all HCPs (93%), felt that there was little public awareness about BCiM. These results are supported by research which shows poor levels of awareness and knowledge of BCiM around the world; including in Brazil (Faria et al., 2021), India (Goyal et al., 2020), Hong Kong (Co et al., 2020), the Netherlands (Bootsma et al., 2020) and the US (Thomas, 2010).

Across the three studies in this PhD, many participants felt the lack of awareness of BCiM was due, in part, to the perception of breast cancer as a female disease and the "pinkness" of breast cancer awareness campaigns. In study 1, several men felt excluded by the pinkness associated with breast cancer campaigns. Similar sentiments were shared by ICs in study 2 who felt the prevailing pinkness perpetuates a general lack of awareness of BCiM among the general population. These findings are strongly supported by the HCPs in the final study. In study 3, 96% of HCPS felt that awareness campaigns portray breast cancer as a female disease. The 'pinkification' of breast cancer and how it is portrayed in breast cancer awareness campaigns serves to reinforce gender misconceptions that breast cancer only affects women has also been explored by previous research (Francis, 2018; Quincey et al., 2016; Sulik, 2012; Thompson & Haydock, 2020). However, this did not appear to impact men's sense of masculine self-esteem; the quantitative results in study 1 show men with breast cancer generally scored high on masculine self-esteem. However, there was a wide variation in scores which indicates whilst some men with breast cancer may struggle with the impact of breast cancer on their masculine self-esteem, others are less affected.

The general lack of awareness of BCiM made it difficult for both men with breast cancer (study 1) and their ICs (study 2) to disclose the diagnosis and share the details of their illness with others. Similar experiences of men feeling uncomfortable sharing a diagnosis due to lack of awareness of BCiM, concerns surrounding how it may make others feel and fear about the reaction of others are reported in the literature (Pitusikin, 2007; Sime, 2012; Quincey et al., 2016).

Finally, several men in study 1 were concerned about the lack of awareness of BCiM among HCPs. Some felt HCPs lack experience in treating male patients with breast cancer due to the rarity of the disease and expressed the need for raising awareness and training of BCiM for medical staff. These findings are supported by the results of study 3; only one participant (a surgeon) out of 62 reported having received specific training on supporting men with breast cancer, although nearly half (42%) of the whole sample felt training on supporting men with breast cancer would be useful. Research conducted by Fentiman (2018) claims that due to the rareness of the disease, many HCPs are never confronted with BCiM and they often lack experience in dealing with BCiM patients; therefore highlighting the importance of the need to raise awareness of BCiM.

To raise awareness of BCiM, several participants in both studies 1 and 2 found meaning and purpose from their breast cancer experience and became advocates. They expressed a sense of responsibility to the wider world and used their experiences to inform others and to eradicate stigma associated with the disease. These mirror the experiences of other men with breast cancer who similarly discussed becoming advocates to raise awareness of the disease in men (Egestad et al., 2019; Naymark, 2006; Pituskin et al., 2007; Quincey et al., 2016; Sime, 2012).

To summarise, across the three studies in the PhD, findings show there is a distinct lack of awareness of BCiM among both the public and HCPs. Participants often felt the feminisation and pinkness of breast cancer awareness campaigns contribute to the general lack of awareness of BCiM. As a result, many men and their ICs struggle to share the diagnosis with others and consequently, rarely benefit from the support of family and friends. Conversely, others may become advocates of BCiM to raise awareness of the disease in men.

Implications for future research

- Potentially develop and evaluate awareness campaigns for BCiM on a societal level. Public awareness campaigns are an important platform to increase knowledge, improve screening rates and may save lives, be cost-effective and have long-term health benefits. A recent example of raising awareness on a societal level is the late campaigner, Dame Deborah James (Bowel Babe) who had terminal bowel cancer. The toilet roll manufacturer Andrex and the retail company Marks & Spencer partnered with the charity Bowel Cancer UK to add bowel cancer symptoms to packs of toilet roll to raise awareness on a societal level.
- Aim to increase awareness among HCPs of the psychosocial impact and potential support needs of BCiM patients and their ICs.

Implications for practice

Awareness of BCiM is low and most of the general public do not know men are at risk of breast cancer. There is a need to raise awareness of BCiM on a societal level. A way of increasing awareness would be for existing campaigns to include more men. These should aim to improve awareness of the risk factors of BCiM, forms of self-care and self-examination, screening and the benefits of prompt action and treatment. Finally, to increase awareness among HCPs, online education training courses could be provided as well as including more BCiM related topics in basic medical training.

7.4 Lack of male specific breast cancer information

The lack of male specific information was highlighted by participants across the studies. In both study 1 and 2, participants were concerned about the lack of gender relevant information provided. The information provided lacked relevance and often included content and details which only affect women (e.g., menstrual functioning and vaginal dryness, or wearing a blouse and skirt to the mammogram appointment). None of the participants were provided with information specific to either men with breast cancer or their role as an IC for a man with breast cancer. For some, this contributed to their sense of isolation.

The lack of male specific information provided to men with breast cancer is documented in other research with BCiM patients (Bootsma et al., 2020; Egestad et al., 2020; Farrell et al., 2014; Quincey et al., 2016; Midding 2019). The under-representation of men in patient information resources and can be a major concern for men with the disease (Pituskin et al., 2007), and can lead to them feeling ill-informed and marginalised (Quincey et al., 2016).

Several ICs expressed how the lack of male specific information led to uncertainty in their role. As a result, they struggled with how to appropriately discuss topics and how best to provide support.

These findings were further corroborated by the HCPs in study 3, where the vast majority (81%), felt that there was not enough information specifically for men with breast cancer. These findings are supported in a recent mixed methods study conducted with men with breast cancer (Bootsma, 2020). Similarly, the authors reported participants lacked information specifically about acute or late side-effects, particularly the sexual side-effects of treatment.

In conclusion, breast cancer information provided to men is typically designed for female patients. The materials provided should be inclusive and tailored to support the needs of both men and women with breast cancer. Although charities such as Macmillan, Breast Cancer Now and Walk the Walk have online resources for men with breast cancer, it appears that neither patients nor their ICs in the UK are routinely made aware of their existence. Similarly, relevant support materials should be provided to the ICs, to provide them with the knowledge and skills to effectively perform their role. Material routinely provided to patients and their ICs should include male-specific information such as pictures of male bodies post mastectomy and contain information on the sexual side effects of treatment. Furthermore, in the absence of specific support, ICs in the UK should be signposted to generic support for caregivers of cancer patients such as Maggie's Centres or Marie Curie.

This theme interrelates with the other main themes in the PhD, namely, isolation, lack of support, treatment concerns, appearance related concerns. Implications for research and practice are outlined below.

Implications for future research in this area

- Intend to include men with breast cancer as PI advisors to co-produce and evaluate evidence-based information resources inclusive of male patients with breast cancer
- Aim to conduct qualitative research with the ICs of men with breast cancer, to explore their insights and views to better understand the support information needed for this group

Implications for practice

These findings indicate an urgent need for men with breast cancer and their ICs to be provided with appropriate support materials which are inclusive of men, and indeed all genders, from the beginning of their breast cancer journey. In the UK, this is normally the point when they are referred for further tests by their GP. Materials including pictures of male mastectomy and body image changes due to treatment and may serve to better prepare men and lessen the impact of appearance related concerns. As discussed below (section 7.10) the main breast cancer charities in the UK (Macmillan, Breast Cancer Now, Walk the Walk, Penny Brohn UK) now include men in their websites and provide male specific breast cancer information. This online information widely includes images of male mastectomy, treatment and signposts men to other support services. However, despite these resources being available, most men with breast cancer and their ICs who participated in this research, were not aware of their existence. To enable HCPs to signpost patients and their ICs to these resources, there is a need to inform them of available sources of information and support.

Furthermore, when discussing gender and healthcare in general, there is a need to move away from gender binary terms in healthcare literature, and to adopt more fluid and flexible constructs to allow for multiple dimensions of gender (Hart et al., 2019). Simple recommendations needed to make information relevant were suggested by ICs in study 2 which include using the term ‘people’ rather than referring to men or women with breast cancer.

7.5 Lack of support

The lack of support was a prominent theme highlighted by participants across each of the three studies and is inter-connected to all the other themes.

In studies 1 and 2 a large number of participants raised concerns about the distinct lack of social, emotional or practical support. In both these studies, some participants reported reaching out to support groups but were made to feel unwelcome, or the group did not cater for their needs. For ICs in study 2, the lack of support had a significant impact on their ability to work, which provided additional stress and anxiety and had a detrimental impact on their mental health. These findings are corroborated by the results of study 3; the majority of HCPs (67%) agreed there is little support for men with breast cancer, whilst 66% agreed that there is little support for the ICs of men with breast cancer.

Participants in both study 1 and 2 drew comparisons and highlighted disparities in the provision of support between male and female breast cancer patients. These findings are further supported by research which has shown that men with breast cancer receive less social and emotional support than female breast cancer patients (da Silva, 2016). A comprehensive review of evidence conducted by Fentiman (2018) indicates the emotional support needs of men with breast cancer are often not met. Furthermore, men with breast cancer tend to rely on the support of their partners for emotional and social support, rather than formal support services (Iredale et al., 2005; Thompson & Haydock, 2020). The unmet support needs of female partners of men with breast cancer have been similarly highlighted in research conducted by Egestad et al., (2019). The authors advocate for tailored support for partners of male patients with breast cancer.

In conclusion, the findings across the three studies in the PhD show that there is a distinct lack of support for men with breast cancer and their ICs. ICs often play an important role in the psychosocial support of men with breast cancer which often increases the care burden. There is a need to improve the emotional and practical support available for men with breast cancer and their ICs in the UK. As discussed, despite information and peer support being available for men with breast cancer, many are not aware of these resources. Finally, HCPs should identify the needs of all of those impacted by cancer, not just the patient. They have a key role to play in identifying support needs and signpost to available support early in the cancer diagnosis. The theme is inextricably linked to the 'Isolated and alone' theme (chapter 5, section 5.5.5). Implications for research and practice are outlined below and explored in more depth in section 7.10.

Implications for future research

- Aim to conduct a qualitative study, such as discursive analysis, with men with breast cancer to gain detailed insight into their informational and emotional support needs at different stages of the disease
- Intend to conduct a qualitative study with the ICs of men with breast cancer to explore their views of different methods of support in more depth. These would potentially help them to effectively manage the patients' needs whist managing their own well-being
- Potentially conduct a qualitative study with the bereaved carers of men with breast cancer to explore their support needs after the death of a loved one from breast cancer

- To draw on existing research in a range of health conditions to explore different methods of support for BCiM patients and their ICs.
- To use PI input to explore the development of an informative website or app to provide practical up-to-date information as well as online interventions to support men with breast cancer and their ICs about specific issues.
- Plan to conduct a feasibility study with BCiM patients and their ICs regarding an informative website or app.

Implications for practice

There is an urgent need for more support to be provided to both men with breast cancer and their ICs. HCPs, breast cancer specific and generic cancer charities and organisations are well placed to provide sources of support to BCiM patients and their ICs as needed. A stepped care approach to the provision of evidence-based psychosocial support for men with breast cancer and their ICs is proposed in section 7.10

7.6 Treatment concerns

Participants across the three studies raised concerns surrounding treatment. These included concerns about the lack of medical research conducted on men with breast cancer as well as the adverse side-effects of treatment.

In study 1, many participants expressed concerns about the treatment they received. Most were worried their treatment and medication had been tested and developed for female patients with breast cancer and had not been adequately tested on a male population. This led some men to lack confidence in their healthcare and to question the appropriateness of their treatment. These findings were supported by the ICs in study 2 and captured in the sub-theme 'Mistrust of medical decisions and treatment'. Many of the ICs echoed these sentiments and were concerned about the lack of research in men with breast cancer and worried about the suitability of treatment. The fears expressed by men with breast cancer (study 1) and their ICs (study 2) were corroborated by the HCPs in the final study. In study 3, 49% of HCPs agreed that men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men.

Research studies have shown clear biological, epidemiology and prognosis differences in male and female breast cancer (Chen et al., 2012; Fentiman, 2016; Gucalp et al., 2018). Results of a critical review highlighted how BCiM there are important molecular differences, and BCiM is not congruent with the female disease (Fentiman, 2016). Fentiman (2016) further argues there is a need to recognise these important biological differences and develop new treatments for BCiM which are based on differences rather than similarities with female breast cancer.

The quantitative results in study 1 illustrated the negative impact of treatment and showed that quality of life was significantly lower for those men currently undergoing treatment than those not currently undergoing treatment. Participants across both studies 1 and 2 were affected by the side-effects of breast cancer treatment, in particular the hormone therapy, Tamoxifen. These can include erectile dysfunction and decreased libido and were concern for a number of participants. For some, this impacted their personal relationships. These findings are corroborated by research which has shown the loss of libido and erectile dysfunction associated with Tamoxifen therapy in men with breast cancer. This may further impact men's sense of masculinity as male sexual potency is a central component to hegemonic masculinity (Donovan

& Flynn, 2007; Farrell et al., 2014; Halbach et al., 2019; Nguyen et al., 2020; Quincey et al., 2016b, 2021; Sime, 2012).

Additional treatment concerns were raised by participants in study 1 which included increased weight, lymphoedema, and fatigue. These had a negative impact on their physical and emotional well-being. Several ICs in study 2 found that the side-effects of treatment increased their tasks and responsibilities as they had to provide extra care and support. Similar experiences are documented in research exploring the impact of comorbidities on the ICs of lung and colorectal cancer patients who similarly reported the additional demands of comorbidities increased the risk of poor mental health and diminished quality of life among ICs (van Ryn et al., 2011).

A number of ICs in study 2 discussed personality changes in the men they were supporting. For some, these were long-lasting and characterised by extreme moods and depression which were difficult to manage. One IC described grieving for the person he was before breast cancer. For some, the mental health issues affected marital relationships and other family relationships which broke down under the strain. These findings are supported in research with other cancer groups. A systematic review and meta-analysis of prevalence rates of depression and anxiety in prostate cancer patients suggested that rates across the treatment spectrum are relatively high (Watts et al., 2014). Furthermore, depression in cancer patients can greatly diminish quality of life and increase the negative impact on families throughout the course of the disease (Smith, 2015).

In conclusion, men with breast cancer and their ICs frequently experience concerns about their treatment. Throughout the three studies in this PhD, the lack of research conducted with men with breast cancer was a concern for many patients, ICs and HCPs. Many men (study 1) and their ICs (study 2) were unaware of the side effects of treatment and subsequent comorbidities, including the impact on mental health. This theme is closely related to the 'Lack of awareness of the need for gender appropriate materials for men with breast cancer' highlighted in chapter 2 (section 2.2.1.4). These findings are further corroborated by the HCPs in study 3, where the vast majority expressed their concerns that treatment they receive has not been sufficiently tested on men. Implications for research and practice are outlined below and explored in more depth in section 7.10.

Implications for future research

- To conduct qualitative research with BCiM patients and their ICs to explore in more depth their awareness of treatment side-effects; an interesting area to explore is what contributed to a lack of awareness of this issue; Is it because the information (leaflets etc.) are tailored to women and therefore ICs do not think the information is relevant to male patients, or other contributing factors?
- Aim to conduct mixed methods research with HCPs to explore their experiences of providing care and support to men with breast cancer. Areas to explore may include personal conversations with patients as well as acceptability of decision aids. These could be used to provide information regarding treatment options, and to inform and prepare men and their ICs of possible side-effects, and to aid discussion regarding patient expectations.
- Potentially conduct a feasibility study of a decision aid to support BCiM patients

- Intend to conduct mixed methods research with HCPs to inform the design of training materials to help them explain breast cancer treatment and side-effects to BCiM patients and their ICs, and to direct them to resources.

Implications for practice

There is a need to include men with breast cancer in clinical trials, especially in hormonal therapy trials, where data are lacking. The provision of evidenced based targeted information may help patients and their ICs make informed decisions about their treatment. As well as general side-effects of breast cancer treatment, patients and their ICs also need to be advised on men's experiences of those side-effects and the impacts they have on their long-term mental health.

HCPs are encouraged to identify and address treatment concerns in patients and their ICs and to recognise that patients' experiences of treatment are diverse and to tailor support accordingly. Finally, decision aids may help men with breast cancer make an informed choice about their treatment and may also help some HCPs focus on what is important for each patient (Clarke et al., 2021). The PEGASUS intervention (Patient Expectations and Goals: Assisting Shared Understanding of Surgery) is an intervention designed to elicit patients' expectations around breast cancer surgery, to set patient-centred goals and aid the discussion of expectations and goals with the surgical team. HCPs including specialist nurses and psychologists are trained to deliver the intervention, the conversation is recorded on a specially designed sheet which is later used to facilitate discussion during the surgical consultation (Clarke et al., 2021). The intervention has shown to be a helpful tool for both female patients and HCPs (Tollow et al., 2021). Future research could be conducted with BCiM patients and HCPs to explore whether this intervention may be considered for adaption.

Further consideration could be given to the format of providing current evidence-based information on treatment options, including the benefits and harms. These could be in the form of printed materials, videos, and/or interactive online programs such as the iCanDecide tool (Hawley et al., 2018).

Appearance related concerns

Men with breast cancer (study 1) and HCPs (study 3) raised concerns about appearance related issues. In study 1, there was a broad range of appearance related concerns among men who had received treatment for breast cancer. The quantitative data showed a wide range of scores in the body image measures used to explore the nature and extent of body image concerns in this population (chapter 4, section 4.10.3). Whilst some men were adversely affected by changes to their appearance, others were relatively unaffected. The variation in men's experiences suggests that some individuals are more vulnerable whilst others may be better at managing these challenges. Appearance concerns impacted men's quality of life, with men currently undergoing treatment reporting significantly lower quality of life scores than those not currently undergoing treatment. Similar results have been reported in men with prostate cancer (McCaughan et al., 2013). Furthermore, the quantitative results indicated higher levels of quality of life were associated with lower levels of body image concerns. Similar findings were reported in research with prostate cancer patients (Taylor-Ford et al., 2013).

The results of study 1 further indicated that higher levels of masculine self-esteem were associated with lower levels of body image concerns. These findings were supported by research conducted with prostate cancer patients (Gentili et al., 2022; Langelier, 2018). The results are further supported by the multiple linear regression in study 1, which indicated body image and the demographic variables (time since diagnosis and age) to explain 63% of the variance in masculine self-esteem. Furthermore, higher masculine self-esteem was associated with length of time since diagnosis and older age, similar results have been shown in men with prostate cancer (el Fouhi et al., 2022). Finally, masculine self-esteem partially mediated the relationship between body image and quality of life. The relationships between these three constructs have been explored in a qualitative meta-synthesis of studies of men with breast cancer (Bowie et al., 2022).

The qualitative results of study 1 illustrated how a number of men were self-conscious and took measures to hide their scars, especially when in public. Similar findings were reported in the qualitative research conducted with men with who had received treatment for breast cancer (Midding et al, 2018; Levin-Dagan & Baum, 2021; Donovan & Flynn, 2007; Thompson & Haydock, 2020; Sime 2013; Quincey, 2016). These qualitative studies also reported how men felt self-conscious of their altered appearance. Likewise, they expressed feeling ashamed to show themselves shirtless in public places where they may expose their chests, for example at the beach or swimming pool. They often wore clothes to cover themselves and conceal their scars. Conversely, other men who had a mastectomy, saw their scars as a symbol of survivorship and pride. These mirror the experiences of other men with breast cancer who similarly saw their mastectomy scars as a badge of honour and referred to their scars as a *"warrior wound"* (Rabbee

& Grogan, 2016a) and battle scars *"I could tell a very good story about how I was in the Hussars'* (France et al., 2000).

Further changes to appearance such as hair loss, weight gain, lymphoedema, skin changes due to radiation and the side-effects of fatigue and exhaustion associated with breast cancer treatment also caused concern among participants in study 1. Similarly, body image concerns stemming from treatment have been reported in qualitative research conducted with men with breast cancer (da Silva, 2016; Rabbee and Grogan, 2016; Trusson & Quincey, 2019). There is considerable overlap with the themes 'Treatment Concerns', 'Lack of male specific information" and the 'Lack of support' discussed in this chapter which shows they are interrelated.

Interestingly, none of the participants in study 2 spoke of their role as an IC involving supporting men with appearance related concerns. As discussed in chapter 5 (section 5.6) the researcher did not specifically ask about whether they were aware of appearance concerns in the men they supported. This may be an interesting area to consider in future research.

However, the findings are strongly upheld by the HCPs in study 3, whereby 79% of HCPs agreed that men with breast cancer have concerns about their appearance and body after mastectomy.

In conclusion, the findings illustrate that some men with breast cancer may find changes to their appearance and body functioning due to treatment to be challenging and distressing, whilst others are relatively unaffected. The vast majority of HCPs recognised that men with breast cancer are at risk of body image disturbances after mastectomy. Implications for research and practice are outlined below and explored in more depth in section 7.10.

Implications for future research

- Aim to further investigate the relationships among factors associated with appearance related concerns in men with breast cancer
- Potentially evaluate existing resources for men such as the 'Look good feel better' website which provides advice and guidance on the physical changes men might experience when undergoing treatment.
- Intend to further explore the mediating role of masculine self-esteem in men with breast cancer

Implications for practice

There is a need to develop and provide all male patients with breast cancer relatable resources to prepare men possible changes to their appearance due to treatment. These should include images of male bodies post-mastectomy and possible changes to appearance due to treatment. Peer support and opportunities to meet other men who have previously had surgery may also help men with breast cancer to better adjust to changes to their appearance post treatment. Furthermore, if they cannot connect with other men with breast cancer, access to their stories and experiences may be beneficial e.g., the BCiM section of the Healthtalk website which is available 24/7 (healthtalk.co.uk). The benefits of peer support have been discussed in chapter 5 (section 5.5.6) and chapter 6 (section 6.8.1).

There is a need to recognise that patients' experiences of appearance related concerns are diverse. HCPs should receive training to help identify patients who may be at risk of appearance related concerns. Finally, tailored support for those experiencing appearance related distress should be provided to men with breast cancer and support provided for their ICs.

7.7 Summary of section and next step

This section has highlighted the main themes prevalent throughout the three studies in the PhD and provided suggestions for future research and implications for practice. Table 28 presents a summary of the main themes and recommendations for the future provision of care and support for men with breast cancer and their ICs. The next section will explore a method to identify future research priorities in more depth and propose a stepped care approach to implement evidence-based interventions to support men with breast cancer and their ICs.

Table 28.

Key findings in the PhD and recommendations for practice outlined in this section

Key findings	Recommendations for practice
Isolation	• Identify, develop and provide support for those at risk of isolation • Tailor support according to individual needs • Encourage men to access existing peer support goups e.g., the men's VMU • Signpost to existing resources e.g., the Healthtalk module on BCiM
Lack of awareness	• Increase awareness of BCiM in the general public • Increase awareness of BCiM among hospital staff/training including of how they treat and address male patients in a clinical setting • Increase awareness among HCPs of the psychosocial impact and potential support needs of BCiM patients and their ICs
Lack of male specific information	• Provide gender specific support to men with breast cancer and their ICs • Provide breast cancer literature which is inclusive of men (and represents gender diverse individuals)
Lack of support	• Ensure patients and their ICs are provided with personalised support and information • Ensure patients and their ICs are aware of the support and resources available

Treatment concerns	• Develop training materials to help and support HCPs explain breast cancer treatment to male patients and their ICs • Recognise that patients' perceptions and experiences are diverse • Identify and address treatment concerns in patients and their ICs • Explore the potential use of decision aids to help inform shared decision making
Appearance related concerns	• Develop and provide all male patients with relatable resources (e.g., photographs of male bodies post-mastectomy) • Train HCPs to identify patients who may be at risk and manage this • Recognise that patients' experiences of appearance related concerns are diverse • Identify and provide support for those experiencing appearance related distress • To evaluate existing resources for men such as the 'Look good feel better' • If acceptable and feasible to the target audience, the development of an online website to provide current, male specific information and signpost men and their ICs to sources of support may benefit this population.

7.8 Next step

The NHS Long Term Plan for Cancer states that "*where appropriate, every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support*." (NHS England, 2019). However, the studies in this PhD have highlighted that men with breast cancer and their ICs have unmet support needs. As evidenced in the findings of this PhD, the lack of psychosocial support can result in considerable distress and isolation for many of those impacted by the disease, often with serious implications. This section will suggest ways to identify future research priorities and propose a stepped care approach to implement evidence-based interventions to support men with breast cancer and their ICs.

7.9 Identifying components of future support

Whilst a number of potential research areas have been discussed above, a suggestion for future research could involve a Delphi survey of men with breast cancer, ICs and HCPs to identify the most important components of support. A Delphi survey is a consensus approach whereby a set of experts are asked their opinions on a particular issue (Involve.Org.UK, 2018). Strengths of Delphi research include the wide range of expertise gathered, the low cost to administer, and that the online delivery of questionnaires can generate a wide set of ideas and achieve a rapid consensus (British Psychological Society, 2009).

The Delphi method is particularly useful in areas of limited research, and is a suited technique often used in health and social sciences (Hasson et al., 2000; Niederberger & Spranger, 2020). This technique has also been used in similar populations to those in this PhD, for example, to explore patients' and caregivers' experiences of cancer care (Ellis et al., 2022), with ICs of breast cancer patients (female; Goria et al., 2022), and with HCPs, to identify the unmet information needs and research priorities in female survivors of breast cancer (León-Salas et al., 2022).

7.10 A proposed stepped care approach to the provision of evidence-based psychosocial support for men with breast cancer and their ICs

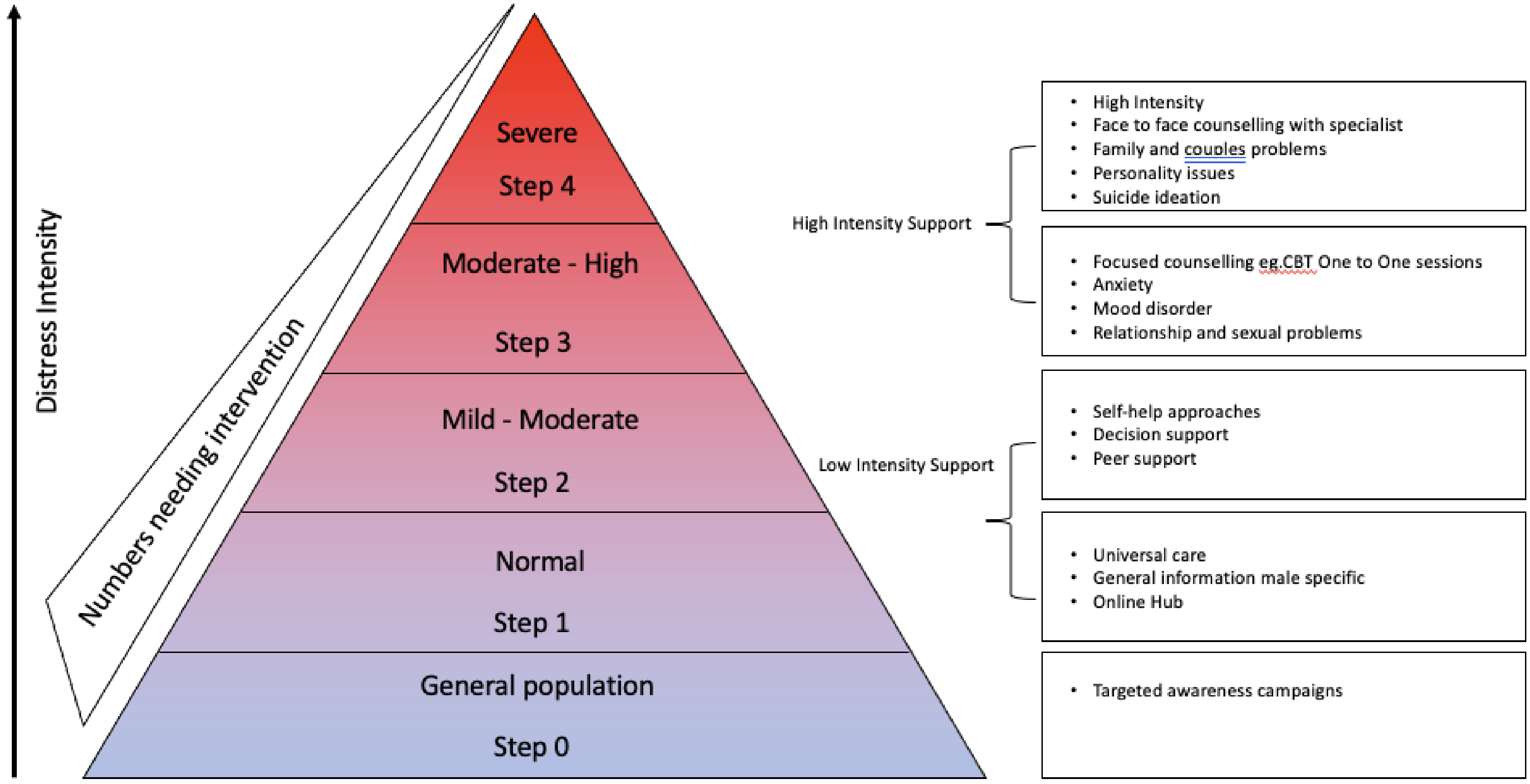
The findings in this PhD have emphasised the urgent need to increase awareness of BCiM on a societal level, as well as highlighted a wide variation in the needs and support preferences for men with breast cancer and their ICs in the UK. Moving forward in supporting men with breast cancer and their ICs, it could be useful to consider a stepped care approach to provide support to those experiencing distress.

Stepped care models were first used in the NHS to help HCPs choose the most effective interventions for patients with mental health disorders (NICE, 2011). These often begin with low-intensive evidence-based interventions and only ‘stepping up’ to more intensive or specialist services if needed. As a result, stepped care models have the potential to improve the accessibility and efficacy of psychosocial care as well as being cost-effective (van Straten et al., 2015). Researchers in other fields have previously suggested a stepped care approach and have been successfully applied to cancer survivors (head and neck cancer and lung cancer patients) in the management of psychological distress (Jansen et al., 2019).

The proposed framework (Figure 12) follows the philosophies of other stepped care models and suggests the grading of interventions according to varying levels of support on a tiered continuum of increasing intensity. As well as featuring a hierarchy of intervention, BCiM patients and their ICs can move between levels as their support needs change. Firstly, the model proposes targeted information campaigns addressed to the general public to raise levels awareness of BCiM. Secondly, all BCiM patients and their ICs are provided with support at Level 1 and if required, after assessment with a trained health care professional, may be offered increased support such as those proposed at levels 2-5.

Figure 12.

Proposed stepped model of care and support for men with breast cancer and their ICs



The existing support and proposed interventions at each level of the framework will now be discussed in more detail. The proposed model is loosely based on the stepped care model to fear of cancer recurrence/progression in oncology services for managing fear of cancer recurrence or progression in cancer (Praden, Sharpe & Menzies, 2021).

Step 0 – General population and societal campaigns

Existing campaigns

Steps are being made around the world to raise awareness of BCiM, which is extremely promising and further highlights the timeliness and relevance of the current thesis. In the UK, breast cancer charities have included men in their media campaigns in recent years (Macmillan, Walk the Walk, Breast Cancer Now, Against Breast Cancer, Tickled Pink Campaign and CoppaFeel). Furthermore, several UK based breast cancer charities collaborated to design the "Check your chest" posters, which highlight possible signs and symptoms of BCiM. The posters have been displayed in hospitals, GP surgeries, chemists, universities, TV stations, prisons, police stations and coffee shops – as well as being shared digitally (walkthewalk.org). On an international level, the month of October is dedicated to breast cancer awareness every year. During this time, campaigns are run to raise awareness and show support for those affected by breast cancer (Breastcancernow.org). In Holland, October 7th is dedicated to International Male Breast Cancer Awareness Day (bmjo.be, 2020) and in 2021, US President Joe Biden designated October 17-23 Men's Breast Cancer Awareness Week (Breastcancer.org). Whilst these steps are promising and these campaigns have undoubtedly raised the profile of BCiM, public awareness of the disease in men still remains low (Bootsma et al., 2020; Co et al., 2020; Goyal et al., 2020; Reis Abdalla et al., 2021; Thomas, 2010).

Proposed interventions

There is a need for more societal-level approaches to increase awareness of BCiM in the UK. These could include:

- More inclusive breast cancer awareness campaigns highlighting that men can get breast cancer. Whilst some organisations such as Breast Cancer Now have recently made their website more inclusive, other organisations could benefit from making make men with breast cancer more visible in their existing media campaigns.
- Campaigns targeted to men. These could be similar to the Public Health England 'Be Clear On Cancer' which is aimed at women aged 70 and over to increase awareness of breast cancer amongst this age group and to increase knowledge about lesser-known symptoms (gov.uk, 2015).
- Use multiple media channels to engage a broad audience of all ages but aimed predominantly at men in their late sixties who are at higher risk of breast cancer (Giunta et al., 2017). In the UK, the popular television soap, Eastenders, ran a storyline of BCiM which raised awareness and made viewers aware of the signs and symptoms. The soap has an extremely large reach and was streamed 366 million times in 2022 (radio times.com).
- Awareness campaigns should specifically target schools, universities, pubs, clubs, and traditional male sporting environments, such as football, rugby and cricket clubs, gyms,

male toilets and changing areas in shops. An example of a successful targeted campaign to raise awareness of breast cancer in women is the partnership between the retailer Marks and Spencer and Breast Cancer Now. The shop placed a poster with guidance on the signs and symptoms of breast cancer in the fitting rooms of its stores.

- Breast cancer awareness campaigns should be encouraged to use a variety of colours other than pink.

Step 1 – Universal care - Information given to people affected by breast cancer. This level is for all people affected by BCiM and experiencing normal levels of distress.

Existing information

As mentioned above, the main breast cancer charities in the UK now include men in their websites and provide male specific breast cancer information, including images of male mastectomy (Macmillan, Breast Cancer Now, Walk the Walk, Penny Brohn UK). A further resource is the Health Talk Online website (www.healthtalk.org), which is an internet-based charity website that shares individuals' experiences of a wide range of health conditions and includes BCiM. Topics cover diagnosis, treatment, family and friends and body image. However, most men with breast cancer and their ICs who participated in research in this PhD were unaware of these resources. Therefore, there is a need to educate people working for support organisations, charities and HCPs (both generic and working in breast cancer), so that they are aware of and able to signpost patients and their ICs towards reputable, detailed information and support.

Proposed interventions

- Male specific information and resources should be provided to all men with breast cancer and their ICs
- Gender specific materials should include information on medical treatment and how to cope with treatment side-effects
- Information about how to talk to and/or assist a family member or friend with breast cancer
- Provide HCP training on available resources so they can signpost men and their ICs to sources of support
- Design and develop an online hub or app specifically for men with breast cancer and their ICs. This could be a single point of access, accessible 24 hours a day. It could provide information and resources which have been developed in consultation and collaboration with clinicians, patients and ICs. The hub or app could also include links to support organisations and peer support groups.

Step 2 – Supportive care for mild to moderate levels of distress. This level is for those men and/or their ICs who are experiencing mild to moderate levels of distress and includes self-help approaches, peer support, and decision support.

Existing support

The Men's VMU (Virtual Meet UP) is a free, monthly, online peer-led resource run by and for men who have/had breast cancer in the UK. The VMU provides men with the opportunity to interact and engage with other men who have had breast cancer and to share their thoughts and experiences in a safe on-line environment. The breast cancer charity, Breast Cancer Now run a peer telephone or email support service run by volunteers who have had a diagnosis of breast cancer, and the service does have male volunteers. Furthermore, on a more international level, the American based charities Male Breast Cancer Happens (formerly The Male Breast Cancer Coalition), HISbreastcancer.org and the Male Breast Cancer Global Alliance bring together men with breast cancer from around the world. A number of these charities work collaboratively to support and unite men with breast cancer.

Whilst these resources may provide comfort and support to many men with breast cancer, feedback from PPI in this PhD have expressed how they may not necessarily meet all patients' needs. Barriers of peer support may include not feeling comfortable talking about personal issues in a group or online group setting, not wanting to hear about others' problems or to share their concerns with others, as well as conflicts in the group which can increase distress (Bender et al., 2021; Jablotschkin et al., 2022). Additionally, patients and their ICs may find that their need for support changes over time. Therefore, there is a need for a broad range of different formats of psychosocial support tailored for the different needs of men with breast cancer.

Proposed interventions

- Provide a variety of support formats to cater for individual preferences of support
- PPI feedback should be sought to inform decisions about what interventions and resources are needed
- Signpost men to services such as the 'Look good feel better' website which provides advice and guidance on the physical changes men might experience when undergoing treatment. It offers virtual or face to face workshops on topics such as skincare, body confidence, grooming and exercise. It also includes an online 'Manual for Men' as well as video tutorials which cover potential challenges of treatment and body image concerns (lookgoodfeelbetter.co.uk).

- As above, an informative website or app specifically for men with breast cancer and their ICs could provide practical up-to-date information as well as online interventions to support men with breast cancer and their ICs about specific issues. The website could be accessed at any time so that interventions are readily available. It could also signpost users to sources of support such as peer support groups.
- Provide men with breast cancer and their ICs with decision aids, to inform them of treatment options and educate them of possible short and long-term side effects
- Provide telephone-based guided self-help based on the principles of CBT to support with emotions
- Provide different types of peer support to help with social isolation such as befriending and buddying.

Step 3 – Supportive care for moderate to high levels of distress. This level includes one-to-one sessions facilitated by a trained counselling professional.

Existing support

Charities such as Macmillan fund psychological and emotional support services that are provided by Macmillan Professionals. These can help reduce depression, anxiety, and pain, improve self-management and coping skills, and help improve quality of life in cancer patients (macmillan.org.uk).

Proposed interventions

To train NHS and private counselling professionals on the specific challenges facing men with breast cancer and their ICs. This level may be provided by Cognitive Behavioral and High Intensity Therapists who deliver Cognitive Behavioural Therapy (CBT) to men with breast cancer and/or ICs experiencing moderate to high levels of depression and anxiety. CBT is an effective way of helping people cope with a number of mental health conditions such as depression, anxiety chronic and pain (NICE.UK). It is also effective in treating depression and anxiety in women with breast cancer (Sun et al., 2019) as well as family caregivers of patients with prostate cancer (Borji et al., 2017). This step may be appropriate if men and/or ICs have not seen an improvement after trying interventions at Steps 1 or 2. Counselling may be provided either online, via telephone counselling or face-to-face.

At this level, therapists may:

- Identify and understand patients'/ICs' problems
- Provide up-to-date and helpful information, including handouts, booklets or links to websites, to read and inform them on where to get further information which might help
- Provide CBT
- Regularly review progress through discussion and through the use of standardised questionnaires.

Step 4 – High intensity support for severe distress. This level includes one-to-one sessions facilitated by a trained professional.

Step 4 treats a small minority of people, usually because the previous steps have not helped sufficiently, or because they may be at risk of significant self-harm or neglect. They may also be dealing with other social factors or comorbidities.

Existing support

Support is currently provided to those experiencing high levels of stress and may be at risk of suicide through the NHS (www.nhs.uk), via clinical psychologists linked with NHS breast cancer services and charities such as MIND (www.mind.org.uk) and The Samaritans (www.samaritans.org).

Proposed interventions

There is a need to ensure that those who provide acute support for those at risk of suicide, or those supporting someone who might feel suicidal, are aware of the specific challenges facing men with breast cancer and their ICs.

- Complex, specialist-led counselling/therapy (such as CBT) provided by highly qualified specialists. CBT is recommened for adults who self-harm (NICE.org.uk).
- Patients may be receiving a combination of medication and other treatments
- Needs may be multiple and complex
- Target areas may include severe couple and family problems
- Although similar to Step 3, the treatments are likely to be more intense and last longer

7.11 Conclusion

Whilst attempts have been made to provide information and support to men with breast cancer, it is unclear whether these have been evaluated and more research is needed to confirm efficacy. There is clear need to focus on developing more gender inclusive support materials and sources of support specifically for both men with breast cancer and their ICs. When evidence-based approaches are available, a stepped care approach to meet their needs could be implemented. To enable HCPs to signpost patients and their ICs more directly to the most appropriate sources of help and support, there is a need to develop multidimensional psychosocial screening and assessment tools and measures that can facilitate the early recognition of concerns. There is a need to increase HCPs' ability to identify individual needs and know when and where to refer men with breast cancer and/or their ICs for specialist support. This could be provided in the form of an online educational training programme, as well as including these topics in basic medical training. A programme could also be offered through workshops at conferences to target key audiences e.g., conferences aimed at HCPs working in breast cancer as well as webinars promoted by professional bodies. Finally, a targeted website or app is potentially an ideal tool to meet the information needs of patients and their ICs.

7.12 Reflection on Biopsychosocial model and implications for theory

The present PhD was exploratory and loosely guided by a broad psychosocial lens (chapter 3, section 3.11). A reflective section on the use of the Biopsychosocial model (Engle, 1977) is incorporated in each study chapter. In the current thesis, the thread of 'isolation' which runs through the three studies highlights the integral component of social support for both men with breast cancer and their ICs within the biopsychosocial model. Whilst study 3 highlights how the model may be used for HCPs to understand interactions among biological and psychosocial components of BCiM and may be used to improve multidisciplinary approaches to patient care.

Throughout this PhD this has been a useful conceptual model to emphasise the importance and interconnected biopsychosocial factors in BCiM. The results of the studies within this PhD indicate the interrelationships of factors which may impact the lives of men with breast cancer and their ICs (Figure 10).

Further research exploring the complexities and dimensions of body image experiences among BCiM patients may benefit from considering the Heuristic Cognitive Behavioural Model (White, 2000). White explored the research conducted in the area and concluded that changes to appearance due to cancer treatment are subjective and do not always mirror reality. He proposed a cognitive behavioural model to conceptualise potential mechanisms and inter-related factors of cancer-related appearance changes. The model proposes body image schema (i.e., level of body image investment), investment in body ideals, self-discrepancies (e.g., between actual and desired body image) which lead to appearance assumptions and can create automatic thoughts and images, which in turn can result in low body image and compensatory behaviours. This model could be used to conceptualise future research or in the design of interventions among men who have received treatment for breast cancer.

Further consideration could be given to a theoretical model of adjustment to cancer, such as the Social-Cognitive Transitions (STC) model of adjustment (Brennan, 2001). Brennan (2001) draws on empirical evidence which demonstrates patients' diverse responses to cancer which may include high distress, as well as healthy personal development (personal growth). The model combines coping theory and social-cognition theory to explore the psychological processes which influence adjustment to cancer and its treatment, and emphasises the social context of an individual's experience. It proposes that individuals have mental maps of the world which are made up of assumptions. These are socially constructed and life-stage dependent, they are flexible and either confirmed or challenged by novel or unexpected life-events, such as a cancer diagnosis. Reponses may include denial and disorientation which may potentially result in the development of new assumptions. These may be maladaptive and may render the individual vulnerable to heightened levels of stress. The model also explains how despite the stress of mental adjustment, some patients experience positive adjustment. For example, patients may be forced to confront their mortality and embrace what time they have left (Brennan, 2001). The model may be useful to consider in the design of interventions to help men with breast cancer to recognise the potential role and meaning of past and present events. This may enable men to draw on their experiences, and to help them understand their thoughts and emotions in response to a diagnosis of breast cancer.

To explore the potentially mediating role of masculine self-esteem in more depth, future research could benefit from exploring factors that influence and encourage self-esteem. The Self-Esteem Enhancement Theory (SET; DuBois, Flay & Fagan, 2009) was designed specifically in relation to health and includes five major constructs; (a) contextual opportunities, (b) esteem formation and maintenance processes; (c) self-esteem; (d) health and well-being; and (e) modifying influences. Rather than focussing on any single factor such as self-esteem, each construct should be given equal consideration, enabling the participant to establish a firm basis to determine their own sense of self-worth.

Finally, to provide optimal patient-centred care, researchers might consider using the Supportive Care Framework (Fitch, 2008) to underpin future studies. The model was originally designed for cancer care professionals to identify the unmet needs of patients and their support persons. It highlights the need to recognise individual differences and the need to tailor interventions to the individual's needs, desired goals and ways of coping. The framework conceptualises seven domains that may impact their needs because of the disease and its treatment, i.e., physical, emotional, social, psychological, spiritual, informational and practical changes. It theorises that a cancer diagnosis may affect a person's ability to meet and satisfy their own needs across these domains, which may potentially result in increased distress and negatively impact their psychosocial well-being (Fitch, 2008). This framework is considered suited to use as a theoretical model in future research to help further identify and better understand the unmet needs of BCiM patients' and their ICs.

7.13 Strengths and limitations of the research conducted in this PhD

This exploratory PhD has provided important insights into the experiences of men with breast cancer, their ICs, and HCPs' experiences and perceptions of their psychosocial support needs. The strengths and limitations of each study have been addressed in the corresponding chapters. However, this section will present an overview of the strengths and weakness of the PhD as a whole.

Strengths

The use of rigorous, standardised measures in study 1 enabled the constructs identified in previous literature conducted with BCiM to be explored in depth. Furthermore, study 2 (ICs) and study 3 (HCPs) have further expanded the field of BCiM research, by being the first to be conducted with these populations in the UK.

Despite the prevalence and obstacles imposed by the Covid pandemic throughout the PhD, fortunately, the research was not adversely impacted. Considering recruitment took place either during or in the aftermath of the pandemic, the participant numbers in all three studies were good.

The combination of qualitative and quantitative methods and the triangulation of results has highlighted important themes pertinent to those impacted by the disease. Finally, building on the findings of the studies conducted in this PhD, suggestions for future research and recommendations for a stepped level support have been proposed.

Limitations

Firstly, a number of the psychosocial measures used in study 1 (chapter 4, section 4.4.7) had been designed for women with breast cancer, and consequently may not have reliably measured the constructs or captured the issues pertinent to men with breast cancer. There is a need to develop standardised measures specifically designed to examine the psychosocial impact of BCiM. The European Organisation for Research and Treatment of Cancer (EORTC) is currently in the process of developing and validating a worldwide questionnaire to collect comprehensive, prospective data about quality of life in men with breast cancer (EORTC.org). There is a need for more measures to be developed and validated to assess different psychosocial variables specifically in this population.

Secondly, the majority of participants across the studies identified as White, which is not uncommon in psychological research (Muthukrishna et al., 2020). This was also prominent across published literature of BCiM, wherein participants from diverse racial and ethnic backgrounds were not sufficiently represented. It is important to reflect upon the cultural diversity of the sample in BCiM due the higher incidence rates of breast cancer in Black men than White men (chapter 2, section 2.1.1; Shin et al., 2014). In relation to study 1, fundamental concepts such as body image and masculinity may be affected by the pressure to conform to cultural ideals (Grogan, 2021) and may influence how men experience breast cancer and their bodies post treatment. Regarding the experiences of ICs in study 2, representation of different cultures is important, as they may differ in family and community structure and may include a network of reciprocal relationships. Many of these may be involved in healthcare decisions, care and support of cancer patients (Daher, 2012).

Poor recruitment of diverse ethnic groups in cancer research is due to a variety of reasons including inadequate recruitment strategies, lack of cultural competency of the researcher, mistrust of the research process and lack of links with community networks (Farooqui et al., 2022). Within this research different purposeful methods were employed during the recruitment phase to improve diversity in the sample. A number of organisations who support cancer sufferers and their carers, with an emphasis on ethnic minority communities, were informed of the research and asked to post the study information on their social media sites. These included Cancer Black Care, Black Men's Health UK, and BlackOut UK, who shared the information with their members. However, despite these efforts, numbers remained low. To increase participation from underrepresented populations, future researchers should invest time and resources to establish relationships with charities and support groups for minority ethnic communities. These organisations should be encouraged to share with their members the need for a broad representation of participants from diverse ethnic backgrounds in research and encourage them to participate.

Thirdly, the inclusion criteria for study 1 was broad and open to transgender and gender diverse people with breast cancer. However, one limitation to the recruitment strategy is that it did not actively recruit people with gender diverse identity. Future breast cancer research should actively include the recruitment of transgender and gender diverse people to gain insight into their experiences and psychosocial needs. It is important that the views and experiences of all those with breast cancer are heard and are better understood.

7.14 Reflection on the impact of Covid on the overall PhD

The impact of Covid on each study has been addressed and reflected upon in the corresponding chapters. This section will include reflections on the general issues faced, obstacles encountered, and lessons learnt from both a personal level and researcher perspective throughout the overall research process.

The PhD was started in 2019, in pre-Covid times, and finished in 2023, when the world had changed significantly. Looking back, it is hard to believe what we experienced; such a devastating illness, living in lock-down, unable to see friends and family, shops, restaurants, universities, and schools closed. The terrifying images of hospital car parks overflowing with ambulances filled our screens, the daily Government updates and the steep graphs indicating the ever-increasing, frightening rise in the levels of new cases and the daily death toll. During this time, myself and my husband had two young children to home-school, keep busy, and most importantly, to keep safe.

I feel incredibly lucky that the PhD was not significantly adversely affected by the pandemic. When lockdown first happened, I was fortunate that recruitment for study 1 had been successful, and the adequate sample size meant I could halt recruitment and start the analysis. When designing study 2, most people had been using online platforms such as Zoom to connect with friends and family as social distancing rules applied which restricted socialising. As a result, participants were largely comfortable using online platforms and were happy to use Microsoft Teams, and this proved an effective way to conduct the interviews. From a researcher point of view, this proved to be an extremely flexible method; it saved on time and travel expense. For participants, it meant they could take part in the interviews from the comfort of their own homes and at a convenient time. However, only being able to see the 'head shot' created by the camera may have limited my ability to fully observe participants' body language which may have provided additional insight into what respondents were feeling.

However, on a personal level, the situation was challenging. Due to school closures, we had our children aged 13 and 10 home-schooled for most of study 2. I found it was stressful and difficult to balance their needs with the time needed to work on the PhD. It was not only the burden and challenges of home-schooling, but also the restrictions and additional emotional support the children needed during these demanding and uncertain times. My husband was also juggling running a business in dire and stressful times. Aware of my role as a mum and wife and the importance of being present and supportive for the family, I felt it was important to try and make things as 'normal' as possible in very strange, frightening, and unsettling time. It took time to adjust and juggle the demands of home-schooling and parenting in such an uncertain time with the demands of the PhD. However, I have found continuing with the research to be a welcome escape to the everyday fears and it has given me a sense of purpose in these strange and frightening times.

Aware of the importance of flexibility as a central and important component of being a researcher, I developed a new work routine under lockdown, whereby I started work at 6.00 am and had two hours before the children woke. I found this to be a productive time which I could dedicate to the PhD uninterrupted. I was keen to keep on track with the progress of the PhD and I appreciated the importance of having something for myself to focus on during this challenging period.

Although schools returned to the classroom after several months, working from home was mandatory for a while longer. During this time, I really missed interacting with others and missed the benefits of talking to other PhD researchers, although I did continue with online supervision which was beneficial.

In conclusion, I feel fortunate the PhD was not too adversely affected by the impact of the Covid. Conducting the PhD through the pandemic has taught me a lot as a researcher, first and foremost; the importance of flexibility, and to always design research studies with a backup plan, in case recruitment is impeded. Most of all, I was extremely aware of the additional stress and burden of the pandemic on all of those who have contributed to this research. I feel humbled that participants found the time to take part when they were facing additional challenges to their already stressful lives. Their time and commitment further drove my desire to complete the PhD and to play whatever role I could in helping to raise awareness and in some way to potentially help improve their lives.

7.15 Reflection on PPI in the overall PhD

Patient and public involvement (PPI) was an integral element to the research process (chapter 3, section 3.7). The incorporation of PPI in each study has been outlined in the corresponding chapters. This section will now provide a general reflection of PPI involvement throughout the PhD.

I found working together with PPI advisors was of immense benefit from the outset and an incredibly rewarding experience. Prior to conducting this research, I had very little knowledge of BCiM. It was during my Master's research I became aware that men could get breast cancer and, to my knowledge, had never met a man with the disease. As I embarked on the PhD journey, I was extremely aware of the possible limitations and challenges I faced. These included being a female researcher conducting research with men, as well as on a topic that I had limited personal experience. Consequently, I recognised the benefit of PPI and was keen to involve a patient advisor from the outset.

I was extremely lucky to meet my main PPI advisor who supported me throughout the PhD. He was diagnosed with breast cancer in 2015 and is a dedicated, passionate, and tireless advocate of raising awareness of BCiM. We met regularly and talked about his experiences, the impact of the disease on his life and his family, and the concerns and challenges they faced. These conversations highlighted issues that I had not previously considered, such as the long-term impact of the disease and the long-lasting side-effects of treatment. It was through these conversations I truly began to understand the devasting impact of BCiM.

Working together was a collaborative process and we discussed my research at length; he provided feedback on study ideas, participant information sheets, the content and wording of online surveys and chapters written for the thesis. I feel that our conversations brought the value of the work I was conducting to life and ensured I was conducting meaningful and relevant research. Through working together over the course of the PhD, I feel we developed a relationship of mutual trust and respect.

I engaged with other PPI advisors at different stages of the PhD. These ICs of men with breast cancer and healthcare professionals. They ICs provided feedback on study designs and the content of interviews in study 2, and the healthcare professionals fed back on the survey in study 3. I also had informal conversations with men with breast cancer I have met whilst conducting this research. These conversations taught me how breast cancer is embedded in their daily lives and for some, the emotional distress which can continue long after there is no clinical evidence of cancer. As mentioned in chapter 3 (section 3.7.2), early in the PhD, I was invited by one of my PPI advisors to attend his breast clinic in a local hospital. I found this was an extremely informative and valuable experience. It was useful to be able to see the clinic environment and to follow patients from having their mammogram through to diagnosis.

Overall, I found the insights I gained through these interactions, along with their feedback, to be incredibly useful. They taught me to look at my work from a different perspective. Finally, I cannot underestimate the value of PPI and acknowledge how it helped shape not only the research, but also me as a researcher. Below is a reflection written from the main PPI advisor on his involvement in the PhD:

"At the age of 58 I was diagnosed with male breast cancer in 2015 and underwent mastectomy, chemotherapy, and radiotherapy. I was given the all-clear in 2016 although still remain on Tamoxifen as a preventative measure.

Once diagnosed I became involved with raising funds for breast cancer charities which led me to get involved with various campaigns raising awareness of breast cancer in men.

I was also involved in the setting up of an online support group for men with breast cancer known as the Men's VMU. It is because of this work that I was introduced to Beth Herring and was asked to be a patient advisor on her PhD.

Over the years I have been very aware of the lack of information and support for men with breast cancer and Beth's research is very important in improving knowledge and awareness.

Being someone who has been on the male breast cancer journey I felt it was very worthwhile sharing my knowledge and views with Beth. Working with Beth has been very much a two-way process and being able to review her work from a patient perspective has been very educational. The knowledge I have gained has allowed me to put myself forwards and be appointed to the NICE Breast Cancer Group, so Beth's work is now indirectly impacting on guidance being developed by NICE for the NHS particularly in relation to men with breast cancer."

7.16 Reflection on research methods

Having completed the PhD, the pragmatic approach is still considered the most suitable to this thesis. This was particularly appropriate due to the exploratory nature of the research and the use of mixed methods which generated important complementary insights (Bishop, 2015).

From the initial design phase of the PhD, I was interested in adopting a mixed methods approach for a variety of reasons. Firstly, I felt there was a need to move away from the volume of qualitative research in the field of BCiM. Secondly, I considered that flexibility of mixed methods together with the different types of data collected would result in a more comprehensive and in-depth exploration and understanding of the issues pertinent to men with breast cancer and their ICs. I believed the different methods would work together to answer the research questions and ultimately better contribute to the applied potential of the research than a standalone method (Fetters & Freshwater, 2015). Furthermore, in pursuing a PhD as a mature student, I was conscious to develop my skillset as a researcher and to garner as much experience as possible during the process. I embarked on the PhD with the mindset that the journey was more than a qualification and completing in-depth research in a specific subject, but also about equipping myself with a wide range of transferable skills (Lam et al., 2019). This was particularly evident in study 2, where I learned to use the NVIVO software for the analysis process as I had previously used hard copies of the data. Furthermore, I also feel I am developing better interview skills; it quickly became apparent that the participants I have interviewed have no-one to talk to about their experiences. Consequently, it was somewhat like a flood gate of emotions opening for participants and they just wanted to talk and 'offload'. Participants seemed to want to talk about every aspect of their experiences and lives, all of which I was eager to hear about, but I was conscious the interview needs to stay on track for the purpose of the research questions. Consequently, I feel my interview skills have developed as I learn skills from each interview, such as how to guide the conversation back on course.

I found conducting the qualitative interviews to be an incredibly rewarding experience, and the interaction with participants really bought the research process to life. I was extremely surprised by how open and honest participants were and how much personal information they shared. I felt honoured to be able to conduct this research and I developed a strong rapport with many of the participants. I did find some of the conversations upsetting, especially those who talked of their loved ones dying, or those with terminal cancer. However, I had a very supportive supervision team who I could talk to afterwards.

In using a mixed methods design, I have become a more versatile researcher. Through conducting both quantitative and qualitative methods I have learnt new skills which will be transferable in a future career in research. Throughout the process, I have increased my awareness of the ethical considerations and practicalities involved in conducting good research. As well as increasing my research skills, I feel I have grown in confidence as a researcher. Finally, the experience has inspired me to continue to work in research in the field of BCiM.

7.17 Dissemination of the findings

The findings of the individual studies have been presented at a variety of national and international academic conferences (Appendix 22). The results of study 2 have been published in a peer reviewed journal (Appendix 25), thereby contributing to the literature on BCiM. Studies 1 and 3 are currently being prepared to submit to the relevant journals in summer 2023. To raise awareness of the present research, the studies and updates have been posted on the Centre for Appearance Research’s social media channels, including Twitter, Facebook and Instagram. See Appendix 23 for a breakdown of each post’s engagement.

The findings have also been shared with cancer organisations, including Breast Cancer Now, Maggie's, Walk the Walk, The Men's VMU and Male Breast Cancer Happens as well as in non-academic settings including The Appearance Matters Podcast (Appendix 22). I am currently working in collaboration with the American charity, Male Breast Cancer Happens, to create an online peer support group for the ICs of men with breast cancer around the world. I have recently been invited by the Male Breast Cancer Global Alliance to be part of a new group of researchers to conduct future studies in men with breast cancer from around the world.

7.18 Conclusion

The studies conducted in this PhD have provided important and novel findings. The research has explored the experiences of men, informal carers, and HCPs, and presents a holistic understanding of BCiM. The results have made a useful contribution to knowledge and have bridged a gap in research. The key thread throughout the PhD was that both men with breast cancer and their ICs are isolated, and findings show there is a lack of awareness and a clear need for evidence-based psychosocial support. Moving forwards, inclusivity must be at the core of breast cancer research, practice, and support. There is a vital need to raise awareness of BCiM and an urgent need for the provision of support specifically tailored to men with breast cancer and their ICs. Ultimately, the delivery of support that addresses their psychosocial needs depends on the HCPs knowledge and skills needed to deliver such support. Therefore, professional education and training of HCPs on the information and resources available will enable them to identify needs and tailor support accordingly. Together, these may help mitigate future issues, challenges and isolation faced by men with breast cancer and their ICs in the UK.

Appendices

APPENDIX 1 - Doctoral descriptors at UWE Bristol and where demonstrated in the current thesis

Doctoral descriptors at UWE Bristol	Where demonstrated in the current thesis
Have conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field.	The three studies in this PhD have explored previously unresearched areas. This program of work has also resulted in a peer-reviewed publication and presentations at academic conferences. The findings have also been shared in non-academic settings such as a podcast episode. This has facilitated the dissemination of new knowledge and raised awareness of the experiences and support needs of men with breast cancer and their ICs (appendix 22).
Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice.	The literature review (chapter 2) has provided a critical overview of the existing research detailing the experiences of men with breast cancer and their ICs. Literature is also incorporated at the beginning of each study to guide the research aims. Furthermore, published research is included in the discussion section of each study as a basis for comparing findings. Lastly, related literature is integrated in the final discussion chapter (chapter 7).
Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the capacity to adjust the project design in the light of emergent issues and understandings.	The three studies conducted in this PhD have explored previously unresearched areas and the results make a novel contribution to the literature. In light of the Covid pandemic, the measures taken to ensure satisfactory recruitment, such as the use of Microsoft Teams to conduct interviews and the 'back-up study' which was planned but not needed, illustrate the researcher's ability to adjust the project in the light of emergent issues (study 3, section 6.3).
Can demonstrate a critical understanding of the methodology of enquiry.	The researcher critically discusses the theoretical underpinnings and the methodology utilised in the PhD (chapter 3). A reflective section on the methodology is presented in the final discussion chapter (chapter 7).

Have developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences.	The researcher has incorporated PI input and synthesised the experiences of participants throughout the PhD. The results have been presented in a coherent manner which can be understood by both academic and lay audiences (appendix 22).
Can critically reflect on their work and evaluate its strengths and weaknesses including understanding validation procedures.	A critical reflection section has been included in each study chapter. A reflective section on the overall PhD is included in the final discussion chapter (chapter 7).

APPENDIX 2 - Glossary of common medical/technical breast cancer related terms and definitions used in the thesis

A

Adjuvant Treatment given after initial treatment, for example chemotherapy or radiotherapy given after surgery.

Advanced breast cancer Breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as secondary, stage 4 or metastatic breast cancer.

Adverse effect An undesired or harmful effect of a treatment.

Alopecia Loss of hair from the head or body.

Alternative therapy Term used to describe therapies used by some people in place of standard medical treatment.

Anaemia Too few red blood cells in the body. It may cause symptoms including tiredness, shortness of **breath and weakness.**

Areolar region The area of dark-colored skin on the breast that surrounds the nipple.

Aromatase inhibitors Breast cancer treatment that works by reducing the amount of oestrogen in the body. A type of hormone (endocrine) therapy.

Arm oedema Swelling caused by excess fluid trapped in the body’s tissues.

Axilla The armpit.

Axillary clearance An operation to remove all or some of the lymph nodes (also called lymph glands) from under the arm (axilla).

Axillary nodes The lymph nodes (also called lymph glands) under the arm (axilla).

B

Benign Not cancer. Benign tumours do not spread into, or invade, nearby tissues.

Bilateral Affecting both the right and left sides of body.

Biopsy Removal of tissue to be looked at under a microscope.

Blood cells Tiny structures produced in bone marrow. Includes red blood cells, white blood cells and platelets.

Blood count The numbers of red and white blood cells and platelets in a sample of blood.

BRCA1 and BRCA2 People who inherit an altered BRCA1 or BRCA2 gene from either parent have a much higher risk of developing breast cancer and some other cancers compared with the general population.

Breast cancer is a disease in which cells in the breast grow out of control. There are different kinds of breast cancer. The kind of breast cancer depends on which cells in the breast turn into cancer. Breast cancer can begin in different parts of the breast.

Breast Care nurse A specialist nurse who provides information and support to people diagnosed with breast cancer.

Breast cancer surgeon Treats breast cancer with surgery, such as a mastectomy.

C

Cancer A disease in which some of the body's cells grow uncontrollably and spread to other parts of the body.

Carcinoma Another term for cancer.

Chemotherapy Treatment aimed at destroying cancer cells using anti-cancer drugs.

Chest wall The muscles, bones and joints that make up the area of the body between the neck and the **abdomen (belly).**

Chromosomes A threadlike structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes.

Chronic A term used to describe an illness, disease or condition that is long lasting and generally slow to progress.

Counsellor A person trained to give guidance on personal or psychological problems

Cognitive impairment Difficulty concentrating or being more forgetful as a result of a cancer diagnosis or treatment. Sometimes called 'chemo brain' or 'chemo fog'.

Complementary therapies A varied group of therapies, such as massage and acupuncture, used alongside conventional medical treatments.

Comorbidities The simultaneous presence of two or more diseases or medical conditions in a patient.

Contralateral The other or opposite side, for example the contralateral breast.

Clinical nurse specialist See Breast Care nurse

Clinical trials Research that aims to improve treatment or care for patients.

E

Endocrine therapy see Hormone therapy.

ER status ER positive (ER+) means the breast cancer has oestrogen receptors. ER negative (ER-) means the breast cancer doesn’t have oestrogen receptors (see Oestrogen receptors)

Epidemiology The branch of medicine which deals with the incidence, distribution and possible control of diseases and other factors relating to health.

F

Fibrocystic breast changes These can lead to the development of fluid-filled round or oval sacs, called cysts. Fibrocystic breasts are composed of tissue that feels lumpy or rope like. These can make breasts feel tender, or lumpy and can feel distinct from other breast tissue.

Breast tissue fibrosis. Fibrous tissue in an area of the breast.

G

Gene Stores the biological information we inherit from our parents, affecting the way we look and how our bodies work and grow.

Genetic Testing The study of a person's DNA to identify genetic differences or susceptibility to particular diseases or abnormalities.

General Practitioners (GPs) - Treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological, and social aspects of care.

Grade – low, medium, high. The look of cells under the microscope.

Gynaecomastia An increase in the amount of breast gland tissue in boys or men, caused by the imbalance of the hormones estrogen and testosterone.

H

HER2 (human epidermal growth factor receptor 2) A protein involved in the growth of cells. Around 15–20 per cent of breast cancers have higher than normal levels of HER2 (known as HER2 positive) which helps the cancer to grow.

Herceptin see Trastuzumab.

Hereditary Characteristics, conditions or illnesses that can be passed from a parent to their child through genes.

Hodgkin lymphoma A cancer of the immune system that is marked by the presence of a type of cell called the Reed-Sternberg cell

Hormone receptor Involved in the growth of cells. In some breast cancers they bind to hormones within the cells (known as hormone receptor positive) and help the cancer to grow.

Hormone therapy (also called endocrine therapy) Drugs that work in different ways to block the effect of oestrogen on cancer cells. Only used if the breast cancer is hormone receptor positive.

Hormones Chemical messengers produced in various organs of the body that control growth and reproduction.

Hormone positive breast cancer Hormone receptor-positive (or hormone-positive) breast cancer cells have either estrogen (ER) or progesterone (PR) receptors or both. These breast cancers can be treated with hormone therapy drugs that lower estrogen levels or block estrogen receptors.

Hypogonadism A condition in which the male testes or the female ovaries produce little or no sex hormones.

I

Immunotherapy A type of targeted therapy that uses the body's immune system to help it fight cancer.

Inflammation Swelling, redness or warmth caused by the reaction of body tissues to injury, infection or irritation.

Inflammatory breast cancer A rare type of breast cancer where the skin of the breast looks red, and may feel warm and tender ('inflamed').

Incidence The rate of new cases of cancer.

Invasive breast cancer Cancer that has the potential to spread to other parts of the body.

L

Local treatment Specific to an area of the body, for example surgery or radiotherapy.

Lymph nodes Also known as lymph glands. Small oval-shaped structures found in clusters throughout the lymphatic system, for example under the arm (axilla).

Lymphatic system The drainage and filtering system of the body, made up of lymph nodes (lymph glands), vessels and fluid. Helps to get rid of waste and fight infection.

Lymphoedema Swelling of the arm, hand, chest or breast area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of breast cancer surgery or radiotherapy to the lymph nodes under the arm and surrounding area.

M

Malignant Cancer (abnormal cells that divide and grow in an uncontrolled way).

Mammogram A breast x-ray.

Mastectomy This is a type of surgery in which all of the breast tissue is removed, including the nipple.

Metastatic breast cancer Another name for secondary breast cancer.

Mortality Cancer mortality is expressed either as number of cancer deaths occurring, or as a mortality rate, i.e., the number of cancer deaths per 100 000 persons per year. Cancer mortality provides a measure of the impact of cancer in a given population.

Multidisciplinary team A multidisciplinary team involves a range of health professionals, from one or more organisations, working together to deliver comprehensive patient care.

N

Neo-adjuvant Treatment given before surgery. Examples are chemotherapy and hormone therapy. Sometimes called primary, for example primary hormone therapy.

O

Oestrogen Receptor (ER) Proteins within cancer cells that attach to the hormone oestrogen and help the cancer to grow. It may be abbreviated to ER, from the US spelling estrogen.

Oncologist A doctor who specialises in cancer (oncology). A medical oncologist specialises in cancer drugs. A clinical oncologist specialises in radiotherapy alone or radiotherapy and cancer drugs.

Oncology Nurse A specialist nurse who cares for cancer patients.

P

Palliative care Focuses on symptom control and support when cancer cannot be cured. Usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers and physiotherapists.

Palliative care consultant A doctor who specialises in palliative care.

Palliative care nurse A nurse specially trained to provide palliative care.

Palliative treatment Aims to control symptoms and slow down the progress of cancer, rather than cure it.

Pathologist A scientist who studies the causes and effects of diseases. They examine laboratory samples of body tissue for diagnostic purposes.

Primary breast cancer Breast cancer that has not spread beyond the breast or the lymph nodes (lymph glands) under the arm (axilla).

Progression The growth and spread of a disease such as breast cancer.

Progesterone A naturally occurring female hormone. It is essential for normal sexual development and the functioning of female reproductive organs.

Progesterone receptors Proteins within cancer cells that attach to the hormone progesterone (may be abbreviated to PR).

Prognosis The outlook of a disease, such as the likelihood of it coming back (recurrence) and the person's life expectancy.

Psychologist An expert or specialist in psychology.

Physiotherapist A person qualifies to treat disease, injury or disability by physical methods such as massage, heat treatment and exercise.

Q

Quality of life A term often used by healthcare professionals and researchers to refer to the well-being of patients during and after their breast cancer treatment. Quality of life can be affected by any of the experiences a patient has from diagnosis through to surviving breast cancer, including the physical, psychological and social implications of the disease and its treatment.

R

Radiotherapy The use of high energy x-rays to destroy cancer cells.

Radiologists Medical doctors who specialise in diagnosing and treating injuries and diseases using medical imaging (radiology) procedures (exams/tests) such as X-rays, computed tomography (CT), magnetic resonance imaging (MRI), nuclear medicine, positron emission tomography (PET) and ultrasound.

Recurrence When a disease or condition returns. There are different types of breast cancer recurrence.

- Local recurrence Breast cancer that has come back in the chest/breast area or in the skin near the original site or scar.
- Locally advanced breast cancer (sometimes called regional recurrence) Breast cancer that has come back and has spread to the chest wall or skin of the breast, or the lymph nodes around the chest, neck and under the breast bone, but has not spread to other areas of the body. Sometimes breast cancer is locally advanced when it is first diagnosed.
- Distant recurrence also called metastatic, advanced, stage 4 or secondary breast cancer. When cancer has spread from the breast to other parts of the body such as the bones, lungs, liver or brain.

Remission When the signs and symptoms of a disease partly or completely disappear. It may be temporary or permanent.

Risk factor Something that increases a person’s chance of developing an illness such as cancer.

S

Secondary breast cancer Breast cancer that has spread to other parts of the body such as the bones, lungs, liver or brain. Also called metastases, advanced breast cancer, secondaries or stage 4 breast cancer.

Sentinal node biopsy Identifies whether the sentinel lymph node (the first lymph node that the cancer cells are most likely to spread to) is clear of cancer cells. There may be more than one sentinel node. Sometimes called sentinel node biopsy (SNB).

Side effects Unwanted effect of treatment.

Social workers Aim to improve people's lives by helping with social and interpersonal difficulties, promoting human rights and wellbeing.

Stage The size of the cancer and how far it has spread.

Steroids May be given as part of cancer treatment, for example to help with side effects of chemotherapy such as nausea and vomiting, or to control some symptoms caused by cancer.

T

Tamoxifen A hormone therapy drug used to treat breast cancer.

Targeted therapy (or biological therapies) A group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

Terminal A term often used when someone is approaching the last few weeks or days of life.

Therapeutic benefit A benefit or effect obtained as a result of treatment.

Thrombosis Occurs when blood forms a clot. If the clot occurs in a major vein, the condition is known as a deep vein thrombosis or DVT.

Tumour An overgrowth of cells forming a lump. May be benign (not cancer) or cancer.

U

Ultrasound scan A scan that uses high frequency sound waves to produce an image.

X

X-ray Used to produce images of dense tissues in the body such as bone or lungs.

Appendix 3 - EBSCO search terms

Men with breast cancer

“male breast cancer” **“breast cancer in men”**	**Impact** **Psychosocial impact** **Impact** **Impact*** **Effect*** **Wellbeing** **Quality of life** **QOL** **Body image** **Self-esteem** **Masculin*** **Appearance concern***

Informal carers

“male breast cancer” **“breast cancer in men”**	**Famil*** **Carer*** **Spouse** **Friends** **Informal carer***

APPENDIX 4 – Summary of psychosocial research involving men with breast cancer, methods and core findings

Authors	Year	Country	Analysis	Title	Methods and sample	Core findings
France et al.,	2000	UK	Content analysis Phenomenological approach	Male cancer: A qualitative study of male breast cancer	Face-to-face unstructured interviews Purposive, *n* = 6	• Delay in diagnosis. • Shock reaction to diagnosis • Stigma • Body image • Causal factors • Lack of provision of male relevant information and emotional support
Williams et al.,	2003	UK	Qualitative Thematic analysis	Experiences of men with breast cancer: an exploratory focus group study	Semi-structured interviews + focus groups Purposive (*n* = 27) Women with breast cancer (*n = 18*) Men with breast cancer (*n = 9*)	• Role of partner • Disclosure • Isolation • Lack of support • Lack of gender specific information • Masculinity • Body image
Naymark	2006	Canada	Qualitative Thematic analysis	Male breast cancer: incompatible and incomparable	Interviews Men with breast cancer (*n* = 6) Healthcare professionals (*n* = 5)	• Gender disparities • Masculinity as a barrier to healthcare • Gender assumptions of behaviour and needs

						• Lack of provision of male relevant information and emotional support
Iredale et al.,	2005	UK	Cross sectional survey and focus groups	The experiences of men with breast cancer in the United Kingdom	- Hospital anxiety and depressions scale and cancer-specific distress and coping scale Purposive sample. Focus groups (n = 4) Questionnaires to men with breast cancer (n = 161) Follow-up interviews with these men (n = 30) Reconvening the focus groups (n = 2) for the men and women with breast	• Diagnosis and disclosure • Information needs • Support • Raising awareness
Brain et al.,	2006	UK	Cross sectional survey	Psychological distress in men with breast cancer.	Hospital anxiety and depression scale, cancer-specific distress, body image scale, COPE scale Convenient sample, *n* =161	• Cancer related stress • Body image concens • Depressive symptons • Avoidance coping • Fear • Uncertainty • Lack of gender-specific materials • Unmet information needs
Pituskin et al.,	2007	USA	Qualitative analysis	Experiences of men with breast cancer: a qualitative study	Exploratory approach. Men with breast cancer (*n* = 20)	• Concerns with disclosure • Poor of awareness of BCiM • Difficulties receiving diagnosis

						- Body image concerns - Role strain - Lack of male-specific information - Helping other men
Donovan and Flynn	2007	UK and overseas	Qualitative Thematic analysis	The Lived Experience of Male Breast Cancer	Semi-structured interviews, email correspondence contributed contextual data Men with breast cancer (*n* =15) Interviews from the UK (*n* =5) and self-volunteered participants from overseas (*n* =10)	- Living with BCiM - Concealment as a strategy for managing a diagnosis - Contested masculinity - Interacting with health services
Thomas, Eileen	2010	USA	Qualitative analysis – contextual analysis and frequency of similar responses	Men's awareness and knowledge of male breast cancer	Semi-structured interviews Men with breast cancer (*n =28*)	- Lack of awareness - Masculinity concerns - Suggestions to improve awareness and education of BCiM
Pemmaraju et al.,	2012	USA	A retrospective review	Retrospective review of male breast cancer patients: Analysis of tamoxifen-related side-effects	Men with breast cancer (*n* =64) treated with tamoxifen Descriptive statistics were used for patient characteristics, side-effects, and discontinuation of tamoxifen.	- High rate of discontinuation of tamoxifen - Side effects – weight gain, sexual dysfunction
Sime	2013	UK	Qualitative	Men’s experiences of having breast cancer: a	Part semi-structured interviews.	- Help-seeking practices - Lack of awareness of BCiM

			Framework analysis - thesis	comparison with women's experiences.	Qualitative Purposive sample of men (*n*= 19) and secondary data from women	• Disclosure strategies • Treatment experiences – lack of choice • Lack of information • Negative experiences in treatment setting • Supportive role of IC's • Masculinity and embodiment concerns • Masculinity changes over the course of the illness
Kipling et al.,	2014	UK	Literature review and in-person written survey (not standardised measures)	Psychological Impact of Male Breast Disorders: Literature Review and Survey Results	Literature review + Written survey with men with breast cancer (*n*=78)	• Anxiety felt both before and after diagnosis and treatment • Masculinity • Side effects of medication • Stigma
Quincey, Williamson and Winstanley	2016	UK	Qualitative synthesis	Marginalised malignancies': A qualitative synthesis of men's accounts of living with breast cancer	Interpretative and evaluative qualitative synthesis of existing academic literature in the field of BCiM.	• Positions BCiM as a marginalised malignancy • Unmet psychosocial needs • Men can experience 'othering' and 'self-stigma' • Masculinity is central to men's experiences • Small changes to the existing care and support could make a difference
Rayne et al.,	2017	South Africa	File review	Male Breast Cancer Has Limited Effect on Survivor's Perceptions of	Retrospective file review of cases men with breast cancer (*n = 23*) and telephone	• Delayed diagnosis • Most did not perceive breast cancer diagnosis as

				Their Own Masculinity: A Record Review and Telephone Survey of Patients in Johannesburg, South Africa,	interviews with men with breast cancer (*n = 18*)	affecting their masculinity, or altering sexual function • Those whose masculinity was affected tended to be black, less aware of BCiM and treated in government hospitals.
Midding et al.,	2017	Germany	Qualitative content analysis	Informational support: Needs and resources of male breast cancer patients	Interviews with men with breast cancer (*n* =27)	• Need for improved informational support • Important role of social support
Midding et al.,	2019	Germany	Mixed methods	Men With a “Woman’s Disease”: Stigmatization of Male Breast Cancer Patients—A Mixed Methods Analysis	Quantitative data (*n* =100) Interviews with men with breast cancer (*n* =27)	• Stigma • Masculinity • Body image • Lack of awareness • Lack of gender appropriate materials
Quincey & Trusson	2019	UK	Qualitative interviews and photographic data. Narrative and thematic analysis.	Breast Cancer and Hair Loss	Data from 2 separate experiential inquiries were analysed together. Study 1 used semi structured interviews from women with breast cancer (*n* =24) Study 2 used structured interviews and participant-authored photographs from men with breast cancer (*n* =31)	• Hair loss is distressing for both sexes • Asserting masculinity and use of humour by male participants • Men discussed loss of body hair • Masculinity • Appearance concerns • Lack of support for men • Need for gender-specific advice and support tailored to men’s needs • Role of healthcare professionals

Walker and Berry	2019	USA	Descriptive content analysis	Men with breast cancer experience stigma in the waiting room	Semi-structured telephone interviews with men with breast cancer (*n* =5)	• Lack of awareness • Stigma • Inappropriate clinical environment
Thompson and Haydock	2019	USA	Grounded theory	Men's Lived Experiences with Breast Cancer: The Double Consciousness of Marginal Men	Interviews (face- to-face (*n* =7) or telephone (*n* =10)	• Isolation • Body talk • Masculinity • Embodiment
Halbach et al.,	2019	Germany	Descriptive statistics and qualitative content analysis	Male Breast Cancer Patients' Perspectives on Their Health Care Situation: A Mixed-Methods Study	Questionnaires completed by men with breast cancer (*n* =100) Interviews with men with breast cancer (*n* =100)	• Lack of awareness • Uncertainty about treatment • Stigma • Care concerns • Challenges surrounding treatment of men in gynaecology settings • Need for better after care
Co, Lee and Kwong	2020	Hong Kong	Retrospective review and telephone interviews	Delayed presentation, diagnosis, and psychosocial aspects of male breast cancer	Retrospective review of men with breast cancer (*n* =56) and telephone interviews with men with breast cancer (*n* =31)	• Lack of awareness of BCiM • Embarrassment at onset • Uncomfortable waiting in breast centres with predominantly female patients
Faria et al.,	2021	Brazil	Thematic analysis and frequency of similar responses	Analysis of knowledge of BCiM among higher education male students	Semi-structured questionnaires Male higher education students at one institution	• Lack of awareness of risk factors, self-examination, or diagnosis of BCiM

					(*n* =299)	
Levin-Dagan and Baum	2021	Israel	Thematic analysis	Passing as normal: Negotiating boundaries and coping with male breast cancer	Semi-structured interviews with men with breast cancer (*n* =31)	• Stigma both inside and outside healthcare settings • Body image concerns and concealment practices • Masculinity
Quincey, Williamson and Wildbur	2021	UK	A multimethod inquiry - verbal and photographic data were analysed using Interpretative phenomenological analysis through the 'visual voice' paradigm.	Men With Breast Cancer and Their Encounters With Masculinity: An Interpretative Phenomenological Analysis Using Photography	Semi-structured verbal-visual interviews with men with breast cancer (*n* =31)	• Masculinities performed at different points of the breast cancer trajectory (from diagnosis, treatment and life when treatment has finished) • How men encounter, perform, utilise and transition between masculinities in their adjustment to breast cancer

APPENDIX 5 - Study 1 online survey

Study title: Exploring men’s experiences and body image concerns following breast cancer. A mixed methods study.

Information

You are being invited to take part in this online study. Before you decide if you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of the study is to explore men's experiences after diagnosis and treatment for breast cancer, including any changes to their body and appearance. We hope the findings will inform the future provision of care and support.

Who is carrying out the research?

This study is being carried out by Beth Herring, a PhD student based at the Centre for Appearance Research at the University of the West of England. The Centre for Appearance Research is the world's largest research group focusing on the role of appearance and body image in people's lives. The PhD is being supervised by Professor Diana Harcourt.

Who can take part in this research?

Men aged 18 years and older who have received a diagnosis or diagnosis and treatment for breast cancer. We are particularly interested in men's views on how their diagnosis and treatment has impacted on how they feel about their body. We are keen to hear from men who have had any kind of treatment, whether it has had a positive or a negative impact on how they feel, or whether it has had no impact at all.

What will participation involve and how long will it take?

If you agree to take part in the study, you will be asked to complete an online survey. The survey will take less than 10 minutes to complete. The survey will ask you questions about your thoughts and feelings regarding appearance and the support available to you.

What about confidentiality?

The information you give us will be treated with the highest level of confidentiality. You will be assigned a unique participant identification code, your name and identity will never be connected to your responses. Information that would make it possible to identify you or any other participant will never be included in any report. Upon completion of the survey, you have the opportunity to provide your email should you wish to be informed of the findings. Your email address will be kept separately from your responses to ensure that your anonymity is protected. Your data may be published in an academic journal or presented at a conference, and whilst your direct quotes might be used, any identifying information will remain anonymous. Data will only be accessible to the researchers working on the programme.

Do I have to complete the whole survey?

Your participation in this research is entirely voluntary and you have the right to answer as many or as few questions as you wish. However the more questions you answer, the more helpful this will be. You also have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw you will need to inform us by email (beth2.herring@uwe.ac.uk) quoting your unique participation identification code. This will enable us to identify all the material that needs to be deleted following your withdrawal from the project.

What are the potential disadvantages and risks of taking part?

We understand that this may be a sensitive topic for some men. We do not expect that participating in this study will have any detrimental effects on you. It is entirely your choice as to what you want to share with the researchers via the survey. We would also like to reassure you that there are no right or wrong answers and no judgements will be made on the basis of what you write.

What are the potential benefits of taking part?

Although we cannot promise that this study will help you personally, we hope that having the opportunity to share your opinions and experiences will be a positive experience. Your participation will contribute towards a greater understanding of appearance related concerns and help inform the development of a future intervention for men who have received a diagnosis of breast cancer. The intervention aims to improve the lives of men who have noticed changes to their appearance and how they feel about their body following breast cancer.

What will happen to the results of this study?

The results of this study will be published in academic journals or presented at conferences. However, you will not be identified in any outputs from the research. We will also provide feedback to participants, so that you will be informed of the study findings.

Who has reviewed this study?

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

What do I do if I want to take part?

If you do wish to take part, please complete the consent form below and you may begin the survey.

Further information and further support:

If you would like any further information about this research or if you have any queries at any time in the future, please contact: Beth Herring (PhD researcher): beth2.herring@uwe.ac.uk or 0117 328 3273 or Professor Diana harcourt: Diana2.Harcourt@uwe.ac.uk

Furthermore, if you have any concerns about breast cancer or any aspect of your treatment, we recommend you contact your GP or your breast care team. Breast Cancer Care, a UK charity, can also provide support including information and online discussion forums: https://www.breastcancercare.org.uk and https://www.breastcancercare.org.uk/information-support/have-i-got-breast-cancer/breast-cancer-in-men. These may be able to advise you on finding the help you need.

Thank you for taking the time to read this information sheet.

STATEMENT OF CONSENT

Before you take part in the survey, we would like to make sure that you have understood the information we have given so far.

In order to take part in the survey you are agreeing to the following:

○ I understand that by consenting to take part in this study I am still able to withdraw without having to give any reasons

○ I understand that I can ask questions about the study after I have completed the survey

○ I understand that I will never be personally identified in any report or write up that stems from this research

○ I understand that my name will be replaced by a unique identification code so that all the data can remain confidential

○ I confirm that I am over the age of 18

I have read and agree to the above statements and I am happy to take part.

○ Yes

○ No [End of survey]

○ Yes, I want to exit the survey [End of survey]

○ No, I want to continue and complete the survey

Thank you for agreeing to complete this survey titled '*Mens' experiences after diagnosis and treatment for male breast cancer'.* We anticipate that the survey should take you about 15 minutes to complete.

Should you wish to withdraw, you will need to inform us by email (beth2.herring@uwe.ac.uk), quoting your unique participant identification code. Your participant identification code will enable us to identify all the material that needs to be deleted due to your withdrawal from the project.

To create your unique participant identification code please enter the first three letters of your mother's maiden name and the day of the month that you were born.

EXAMPLE: If your mother's maiden name is Cooper and you were born on the 10th August you would enter COO10.

Please enter your code in the box below:

____

The survey consists of three sections:

<u>Section 1/3</u>

The first section will ask you questions about you and your treatment.
We really need to understand the sorts of people who have completed the survey. There are a few demographic questions which we will use in our analysis, not to identify individuals.

Please remember that all of your answers are anonymous.

How old are you (years)?

____

How would you describe your ethnic group? Please click one of the following options:

○ White

○ Multiple ethnic group

○ Asian/Asian British

○ Black/African/Caribbean/Black British

○ Other, please specify ____

○ Prefer not to say

What is your relationship status?

○ Single

○ Married/Civil partnership

○ In a relationship but not married or in a civil partnership

○ Divorced

○ Separated

○ Widowed

○ Other (please state) ____

○ Prefer not to say

Which of the following options best describes how you think of yourself?

○ Heterosexual or straight

○ Gay

○ Bisexual

○ Other ____

○ Prefer not to say

What is your employment status?

○ Employed

○ Self-employed

○ Retired

○ Other ____

What country do you live in?

____

The following questions are about your breast cancer diagnosis and treatment.

How long ago did you receive your diagnosis for breast cancer?

Years ____

Months ____

What treatment have you received for breast cancer?

○ Surgery

○ Chemotherapy

○ Radiotherapy

○ Hormonal therapy ((e.g. Tamoxifen)

○ Rehabilitation

○ Other (please state) ____

What type of surgery did you have?

____

____

____

____

____

In what country did you receive your treatment?

____

Are you currently undergoing treatment?

○ Yes

○ No

What treatment are you undergoing?

○ Hormonal (e.g., Tamoxifen)

○ Chemotherapy

○ Radiotherapy

○ Other (please specify) ____

Do you have any additional health issues? Please give details

____

Below is a list of statements that other people with breast cancer have said are important. Please indicate one answer per line to indicate your response as it applies to <u>the past 7 days.</u>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	○	○	○	○	○
I have nausea	○	○	○	○	○
Because of my physical condition, I have trouble meeting the needs of my family	○	○	○	○	○
I am forced to spend time in bed	○	○	○	○	○
I have pain	○	○	○	○	○
I am bothered by side effects of treatment	○	○	○	○	○
I feel ill	○	○	○	○	○

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	○	○	○	○	○
I get emotional support from my family	○	○	○	○	○
I get support from my friends	○	○	○	○	○
My family has accepted my illness	○	○	○	○	○
I am satisfied with family communication about my illness	○	○	○	○	○
I feel close to my partner (or the person who is my main support)	○	○	○	○	○

Please answer the question below, if you feel uncomfortable, please select 'Prefer not to say' option

	Not at all	A little bit	Somewhat	Quite a bit	Very much	Prefer not to say
I am satisfied with my sex life	○	○	○	○	○	○

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	○	○	○	○	○
I am satisfied how I am coping with my illness	○	○	○	○	○
I am losing hope in the fight against my illness	○	○	○	○	○
I feel nervous	○	○	○	○	○
I worry about dying	○	○	○	○	○
I worry that my condition will get worse	○	○	○	○	○

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I am able to work (include work at home)	○	○	○	○	○
My work (include work at home) is fulfilling	○	○	○	○	○
I am able to enjoy life	○	○	○	○	○
I have accepted my illness	○	○	○	○	○
I am sleeping well	○	○	○	○	○
I am enjoying the things I usually do for fun	○	○	○	○	○
I am content with the quality of my life right now	○	○	○	○	○

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I have been short of breath	○	○	○	○	○
I am self-conscious about the way I dress	○	○	○	○	○
One or both of my arms are swollen or tender	○	○	○	○	○
I feel sexually attractive	○	○	○	○	○
I am bothered by hair loss	○	○	○	○	○
I worry that other member of my family might someday get what I have	○	○	○	○	○
I worry about the effects of stress on my illness	○	○	○	○	○
I am bothered about a change in weight	○	○	○	○	○
I am able to feel like a man	○	○	○	○	○

I have certain parts of my body where I experience pain	○	○	○	○	○

You will now be asked how you feel about your appearance, and any changes that may have resulted from your disease or treatment.

Please read each item carefully, and indicate alongside the reply which comes closest to the way you have been feeling about yourself, *during the past week*.

	Not at all	A little	Quite a bit	Very much	Not applicable
Have you been feeling self-conscious about your appearance?	○	○	○	○	○
Have you felt less physically attractive as a result of your disease or treatment?	○	○	○	○	○
Have you been dissatisfied with your appearance when dressed?	○	○	○	○	○
Have you been feeling less masculine as a result of your disease or treatment?	○	○	○	○	○
Did you find it difficult to look at yourself naked?	○	○	○	○	○
Have you been feeling less sexually attractive as a result of your disease or treatment?	○	○	○	○	○
Did you avoid people because of the way you felt about your appearance?	○	○	○	○	○
Have you been feeling the treatment has left your body less whole?	○	○	○	○	○

Have you felt dissatisfied with your body?	○	○	○	○	○

	Not at all	**A little**	**Quite a bit**	**Very much**	**Not applicable**
Have you been dissatisfied with the appearance of your scar?	○	○	○	○	○

Please answer the following:

	Definitely disagree	**Mostly disagree**	**Neither agree nor disagree**	**Mostly agree**	**Definitely agree**	Not applicable
My body is sexually appealing.	○	○	○	○	○	○
I like my looks just the way they are.	○	○	○	○	○	○
Most people would consider me good-looking.	○	○	○	○	○	○
I like the way I look without my clothes on.	○	○	○	○	○	○
I like the way my clothes fit me.	○	○	○	○	○	○
I dislike my physique.	○	○	○	○	○	○
I am physically unattractive.	○	○	○	○	○	○

		Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Some-what agree	Agree	Strongly agree	Not applicable
I rarely think about how I look.	○	○	○	○	○	○	○	○	○
I think it is more important that my clothes are comfortable than whether they look good on me.	○	○	○	○	○	○	○	○	○
I think more about how my body feels than how my body looks.	○	○	○	○	○	○	○	○	○
I rarely compare how I look with how other people look.	○	○	○	○	○	○	○	○	○
During the day, I think about how I look many times.	○	○	○	○	○	○	○	○	○
I often worry about whether the clothes I am wearing make me look good.	○	○	○	○	○	○	○	○	○
I rarely worry about how I	○	○	○	○	○	○	○	○	○

look to other people.	

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I have high self esteem	○	○	○	○	○

Since your cancer diagnosis or treatment, how much have you felt…

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
No longer a whole man	○	○	○	○	○
Lost part of manhood	○	○	○	○	○
Not the man I used to be	○	○	○	○	○
I feel that others think that I am not the man I used to be	○	○	○	○	○
Feel weak and small	○	○	○	○	○
Compared unfavourably to other men	○	○	○	○	○
Have been too emotional	○	○	○	○	○
Hard to think coolly and logically	○	○	○	○	○

Is there anything else about you diagnosis or treatment you would like to share? *Please write your response in the text box below.*

____

____

____

____

____

Is there anything else you would like to tell us about any changes to your appearance that you have noticed since your diagnosis or treatment? *Please write your response in the text box below.*

____

____

____

____

____

Could anything have been done differently by the breast care service that may have improved your experience of changes to your appearance as a result of breast cancer treatment or surgery? If yes, please give details:

____

____

____

____

____

Did you seek any support for appearance-related issues, at any stage following your diagnosis?

○ Yes

○ No

Please give details of support sought for appearance related issues:

____

____

____

____

____

When did you seek support for appearance-related issues?

____

____

____

____

____

What format of support would you have preferred?

Please click one of the following options

○ Group meetings

○ Online support

○ Peer support

○ Other (please specify) ____

Do you think the questions in this survey have fully addressed your appearance-related concerns?

○ Yes

○ No

Please tell us what else we should have asked about:

____

____

____

____

____

Thank you, the main part of the survey is now complete, we just have a few questions left:

How do you prefer your Breast Cancer to be called?

○ Breast cancer

○ Male breast cancer

○ Cancer of the chest

○ Chest cancer

○ Other (please specify) ____

Where did you hear about this study?

○ Word of mouth

○ Social media

○ From a support group

○ Other (please specify) ____

If you would like to receive a summary of the results of this study or hear about future research that we may be conducting on this topic, please add your email address below. Please note that your email address will only be used for contacting you regarding the survey results or future related research. We will ensure that your email address will be kept separately from your responses in any data analysis to ensure confidentiality.

○ I am happy being contacted about future research in this area.

Please provide your email address.

____

○ I would like to receive a copy of the results.

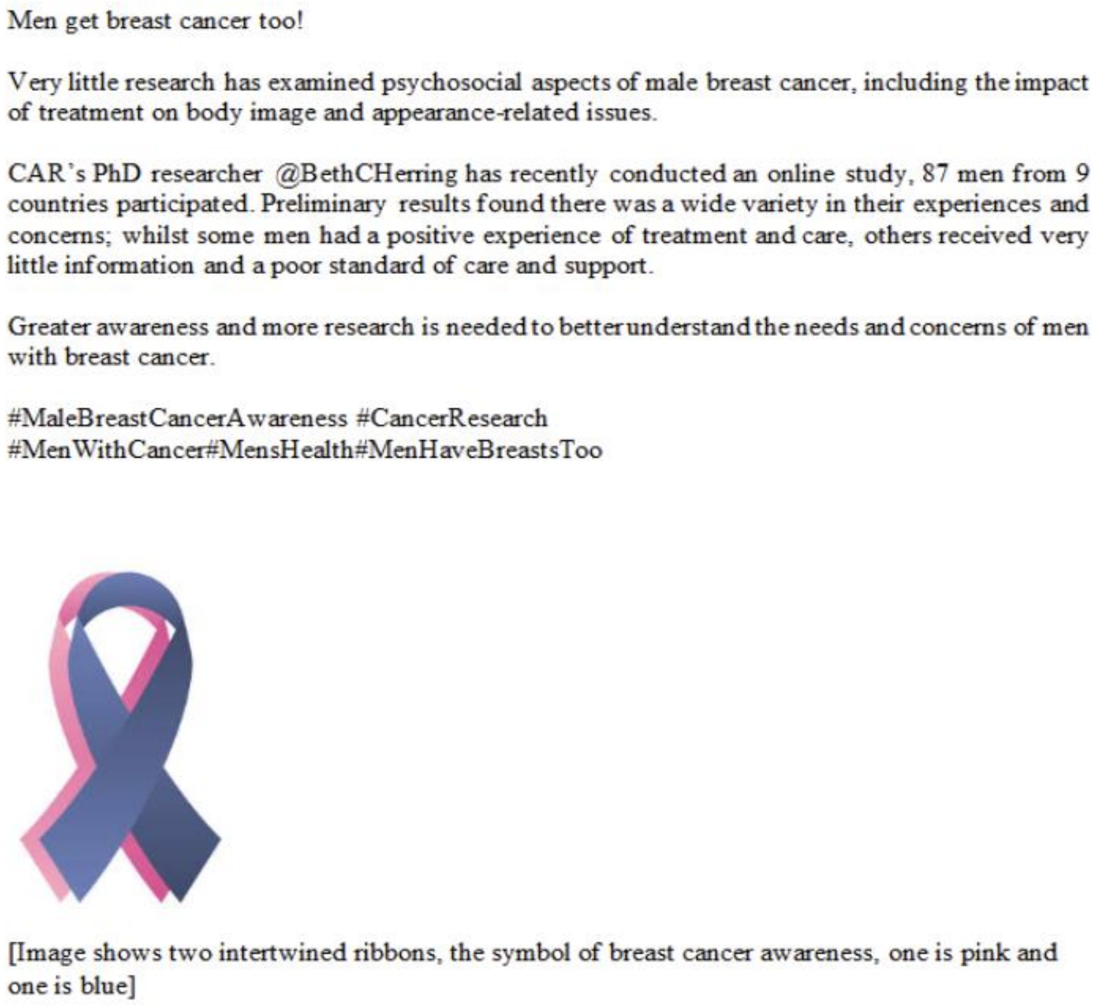
Please provide your email address.

Thank you for taking part in this survey, we very much appreciate your time.

APPENDIX 6 - Study 1 social media recruitment posts

Instagram

Twitter



Men get breast cancer too!

Very little research has examined psychosocial aspects of male breast cancer, including the impact of treatment on body image and appearance-related issues.

CAR's PhD researcher @BethCHerring has recently conducted an online study, 87 men from 9 countries participated. Preliminary results found there was a wide variety in their experiences and concerns; whilst some men had a positive experience of treatment and care, others received very little information and a poor standard of care and support.

Greater awareness and more research is needed to better understand the needs and concerns of men with breast cancer.

#MaleBreastCancerAwareness #CancerResearch
#MenWithCancer#MensHealth#MenHaveBreastsToo

[Image shows two intertwined ribbons, the symbol of breast cancer awareness, one is pink and one is blue]

PhD student @BethCHerring is conducting exciting new research on to #malebreastcancer. Men who have received a diagnosis of breast cancer are invited to complete an online survey. For information go to: https://go.uwe.ac.uk/malebreastcancer

#cancerresearch #menwithcancer

Facebook

Male breast cancer study - participants wanted!

PhD student Beth Herring is conducting exciting new research on men with breast cancer.

In order to better understand the impact of receiving a diagnosis and treatment for breast cancer, she is looking for men who have been diagnosed with breast cancer to complete a brief online survey.

To take part please visit: https://go.uwe.ac.uk/malebreastcancer or contact Beth Herring (beth2.herring@uwe.ac.uk); +44 117 328 3273 for more information.

Thank you for your time and support

APPENDIX 7 - A description of the cancer charities, support groups and individuals involved in recruitment for study 1.

A Man's Pink (USA)

An American website set up by Herb Wagner, following his diagnosis of breast cancer. It provides patients and their families access to information on BCiM. The site also runs a forum to share individual stories and offer peer support to cancer patients and survivors. The webpage allocated a whole page dedicated to help recruit for the study.

Blue Ribbon Foundation (UK), the organisation promotes the health and wellbeing of men. They raise awareness of numerous male health issues, including male breast cancer. They also encourage men to take positive action to safeguard their health and wellbeing, including encouraging men to visit their doctor more often.

Breast Cancer Network Australia (BCNA) is Australia's leading breast cancer consumer organisation. Established 22 years ago, they work to ensure that all Australians who are affected by breast cancer receive the very best care, treatment and support.

Breast Cancer Haven (UK)

A UK charity that offers one-to-one emotional, physical and practical support to anyone affected by breast cancer. They provide counselling and therapies to help with the emotional and physical side-effects from breast cancer as well as help with healthy eating and exercise. They also run support groups. They have seven centres across the country including the West Midlands, Hereford, Wessex, Yorkshire Worcester and two in London.

Breast Cancer Now (UK)

Breast Cancer Care and Breast Cancer Now merged to become one charity, Breast Cancer Now. The charity conducts research and provides information and support to anyone diagnosed with breast cancer. The charity has 63366 members and hosts an online forum which posts to their community. The study was posted on their online forum:

https://forum.breastcancernow.org/t5/Living-with-breast-cancer/PhD-survey-about-male-breast-cancer/m-p/1314556#M94965.

Bust (UK)

A Bristol based charity founded by patients for patients to support the work of the Bristol Breast Care Centre at Southmead Hospital. They provide information and support to men and women who have received a diagnosis and treatment for breast cancer.

HIS Breast Cancer Awareness (USA)

Is an informative website created by a brother and sister who were BRACA 2 positive and were both diagnosed with breast cancer. The website assists those affected by breast cancer, family and friends, health care professionals, and anyone who is interested in learning about the risk, treatment(s), emotional aspect and stigmatism of men dealing with this disease.

Maggie's

A UK charity with centres built in the grounds of 20 major NHS cancer hospitals in the UK and abroad, as well as an online centre. Professional staff provide emotional support and practical advice as well practical advice about benefits and eating well. The centres provide the opportunity to meet others in a similar situation.

One for the Boys (UK)

Is a website which encourages men to talking about cancer by removing the myths around it and changing their attitudes towards their health. They aim to educate men through awareness campaigns and live clinics to know the signs associated with cancer. Ultimately, they hope this will encourage them to seek help and allow for the early detection that can save lives.

Penny Brohn

A UK charity with their national centre in Bristol. They also work in partnership with a range of healthcare providers to help meet the needs of those living with cancer and their families across the country including Liverpool, the midlands, Wolverhampton, London, Brighton, Bristol and Exeter. Penny Brohn provides a holistic approach designed to help patients feel better and live better with cancer, its treatments and side effects. They offer local support including free courses (day or residential), activities and wellbeing events such as yoga and mindfulness.

The Dutch Cancer Society (The Netherlands)

The charity works with all cancer types and is involved in funding of scientific research. They share their knowledge about different cancers and their treatment.

Male Breast Cancer Happens (previously The Male Breast Cancer Coalition, USA)

Male Breast Cancer Happens a not-for-profit patient advocacy organization. They participate in events around the world to raise awareness of male breast cancer.

Additionally, they shares stories from male breast cancer survivors all over the world in a bid to try and reduce the stigma and isolation associated with male breast cancer.

Walk the Walk (UK)

Walk the Walk is a UK based grant making breast cancer charity which raises awareness and runs events and challenges worldwide. It also supports local and national fundraising events to raise awareness of breast cancer in both men and women.

Male breast cancer support groups who promoted the survey online included:

Walk the Walk (UK), One for the Boys (UK), Blue Ribbon Foundation (UK), The Male Breast Cancer Coalition (USA), HIS Breast Cancer Awareness (USA), A Man’s Pink (USA), Breast Cancer Network Australia and The Dutch Cancer Society (The Netherlands).

Individuals who promoted the study through their social media (Twitter and Face Book) included:

Herb Wagner – a MBC survivor and founder of the BCiM support site “A Man’s Pink”. Herb created a page on his site dedicated to promoting this survey.

Professor John Boyages - an Australian breast cancer specialist with more than 35 years' experience in the diagnosis and treatment of breast cancer. John has written a book on BCiM, 'Male breast cancer – Taking Control' and kindly posted this study on Face Book.

Rodney Ritchie - an Australian breast cancer survivor and advocate for BCiM awareness frequently posted the study on his social media channels.

The BBC Sports presenter, **Jake Humphrey**, promoted the study on Twitter. Jake has 908k followers.

APPENDIX 8 - **Example of reflexive log**

21.07.2020 I have just started reading the extracts properly and am starting to feel immersed in the dataset. I am really moved by the experiences of the men, and I am feeling a mixture of sorrow at how lonely their experiences are and anger at how they are often treated in the healthcare system and by society as a whole.

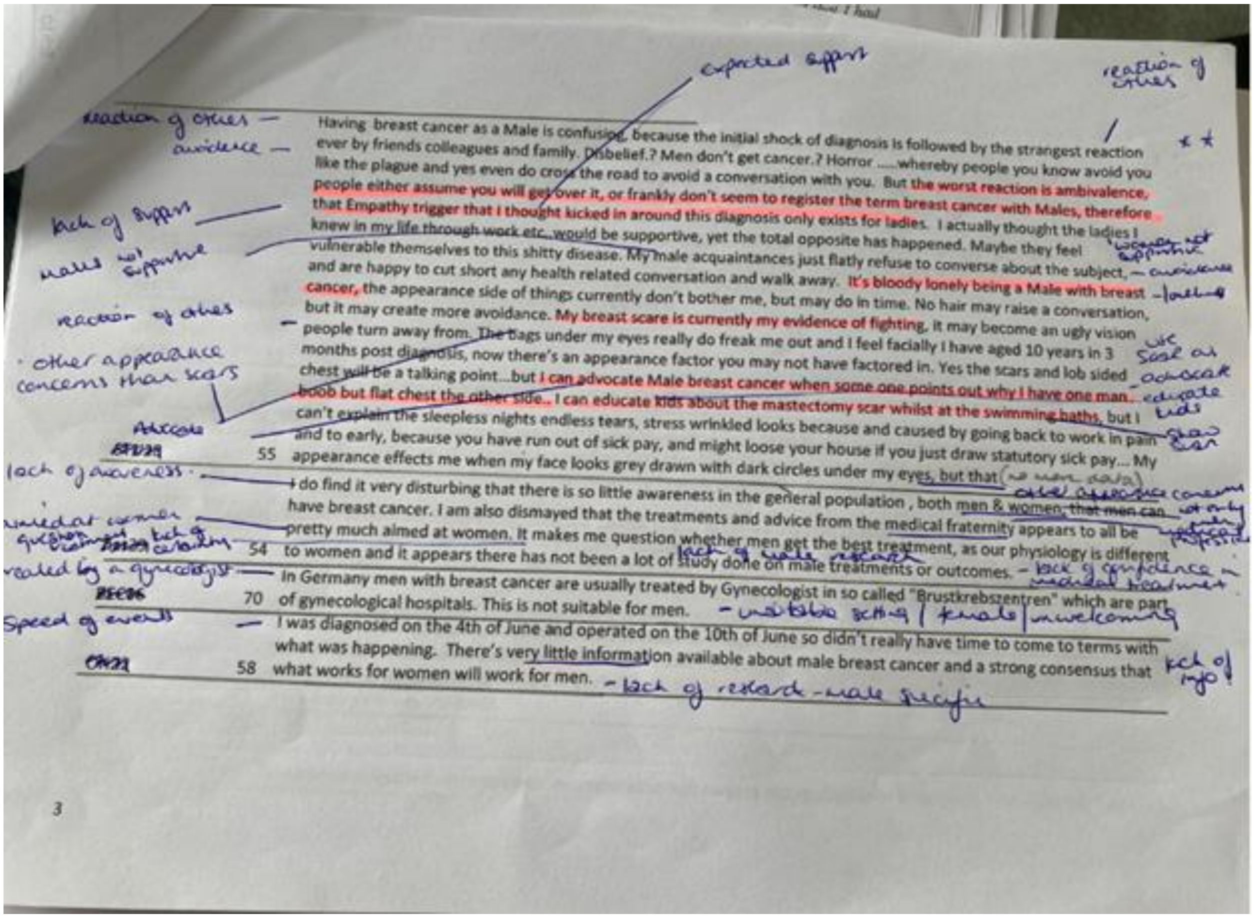
I am so pleased I am undertaking this research and hope to give a voice to these men. I am aware of the importance of research and hoping I can make some kind of difference, however small that may be. The analyis is an emotional rollercoaster of highs and low! I often find myself thinking of their quotes and the sadness of many of their situations long after I have stopped working on the analysis. Some of the language used by the men to describe their struggles and concerns are haunting.

28.07.2020 Hearing the voices of the men and their experiences really brings the research alive! I am starting to see parallels in many of their stories, as well as the similarity of experiences of BCiM patients in different countries around the world.

30.07.2020 As well as similarities there are marked differences in how some men react/cope with breast cancer. It reminds me of the research I conducted with women with breast cancer and the diversity in their experiences… we are all different and all reaction/experience things differently.

11.08.2020 I have had a few weeks off for the kids school holidays and refreshing myself with the data…again I am moved by the men’s responses. Whilst some men only say the odd word, others have poured their hearts out… I get the feeling this may have been the first time for many have been given the opportunity to have a voice and to share their experiences. I am getting the distinct feeling of what a lonely disease breast cancer is for many men and the huge disparities in the care and support provided for women to men with the disease. I have been haunted by some of the experiences, of ‘friends’ making jokes of their cancer and others crossing the road to avoid them. The overwhelming sense of sheer loneliness felt by so many of them is so evident… it really is desperately sad.

APPENDIX 9. Example of coding for study 1 and thematic map



expected support

reaction of others

reaction of others —
avoidance —
lack of support
males not supportive
reaction of others
other appearance concerns than scars
Advocate

Having breast cancer as a Male is confusing, because the initial shock of diagnosis is followed by the strangest reaction ever by friends colleagues and family. Disbelief.? Men don't get cancer.? Horror ......whereby people you know avoid you like the plague and yes even do cross the road to avoid a conversation with you. But the worst reaction is ambivalence, people either assume you will get over it, or frankly don't seem to register the term breast cancer with Males, therefore that Empathy trigger that I thought kicked in around this diagnosis only exists for ladies. I actually thought the ladies I knew in my life through work etc. would be supportive, yet the total opposite has happened. Maybe they feel vulnerable themselves to this shitty disease. My male acquaintances just flatly refuse to converse about the subject, and are happy to cut short any health related conversation and walk away. It's bloody lonely being a Male with breast cancer, the appearance side of things currently don't bother me, but may do in time. No hair may raise a conversation, but it may create more avoidance. My breast scare is currently my evidence of fighting, it may become an ugly vision people turn away from. The bags under my eyes really do freak me out and I feel facially I have aged 10 years in 3 months post diagnosis, now there's an appearance factor you may not have factored in. Yes the scars and lob sided chest will be a talking point...but I can advocate Male breast cancer when some one points out why I have one man boob but flat chest the other side.. I can educate kids about the mastectomy scar whilst at the swimming baths, but I can't explain the sleepless nights endless tears, stress wrinkled looks because and caused by going back to work in pain and to early, because you have run out of sick pay, and might loose your house if you just draw statutory sick pay.... My appearance effects me when my face looks grey drawn with dark circles under my eyes, but that (no more data)

* *
women not supportive
— avoidance
— loneliness
use scar as advocate
educate kids
show scar
other appearance concerns

[redacted] 55

lack of awareness —
[illegible] questioning treatment
lack of certainty

I do find it very disturbing that there is so little awareness in the general population , both men & women, ~~that men can~~ have breast cancer. I am also dismayed that the treatments and advice from the medical fraternity appears to all be pretty much aimed at women. It makes me question whether men get the best treatment, as our physiology is different to women and it appears there has not been a lot of study done on male treatments or outcomes. — lack of confidence in medical treatment

not only men
medical profession
lack of male research

[redacted] 54

treated by a gynecologist —

In Germany men with breast cancer are usually treated by Gynecologist in so called "Brustkrebszentren" which are part of gynecological hospitals. This is not suitable for men. — unsuitable setting / female / unwelcoming

[redacted] 70

Speed of events —

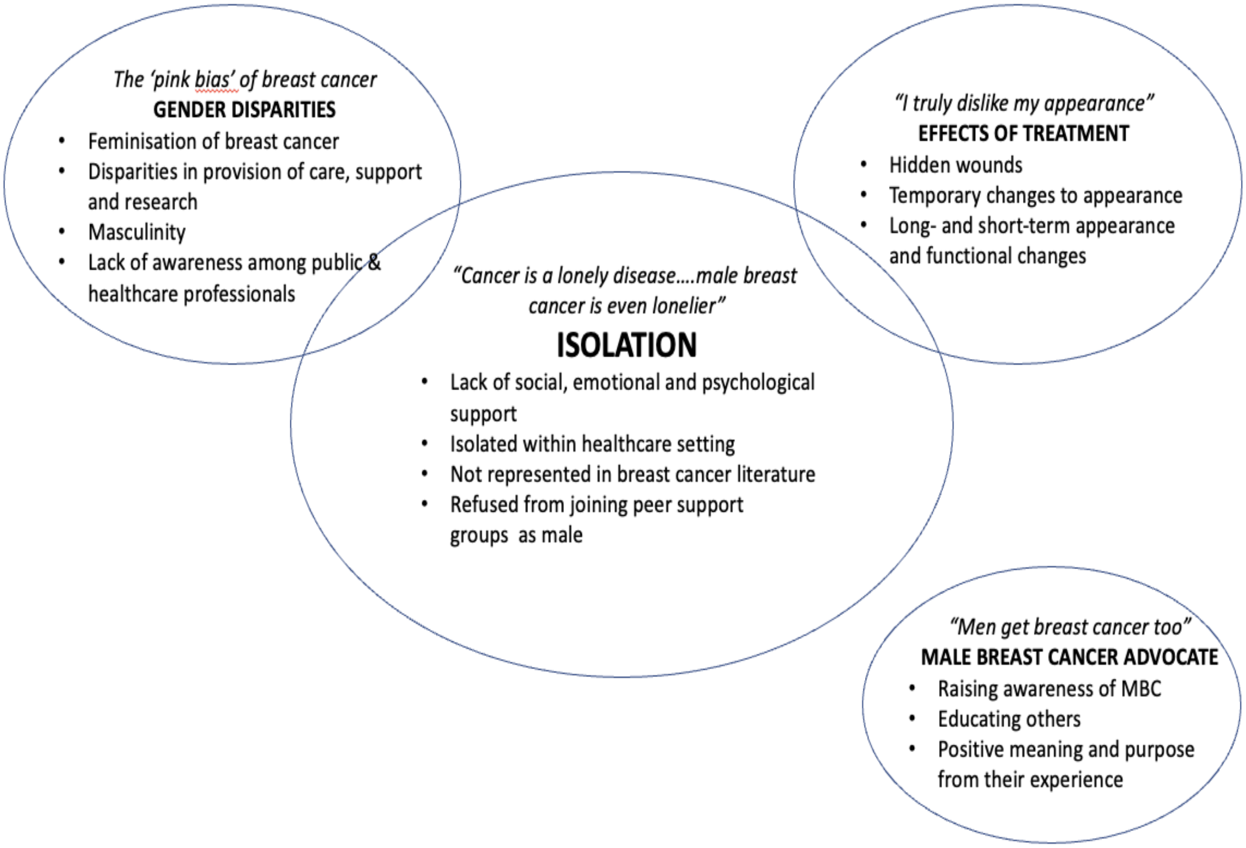
I was diagnosed on the 4th of June and operated on the 10th of June so didn't really have time to come to terms with what was happening. There's very little information available about male breast cancer and a strong consensus that what works for women will work for men. — lack of research — male specific

lack of info!

[redacted] 58

3

Initial thematic map showing interaction of themes



APPENDIX 10 - Study 1 feedback letter to stakeholders

Centre for Appearance Research
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
United Kingdom

Exploring men's experiences after diagnosis and treatment for male breast cancer.

November 2020

Why was the research conducted?

The research study, with which you kindly helped recruit participants, was the first in a series of studies for a PhD in male breast cancer. There has been little research conducted on the psychological and social impact of breast cancer in men and this study aimed to gain a better understanding of areas where men may be concerned about changes to their appearance and exploring influencing factors. It also explored men's experiences of support for appearance-related issues and their treatment. Research is needed to clarify the extent and type of these needs and the findings will help guide the next studies in this PhD. Ultimately, the research aims to help improve the future provision of support for men with breast cancer.

What did I do?

The invitation to participate in the research was posted on social media channels and online forums of number of cancer charities and support organisations globally. A number of cancer specific charities also advertised the study in their centres and informed men of the research.

This attracted a good level of interest and 87 men from 9 countries across the world took part in the survey. This was a very large sample for research in this area since the limited amount of previous studies typically included around ten to twenty men.

There were two main aims of the study:

- To gain a better understanding of areas where men may be concerned about changes to their appearance and exploring influencing factors.

- To gather information on existing support and support needs that are not currently being met.

What did I find?

When receiving a diagnosis and treatment for any type of cancer, patients are faced with very individual situations and challenges. This study in men with breast cancer found there was a wide variety in their experiences and concerns; whilst some men had a positive experience of treatment and care, others received very little information and a poor standard of care and support. This summary aims to provide an overview of the key findings from the survey exploring men's experiences of breast cancer.

Appearance concerns

There was considerable contrast in how men experienced and managed the impact of change to their appearance due to cancer treatment. Whilst some participants embraced their mastectomy scars as a sign of beating the disease, a large number of men were self-conscious and struggled with their changed appearance. Others reported finding the side-effects of treatment such as weight gain and Lymphedema difficult to manage and a large number of participants struggled with the side-effects of the hormone therapy, Tamoxifen.

Information needs

Participants talked about the need for readily available, gender specific information about breast cancer in men. They suggested this could be achieved with simple, inexpensive changes such as removing words specifically related to female bodies and providing images of men.

Related to this is the need for more research to be conducted on men with breast cancer. A large number of men expressed their concerns about hormone treatments they were receiving and the lack of clinical trials conducted on men.

Some participants also felt the clinical setting is currently too focused on female patients. They suggested the environment could be more welcoming to men as well as staff needing to be more aware and inclusive of male patients.

Sources of support

Whilst emotional and support was most frequently received from family and friends, a large number of men experienced considerable emotional and social isolation. Although some men received excellent support from charities and healthcare professionals, in general, participants felt there was there was a lack of support and some men described being denied access to breast cancer support groups as they were male. This was frequently contrasted with the amount of professional and peer support provided for women with breast cancer. Lack of support, social isolation and subsequent unmet needs was a source of concern for a large number of participants.

Finally, a few men found meaning and purpose from their breast cancer experience and used their personal experiences and altered appearance to become a Male Breast Cancer advocate, to help educate others and raise awareness of the disease.

How have the results been used and what is next?

This study has provided a valuable insight to a broad range of social, healthcare, support systems and concerns facing men with breast cancer. To date, the results have been presented at The Male Breast Cancer Conference (August 2020). Due to the current Covid-19 pandemic this was hosted online and can be seen here: https://malebreastcancercoalition.org/mbcc-2020-conference-kc/ I also aim to present the study at future conferences. The research is currently in the process of being submitted for publication in academic journals.

What do you think – any comments?

Thank you once again for your support in helping to recruit participants for this research study, I very much appreciate your time. I hope this summary provides you with brief details about the study which you may find interesting. If you have any comments or would like any further details about the study, please do not hesitate to contact me. As the research is ongoing, your feedback may be incorporated in subsequent studies and is greatly appreciated. Once again, my email is beth2.herring@uwe.ac.uk

With best wishes,

Beth Herring

Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring

PhD researcher

Centre for Appearance Research

University of the West of England

Study 1 Feedback letter to participants

Centre for Appearance Research
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
United Kingdom
https://www.uwe.ac.uk/research/centres-and-groups/appearance

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What do you think – any comments?

Thank you once again for participating in this research, I very much appreciate your time. I would like to reiterate that all responses are treated anonymously, and I hope this summary provides you with brief details about the study which you may find interesting. If you have any comments or would like any further details about the study, please do not hesitate to contact me. As the research is ongoing, your feedback may be incorporated in subsequent studies and is greatly appreciated.

Finally, the information you have shared has been fundamental in guiding the next stage of the PhD. If you would be interested in receiving information about future studies, I would very much like to hear from you. Once again, my email is beth2.herring@uwe.ac.uk

With best wishes,

Beth Herring

Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring

PhD researcher

Centre for Appearance Research

University of the West of England

Instagram feedback post for study 1

Men get breast cancer too!

Very little research has examined psychosocial aspects of male breast cancer, including the

impact of treatment on body image and appearance-related issues.

CAR’s PhD researcher @BethCHerring has recently conducted an online study, 87 men from 9 countries participated. Preliminary results found there was a wide variety in their experiences and concerns; whilst some men had a positive experience of treatment and care, others received very little information and a poor standard of care and support.

Greater awareness and more research is needed to better understand the needs and concerns of men with breast cancer.

APPENDIX 11 - Study 2 interview schedule

Introductory questions

Introduce the study: This study is exploring the experiences and support needs of people (for example wives, partners, family members or friends) who are supporting, or have supported, a man who has been diagnosed with breast cancer. I hope to gain a clearer, more complete understanding of the impact of male breast cancer.

- Please can I check you understand that the interview is being recorded?
- I also want to confirm you understand your right to terminate the interview at any time and if you wish to withdraw, email myself or my supervisor, Diana Harcourt, up to four weeks following this interview, you do not need to give a reason.
- Are you OK to begin?

Start –

What is the relationship between you and the breast cancer patient you care for? If married – how long have they been married to xx/if friends, how long have they known xxx.

(e.g. when did xxx receive his diagnosis for MBC? What has it been like since xxx received his diagnosis for breast cancer)

I'd like to talk about your role supporting xxx:

How do you support xxx? [What does your role consist of?]

Do you think that your caring role has changed over time? How was it when xx was first diagnosed, did he have surgery? How was it after that? During treatment?

How has xxx's diagnosis impacted you? How has it changed your life? What's different? What has it been like emotionally for you? What aspects of your life has been affected?

What do you find the hardest? What have been the biggest challenges?

Is there an element of caring that you find rewarding?

Do you think you've picked up new skills?

Now I'd like you to think about what has the effect of caregiving has been?

If not raised above - How has the diagnosis impacted you? How has it changed your life? What's different? What has it been like emotionally for you? What aspects of your life have been affected?

Do you think you have changed as a person? How do you think you may have changed?
What about the effect on your relationship with the person you care for? Has it changed? If so, how has it changed?

How would you describe the impact of male breast cancer on you/your relationship?

Do you discuss your concerns with your husband/partner/family member/friend you care for? If yes, how was that/if not, why not?
How about other relationships with friends and family? Have these changed? If so, how?

I'd now like you to think about the support you have received:

Do/did you receive any support?
What type of support did you receive?
When was this? Who recommended the support? How was it for you?
(This may be formal or structured support form HPs or organisations. If not – why not? If they didn't, follow up to find our why – was it not available/offered, did they not want to ask for it? Did they feel the focus should be on the man etc)?
What do you feel makes it easier for you to provide care/support for xxx?
What makes it harder to provide care for xxx?
Do you feel that your support needs changed over time? How have they changed? I.e. what was it like when he was first diagnosed? During treatment? How is it now? How has all this made you feel? What has it all been like for you?

What support do you feel would help you now/throughout this experience? Probe re specific types of support, e.g., practical, emotional.
Or, if you don't feel you need support, how do you think other carers might want/need help with?
How do you feel other members of the family gave been impacted (e.g., children) and whether they might benefit from support?

Are you in touch with anyone else (e.g. any wives/partners/friends/informal carers) of men with breast cancer (i.e., if the men don't know other men with BC, do their carers know other carers who are in their situation or are they feeling isolating too?) If yes, how? What support do they provide each other? Does this help? How does this help?
If no, how does this make them feel? Would they like to be in touch with other people in a similar situation?
What sort of support system would you like? What would your thoughts be about:
- attending a group session/online chat/Zoom meeting for carers of men with breast cancer?
- ask about their preferred structure and facilitators e.g., structured (specific topics addressed in each session) or unstructured (free for all to just talk), ; ran by a peer (a fellow carer) or different HCPs (e.g., a psychologist)

What are your hopes for future support for carers of men with breast cancer?

To finish

Can you identify any positives as a result of either male breast cancer or your experiences providing care and support for xxxx? *End on a positive.*

Is there something that I have not asked that you think I should know to better understand your experience as carer for a man with breast cancer?

Do you have any questions for me?

'I think that's basically everything I had to ask you to talk about, do you have anything else you'd like to say or any final thoughts or any thing you'd like to follow up that I haven't asked you?'

Should find talking about your experiences today upsetting and feel you need more support, please remember the charities Breast cancer now, Macmillan and Carers UK who provide information, practical and emotional support to people caring for those with cancer.

Thank you very much for taking part today and for sharing your experiences. Your time is very much appreciated.

General conversation to end the interview such as asking participants what they had planned for the rest of the day.

APPENDIX 12 - Study 2 Social media recruitment posts

*The image was used in the social media posts. Permission to use image was granted from photographer for use in social media posts and to include in thesis appendices.

Instagram

Male breast cancer study - participants needed!

PhD researcher Beth Herring is conducting new research to better understand the experiences of wives, partners, family members and friends who currently support and care for men with breast cancer or have provided support and care in the past. She is inviting them to take part in a telephone or online interview.

If you are interested, please contact Beth Herring (beth2.herring@uwe.ac.uk) or follow the below link for more information:
https://go.uwe.ac.uk/malebreastcancercarers
Thank you for your time and support

#MaleBreastCancer#MaleBreastCancerAwareness #CancerResearch
#MenWithCancer#MensHealth#MenHaveBreastsToo

Alt-text
Image shows a white middle-aged man looking into the camera. His is not wearing a shirt and has a mastectomy scar on the right-hand side of his chest.

Twitter

Men with breast cancer are often cared for by those close to them. There is minimal research exploring their experiences. CAR's PhD researcher @BethCHerring is interviewing carers of men with breast cancer: https://go.uwe.ac.uk/malebreastcancercarers

#MaleBreastCancer #CancerResearch#MensHealth

Alt-text
Image shows a white middle-aged man looking into the camera. He has not wearing a shirt and has a mastectomy scar on the right-hand side of his chest.

Facebook

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Thank you for your time and support

#MaleBreastCancer#MaleBreastCancerAwareness #CancerResearch #MenWithCancer#MensHealth#MenHaveBreastsToo

Alt-text
Image shows a white middle-aged man looking into the camera. He is not wearing a shirt and has a mastectomy scar on the right-hand side of his chest.

Appendix 13 - Study 2 Recruitment letter to charities who had supported recruitment for study 1

Centre for Appearance Research

UWE Bristol University of the West of England

Dear xxx,

I hope you are well.

You may remember **XXXXX [add charity name]** your charity kindly helped with participant recruitment for a study conducted last year as part of my PhD into the experiences of men with breast cancer. Your help and support was invaluable, thank you. I am writing to ask if you would kindly help promote the next study in my PhD.

In order to gain a broader understanding of the impact of male breast cancer, I am now undertaking a study to:

Explore the experiences and support needs of people such as wives, partners, family members or friends who support, or have supported, a man who has been diagnosed with breast cancer.

I have ethics approval for this study from the Faculty of Health & Applied Science Research Ethics Committee at UWE, Bristol.

I am currently recruiting men or women, over 18 years of age, who support, or have supported, a man with breast cancer to take part in an interview (either via telephone or Microsoft Teams). This study aims to better understand the experiences of caring for a man with breast cancer and the impact on their lives and relationships. It will also explore the practical and emotional aspects of caring and identify the types of support that would be helpful, along with preferred sources of support.

Together with the findings from the first study, this research aims to provide a more holistic understanding of the psychosocial impact of breast cancer in men. I will of course feedback the findings of the study to your organisation and I aim to publish the results in peer reviewed journals and present the findings at conferences. I hope ultimately, the research will help improve the lives of men with breast cancer.

Your help promoting my previous study was invaluable and I would greatly appreciate it if you would be able to support recruitment once again, in whatever way would suit you and your organization best. I would be very pleased to discuss this with you. I have attached some possible wording for social media posts if you are able to help promote the study, and of course, please feel free to amend if you prefer.

Please do not hesitate to contact me should you want any further information about this study or any aspect of my PhD research.

Best wishes,

Beth

Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring
PhD researcher

Centre for Appearance Research

University of the West of England

Recruitment letter to participants from study 1 who requested to hear about future research. Letter includes study details to share with potential participants.

Centre for Appearance Research
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
United Kingdom
www.uwe.ac.uk/car

Dear name,

I hope you are keeping well. You may remember that you took part in an on-line survey last year exploring men's experiences after diagnosis and treatment for male breast cancer. Your participation and shared experiences were invaluable in this study.

I am writing following your interest in hearing about further research that I am conducting, and to ask if you are willing to be of further assistance. In order to gain a broader understanding of the impact of male breast cancer, I am now undertaking a study that will explore:

The experiences and support needs of people (for example wives, partners, family members or friends) who are supporting, or have supported, a man who has been diagnosed with breast cancer.

I am currently in the process of recruiting men or women, over 18 years old, to take part in an interview. I would be very grateful if you could please pass on details of this study to anyone who has provided you with emotional and/or practical support since you received a diagnosis of breast cancer. You can do this by forwarding them this link to the study:

https://go.uwe.ac.uk/malebreastcancercarers

The link will take them to an information page that explains the study in detail, a consent form (which must be completed if they decide to take part) and a brief demographics questionnaire. The demographic information enables us to understand the sorts of people who have taken part in the study and will be used in our analysis, nor to identify individuals.

The study aims to better understand the experiences of caring for a man with breast cancer and the impact on their lives and relationships. It will also explore the practical and emotional aspects of caring and identify the types of support that would be helpful, along with preferred sources of support. Together with the previous study, the research aims to provide a broader understanding of breast cancer in men.

It is estimated that the interview will last approximately 45 minutes to an hour and will take place either over Microsoft Teams or the telephone, whichever they prefer. All information will be treated as confidential, participants will create a pseudonym (a false name), all names will be changed so that no one will be identified in any outputs from this research and no information from previous studies will be shared with the interviewees.

Please be reassured that whoever you pass this information onto, that they do not need to take part, but if they do, I would be very grateful. Furthermore, if you or they have any queries, would like any further information about the research, please do not hesitate to contact me on beth2.herring@uwe.ac.uk

I very much appreciate your help and support in forwarding this information to anyone that you feel may wish to participate, in order to help us better understand the experiences and potential support needs of informal carers of men with breast cancer.

Many thanks and best wishes,

Beth Herring

Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring

PhD researcher

Centre for Appearance Research

University of the West of England

Appendix 14 - Study 2 Online study information, participant consent and demographic data collection

Exploring the psychosocial support needs of informal carers of men with breast cancer

You are being invited to take part in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being carried out and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like further information.

What is the purpose of the study?

The purpose of the study is to explore the experiences and support needs of people (wives, partners, family members, friends) who support, or have supported, a man who has been diagnosed with breast cancer. We are interested in hearing about your experiences of caring and supporting a man with breast cancer and the support you received. We would like to hear about areas of support you feel were good, and those you think are lacking for both yourself and/or the person you care for. We would also like to hear about how you have managed the illness with your partner, relative or friend and the impact this might have had on your life.

Who is carrying out the research?

This study is being carried out by Beth Herring, a PhD researcher based at the Centre for Appearance Research at the University of the West of England, Bristol . The PhD is being supervised by Professor Diana Harcourt.

Who can take part in this research?

Men and women, aged 18 years and older who support, or have supported, a man who has received a diagnosis for breast cancer.

What will participation involve and how long will it take?

Participation will include being interviewed by the researcher, Beth Herring. You can choose whether to have the interview via the online platform, Microsoft Teams, or over the telephone. It is estimated the interview will last approximately one hour. As the interview is confidential, we ask that nobody else, including the patient, can overhear what you say.

Beth will ask about your experience of supporting and caring for a man with breast cancer, and what support, if any, was available to you, and your views on that, and what you feel would benefit men with breast cancer and their carers.

The interview will be audio recorded, and Beth will then type up the recording. Data will be securely stored for 3 years following completion of the PhD. Once this period has lapsed all electronic copies of the data will be deleted, and any hard copies will be disposed of in confidential waste.

What about confidentiality?

The information you provide will be treated with the highest level of confidentiality. You will be asked to choose a unique pseudonym (a false name) and your name and identity will never be connected to your responses. Information that would make it possible to identify you or anyone else will never be shared with anyone other then the interviewer (Beth Herring) and her supervisor (Professor Diana Harcourt). You will not be identified in any outputs from this research. You have the opportunity to provide your email details should you wish to be informed of the study findings and future research. Your email address will be kept separately from your interview data to ensure that your anonymity is protected. Your data may be published in academic journals or presented at conferences, and whilst your direct quotes might be used, you will not be identified.

How will the interview work?

Your participation in this research is entirely voluntary and you have the right to answer as many or as few questions as you wish during the interview. However, the more questions you answer, the more helpful this will be. You have the right to stop the interview at any time without giving reason.

You also have the right to withdraw from the study up to four weeks after you have completed the survey. Should you wish to withdraw you will need to inform the researcher by email (beth2.herring@uwe.ac.uk) quoting your chosen pseudonym (false name). This will enable us to identify all the material that needs to be deleted following your withdrawal from the project.

What are the potential disadvantages and risks of taking part?

We understand that this may be a sensitive topic, however we do not expect that participating in this study will have any detrimental effects on you. However, some participants may find talking about their experiences upsetting. If you do become distressed, the interviewer will check you are ok and ask if you wish to continue. You will also be given the option to terminate the interview and continue another day, or if you prefer, to withdraw from the study.

Confidentiality will be maintained at all times, except in the unlikely event, that you disclose potential intent to harm either yourself or others, If this occurs the interviewer will have to share this information with her supervisor, Professor Diana Harcourt. You will be informed if confidentiality has to be broken.

It is entirely your choice as to what you want to share with the researcher during the interview. We would also like to reassure you that there are no right or wrong answers, and no judgements will be made on the basis of the answers that you provide.

What are the potential benefits of taking part?

Although we cannot promise that this study will help you personally, we hope that having the opportunity to share your opinions and experiences will be a positive experience. Your participation will contribute towards a greater understanding of the needs of those who provide care and support for men with breast cancer. We will share the findings with health professionals, with the aim of increasing awareness and understanding of male breast cancer, so that care and support for all those impacted by the disease might be improved in the future.

What will happen to the results of this study?

The results of this study will be published in academic journals or presented at conferences. However, you will not be identified in any outputs from the research. We will also provide feedback to all those participants who request this option, so that you will be informed of the study findings.

Who has reviewed this study?

This study has been reviewed and approved by the University of the West of England Research Ethics Committee.

Please take a moment to read below how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in this study [*The UWE Privacy Notice for Research Participants is displayed*].

If you have any questions about this study at any stage, please do not hesitate to contact beth2.herring@uwe.ac.uk or Diana2.Harcourt@uwe.ac.uk.

What do I do if I want to take part?

If you would like to take part, please read and complete the consent form below. You will then be asked to provide a unique pseudonym (false name) and asked a few questions about yourself. This enables us to understand the sorts of people who have taken part in the study. There are a few demographic questions which we will use in our analysis, not to identify individuals. Please remember that all you answers are anonymous. Finally, you will be asked to provide your contact details for the researcher to arrange a time which suits you to carry out the interview.

If you have any questions at any stage, please contact Beth Herring (PhD researcher): beth2.herring@uwe.ac.uk or Professor Diana Harcourt (Primary Supervisor): Diana2.Harcourt@uwe.ac.uk For further information and support about caring for someone with cancer:

The UK cancer charities Breast Cancer Now and Macmillan provide information, practical and emotional support to those caring for someone with cancer. Please visit: https://www.breastcancernow.org/information-support/facing-breast-cancer/how-support-someone-breast-cancer or https://www. macmillan.org.uk/cancer-information-and-support/supporting-someone/emotional-support-for-carersAlso, the charity, Carers UK, provides help and advice in caring and a support network for carers across the UK. Please visit: https://www.carersuk.org. If you have any concerns, these charities may be able to advise and help you.

Thank you for taking the time to read this information sheet. If you would like to continue, please read and complete the consent form.

STATEMENT OF CONSENT

Before you take part in the interview, we would like to make sure that you have understood the information we have given so far.

In order to take part in the interview you are agreeing to the following:

- I understand that by consenting to take part in this study I am still able to withdraw without having to give any reasons
- I understand that I can ask questions about the study after I have completed the interview
- I understand that I will never be personally identified in any report or write up that stems from this research
- I understand that my name will be replaced by a unique pseudonym (false name) so that all the data can remain confidential
- I consent to data gathered from this study being used in publications, other forums, and future research
- I confirm I am 18 years old or over
- I consent to the interview being audio recorded

I have read and agree to the above statements and I am happy to take part.

○ Yes

○ No

Thank you for choosing to take part in this study titled 'Exploring the psychosocial support needs of informal carers of men with breast cancer'

Please enter your first name in the box below

____

Give yourself a pseudonym (a false name) Please enter your pseudonym in the box below

____

Should you wish to withdraw, you will need to inform us by email (beth2.herring@uwe.ac.uk), quoting your first name and pseudonym. This will enable us to identify all the material that needs to be deleted due to your withdrawal from the project.

Please provide your email address or telephone number in the box below so the researcher can contact you:

____

You will now be asked a few questions about yourself. We really need to know the sorts of people who have taken part in this research. These responses will be used in our analysis, not to identify individuals.

Please remember that all of your answers are anonymous.

How old are you (years)?

____

How would you describe your ethnic group? Please click one of the following:

○ White

○ Multiple ethnic group

○ Asian/Asian British

○ Black/African Caribbean/Black British

○ Other, please specify ____

○ Prefer not to say

What is your relationship status?

○ Single

○ Married/Civil partnership

○ In a relationship but not married or in a civil partnership

○ Divorced

○ Seperated

○ Widowed

○ Other, please state ____

○ Prefer not to say

Which of the following options best describes how you think of yourself?

○ Heterosexual or straight

○ Gay

○ Bisexual

○ Other, please state____

○ Prefer not to say

What is your employment situation?

○ Employed

○ Self-employed

○ Retired

○ Other, please state ____

What is your relationship to the man with breast cancer you provide help and support to?

____

Where did you hear about this study?

☐ From the male breast cancer patient I help and support

☐ Word of mouth

☐ Social media

☐ Support group

☐ Other, please specify ____

If you would like to receive a summary of the results of this study, or to hear about future research that we may be conducting on this topic, please add your email address below.

Please note that your email address will only be used for contacting you regarding the study results or future related research. We will ensure that your email address will be kept separately from your responses in any data analysis to ensure confidentiality.

☐ I am happy being contacted about future research in this area. Please provide your email address ____

☐ I would like to receive a copy of the results. Please provide your email address ____

Thank you for taking the time to read and complete this information sheet and consent form, I will be in touch shortly. I very much look forward to talking to you.

Appendix 15 - Study 2 Follow-up email to participants post interview

Dear X,

Thank you very much for sparing your time recently to help with my research into the experiences of informal carers of men with breast cancer. The information you kindly shared was very helpful, interesting and insightful. I hope that by better understanding informal carers' experiences and any support needs they might have, we will be ale to inform the support available in the future.

As previously discussed, I will be in touch with more detailed results of the study in due course. However, in the meantime, if you have any queries or would like further information about the study, please do not hesitate to contact me via email, beth2.herring@uwe.ac.uk

Sometimes discussing experiences, especially around sensitive issues, can be emotional. Should you need to talk to someone about any aspect of the issues explored in this research, please do not hesitate to contact either myself, or if you feel you need additional support, the UK cancer charities Breast Cancer Now and Macmillan provide information, practical and emotional support to those caring for someone with cancer:

https://breastcancernow.org/information-support/facing-breast-cancer/how-support-someone-breast-cancer

https://www.macmillan.org.uk/cancer-information-and-support/supporting-someone/emotional-support-for-carers

Also, the charity, Carers UK, provides help and advice on caring and a support network for carers across the UK: https://www.carersuk.org/. If you have any concerns, these charities may be able to advise and help you.

Thank you once again for taking the time to participate in this research, I very much appreciate your time.

Best wishes,

Beth

Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring

PhD researcher

Centre for Appearance Research

University of the West of England

Appendix 16 – Study 2 extract of reflective memo

22.03.21

I have now completed three interviews of informal carers of men with breast cancer and felt this would be an interesting time to reflect about my experiences to date and what I have learned so far from conducting these interviews. I have been surprised at the disparity in people who have taken part and those I have in the diary to interview in the coming week, ranging from wives, widows, mothers and daughters of men with breast cancer.

What has been apparent is that all of those I have spoken to have had no-one to talk to. Taking part in this interview seems like a flood gate opening for them and they just want to talk and talk and talk and off load what they have been dealing with, often for many years. I find myself having to constantly steer the conversation back to the topic of caring as they seem to want to talk about every aspect of how BCiM has impacted and pervaded every aspect of their lives. I am of course eager to hear everything, but I am also mindful that the interview needs to stay focused. However, I feel my skills as an interviewer are developing as I learn more from each interview and am learning skills such as how to guide the conversation back on course.

Whilst I had previously thought that informal carers would be isolated and coping very much on their own, however, I had not fully understood the extent of isolation, the impact of the illness and the lack of support on their lives and those around them. I am awestruck by their strength and selflessness. They put everyone’s needs before their own, they are living in a state of uncertainty and are often scared about what the future may hold.

I have interviewed two participants who have lost loved ones to breast cancer, one widow and one daughter, and the devastation some 12 years is still very raw. For the daughter the impact of being a young carer for her brother at the age of 11 and losing her Dad has affected many aspects of her life and continues into adulthood. For both, I was struck by the clarity of how they remembered events and how the feelings were still very painful. For one woman whose husband had died from breast cancer 12 years ago and she has since met a new partner, I was touched by how she kept his memory alive by having an anniversary dinner, talking about him to her children and family and having photographs of him around the house, and how her new partner supported her in this.

04.05.21

I am aware of the impact on participants taking part in the study and how powerful the conversations have been. None of the participants I have spoken to so far have ever spoken to anyone about their experiences caring for a man with breast cancer. I have had a number of participants who have said they have found our conversation to be like therapy and how they have enjoyed talking and that taking part has been a powerful experience. For one participant (Becksbud), she found how our conversation has bought to the forefront that this should be a conversation she should be having with the man with bc she helps to support.

I was taken aback with the honesty of ‘Becksbud’ – I had presumed before I conducted the interview that it would be along the lines of what she had done to support her friend, and I found I was shocked and surprised with her honesty about how she had struggled to provide support and how she felt she had failed her friend. This has taught me the importance not to go into a situation with preconceived ideas.

Appendix 17 – Study 2 Feedback letter to stakeholders

Centre for Appearance Research
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
United Kingdom
https://www.uwe.ac.uk/research/centres-and-groups/appearance

The Experiences and Psychosocial Support Needs of Informal Carers (Wives, Husbands, Partners, Family Members or Friends) of Men with Breast Cancer

Why was the research conducted?

The research study, for which you kindly helped recruit participants, was the second in a series of studies for a PhD in male breast cancer. There has been no research conducted to date which specifically explores the experiences of informal carers of men with breast cancer in the UK. Subsequently, this study aimed to gain a better understanding of the impact of the disease on those providing care and identify areas where carers may need support. Research is needed to clarify the extent and type of these needs, and the findings will help guide the rest of this PhD. Ultimately, my research aims to help improve support for people whose lives are impacted by male breast cancer.

There were two main aims of the study:

- To gain a better understanding of the experiences of informal carers and the impact male breast cancer has on their lives and relationships.

- To gather information on existing support and support needs that are not currently being met.

What did I do?

Twelve participants took part in semi-structured interviews and thematic analysis was conducted on the data using NVivo software.

What did I find?

This summary aims to provide an overview of the key findings from the interviews exploring the experiences of carers of men with breast cancer:

The impact of caring

Caring for a man with breast cancer impacted many aspects of carers lives. Participants gave clear examples of practical and emotional support that they provide and described how they often bear the pressures and responsibilities of caring and support for the physical and emotional wellbeing of the patient. They frequently portrayed themselves as a 'gate-keeper' to medical appointments, healthcare providers and professionals. They often felt they had to be strong, positive and to try to maintain normality and a sense of life carrying on as normal, especially when children were involved. The ripple effect of the disease on their relationship, social life, family, and finances was frequently reported. For some, the physical and psychological effects of caring had a negative impact on their own health.

Unmet needs of informal carers and male breast cancer patients

Unsurprisingly, most of the participants spoke of their shock reaction to the diagnosis. Most had never heard of breast cancer in men and reactions included disbelief and distress which led to difficulties accepting the illness.

Carers found it difficult to access information about male breast cancer. Available literature portrayed the illness as a female disease, were written for women and did not represent men. Materials included non-relevant information such as menstrual cycles, suggested 'wearing a blouse and skirt to the mammogram appointment' and diagrams of female breasts. This often resulted in carers feeling uncertain about how the illness impacts men and affected how they should best support the patient. Participants expressed how the patient often felt excluded within the hospital setting and voiced disparities between female and male breast cancer care and support. There was also concern at the lack of research in male breast cancer and subsequent mistrust and uncertainty of medical decisions and treatment, particularly Tamoxifen. A large number raised concerns about adverse side-effects, sometimes long-term, associated with the drug.

Isolation

The vast majority of participants were not offered formal support and often expressed feeling isolated. One participant was offered formal support at the palliative care stage. Social lives and relationships outside the house were often impacted as carers had less time to spend with other family members and friends, which also led to isolation and loneliness. Participants described how the support of friends and family, although initially present, often dwindled and they were left as the sole carer. As a result of isolation, many carers did not know about their rights, benefits or services they may be entitled to.

Participants talked about the impact of COVID which necessitated a number of cancer patients to shield and government restrictions preventing households meeting. Due to these protective measures, many carers were unable to see their family and friends and faced distinctive challenges which they felt compounded isolation.

Advocate for MBC

Many carers were shocked at the lack of awareness of male breast cancer and took action to educate others and to raise the profile of the disease. For example, they challenged the discriminatory provision of care of male and female breast cancer patients by an insurance company, held meetings with the director of hospitals, were vocal on radio shows which discussed breast cancer but did not include men and set up a male breast cancer campaign to raise awareness. Participants spoke passionately about the need to raise awareness of the illness in men, to share their story, educate others and to improve the support for future patients and their carers.

Implications for future support

There is an opportunity for breast cancer organisations and charities to help provide care and support to the informal carers of men with breast cancer. Potential avenues of support could include:

- Helping raise general public awareness of breast cancer in men and the impact on their carers;
- Including men in breast cancer information booklets and using more inclusive language and/or gender-neutral terms and include pictures of male mastectomy;
- Providing an online peer support group or forum dedicated to the informal carers of men with breast cancer which would create a safe space for carers to provide each other with emotional support and practical tips for caring, sharing information and advice on medical and treatment experiences.

Together, these could foster a sense of community, improve confidence, increase ability to cope, and help learn how best to support and provide care for the patient.

How have the results been used and what is next?

This study has provided a valuable insight to a broad range of concerns facing the informal carers of men with breast cancer. The results of the study were presented at The Male Breast Cancer Conference (August 2021), this is the largest, non-profit male breast cancer awareness organisation based in America, which aims to raise awareness of male breast cancer worldwide. Due to the current Covid-19 pandemic this was hosted online and can be seen here: https://malebreastcancercoalition.org/mbcc-conference-2021/. The study will also be presented at future conferences aimed at audiences of health care professionals and researchers. The study is currently in the process of being submitted for publication in academic journals. The findings will also be fed back to the participants who took part in the study.

What do you think – any comments?

Thank you once again for your support in helping to recruit participants for this research, I very much appreciate your time. I hope this summary provides you with brief details about the study which you may find interesting. If you have any comments or would like any further details about the study, please do not hesitate to contact me. As the research is ongoing, your feedback may be incorporated in subsequent studies and is greatly appreciated. Once again, my email is beth2.herring@uwe.ac.uk

With best wishes,

Beth Herring
3rd September 2021
Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring
PhD researcher

Centre for Appearance Research

University of the West of England

Study 2 Feedback letter to participants

Centre for Appearance Research

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https://www.uwe.ac.uk/research/centres-and-groups/appearance

The Experiences and Psychosocial Support Needs of Informal Carers (Wives, Husbands, Partners, Family Members or Friends) of Men with Breast Cancer

Why was the research conducted?

The research study for which you kindly helped, was the second in a series of studies for a PhD in male breast cancer. There has been no research conducted to date which specifically explores the experiences of informal carers of men with breast cancer in the UK. Subsequently, this study aimed to gain a better understanding of the impact of the disease on those providing care and identify areas where carers may need support. Research is needed to clarify the extent and type of these needs and the findings will help guide the next studies in this PhD. Ultimately, the research aims to help improve the future provision of support for those caring for men with breast cancer.

There were two main aims of the study:

- To gain a better understanding of the experiences of informal carers and the impact male breast cancer has on their lives and relationships.

- To gather information on existing support and support needs that are not currently being met.

What did I do?

Twelve informal carers took part in semi-structured interviews, this is considered an acceptable number of participants for exploratory research into a topic like this which has not been researched before. The interview recordings were typed up verbatim by the researcher and any information that could identify participants was removed. Thematic analysis was conducted on the data using NVivo software.

What did I find?

This summary aims to provide an overview of the key findings from the interviews exploring the experiences of carers of men with breast cancer.

The impact of caring

Caring for a man with breast cancer impacted many aspects of carers' lives. Participants gave clear examples of practical and emotional support that they provide and described how they bear the pressures and responsibilities of caring and support for the physical and emotional wellbeing of the man they are helping. They often portrayed themselves as a 'gate-keeper' to medical appointments, healthcare providers and professionals. They often felt they had to be strong, positive and to try to maintain normality and a sense of life carrying on as normal, especially when children were involved. The ripple effect of the disease on their relationship, social life, family, and finances was frequently reported. For some, the physical and psychological effects of caring had a negative impact on their own health.

Unmet needs of informal carers and male breast cancer patients

Unsurprisingly, most of the participants spoke of their shock reaction to the diagnosis. Most had never heard of breast cancer in men and reactions included disbelief and distress which led to difficulties accepting the illness.

Carers found it difficult to access information about male breast cancer. Available literature portrayed the illness as a female disease, were written for women and did not represent men. Materials included non-relevant information such as menstrual cycles, suggested 'wearing a blouse and skirt to the mammogram appointment' and diagrams of female breasts. This often resulted in carers feeling uncertain about how the illness impacts men and affected how they should best provide support. Participants expressed how the patient often felt excluded within the hospital setting and voiced disparities between female and male breast cancer care and support. There was also concern at the lack of research in male breast cancer and subsequent mistrust and uncertainty of medical decisions and treatment. In particular, many were extremely concerned about the medical treatment prescribed for men, particularly, the hormone therapy Tamoxifen. They were worried about men being prescribed a female hormone drug as well as the changing parameters of how long it was prescribed. A large number raised concerns about the adverse side-effects, sometimes long-term, which posed significant challenges to the quality of life and well-being of patients.

Isolation

The vast majority of participants were not offered formal support and often expressed feeling isolated. Two participants were offered formal support at the palliative care stage. Social lives and relationships outside the house were often impacted as carers had less time to spend with other family members and friends, which also led to isolation and loneliness. Participants described how the support of friends and family, although initially present, often dwindled and they were left as the sole carer. As a result of isolation, many carers did not know about their rights, or the benefits and services they may be entitled to.

Participants talked about the impact of COVID which necessitated a number of cancer patients to shield (staying at home at all times) and government restrictions which prevented households meeting. Due to these protective measures, many carers were unable to see their family and friends and faced distinctive challenges which they felt compounded isolation.

Advocate for MBC and implications for future support

Many carers were shocked at the lack of awareness of male breast cancer and took action to educate others and to raise the profile of the disease. For example, they challenged the discriminatory provision of care of male and female breast cancer patients by an insurance company, held meetings with the director of hospitals, were vocal on radio shows which discussed breast cancer but failed to mention men and set up a male breast cancer campaign to raise awareness. Participants spoke passionately about the need to raise awareness of the disease in men, to share their story, educate others and to improve the support for future patients and their carers.

Participants felt strongly that they needed more support. Perceived benefits included: emotional support and practical tips for caring, sharing information and advice on medical and treatment experiences, managing side-effects and sharing information on the advice and support available. Participants expressed how a support group may foster a sense of community, improve confidence, increase ability to cope, and help learn how best to support and provide care for the patient. In turn, it was recognised how support for carers would not only benefit themselves but ultimately the man they were caring for.

Participants suggested several methods of support including online forums and Facebook support groups, specifically for the informal carers of men with breast cancer. Some had experience of using such support groups in the past for other issues and had found them useful platforms. They particularly found the anonymity of online forums and the ability to access and read other people's posts to be beneficial. Furthermore, they found online groups fostered the sense of a community. Most felt an online peer support group, would be the most beneficial method to support their needs. There was a general consensus that due to the rarity of the illness in men, an in-person group meeting would not be feasible, sand most participants said they felt comfortable with platforms such as Microsoft Teams and Zoom following their use during the COVID-19 pandemic.

How have the results been used and what is next?

This study has provided a valuable insight to a broad range of concerns facing the informal carers of men with breast cancer. The results of the study were presented at The Male Breast Cancer Conference (August 2021), this is the largest, non-profit male breast cancer awareness organisation based in America, which aims to raise awareness of male breast cancer worldwide. Due to the current Covid-19 pandemic this was hosted online and can be seen here: https://malebreastcancercoalition.org/mbcc-conference-2021/. The study will also be presented at future conferences aimed at audiences of health care professionals and researchers. A paper on this research is currently being prepared for submission to academic journals. The findings will also be fed back to the healthcare professionals and charities who provided their support for the study.

What do you think – any comments?

Thank you once again for participating in this research, I very much appreciate your time and hope this summary provides you with brief details about the study which you may find interesting. I would like to reiterate that all responses are treated anonymously. If you have any comments or would like any further details about the study, please do not hesitate to contact me. As the research is ongoing, your feedback may be incorporated in subsequent studies and is greatly appreciated.

Finally, the information you have shared has been fundamental in guiding the next stage of the PhD. If you would be interested in receiving information about future studies, I would very much like to hear from you. Once again, my email is beth2.herring@uwe.ac.uk

With best wishes,

Beth Herring

PhD researcher
Centre for Appearance Research
University of the West of England
Contact: Email: beth2.herring@uwe.ac.uk or Twitter: @BethCHerring

Appendix 18 - Study 3 Online survey

Care and support for men with breast cancer and their informal carers (e.g. partners, relatives and friends).

Thank you for your interest in taking part in our study.

Before deciding if you wish to take part, please read the following information carefully.

If anything is unclear, please contact beth2.herring@uwe.ac.uk

Study information

The study aims to explore your experiences, professional views and perceptions of the support needs of men with breast cancer, as well as those of their informal carers. Your views will be explored via an online survey. It is being carried out by Beth Herring, a PhD researcher based at the Centre for Appearance Research at the University of the West of England, Bristol. The PhD is supervised by Professor Diana Harcourt, Dr Helena Lewis-Smith and Dr Nicole Paraskeva. We welcome participation from any UK based healthcare professionals currently, or previously, involved in the treatment, care and support of breast cancer patients and/or their informal carers. This includes, but is not limited to, breast cancer surgeons, breast care nurses, oncology nurses, oncologists, radiologists, general practitioners (GP's), social workers, psychologists and counsellors.

As male breast cancer is rare, we understand that you may have only encountered a few, if any, male breast cancer patients and/or their informal carers. However, we would still appreciate your views.

We anticipate that the survey will take approximately 5 minutes.

Participation is entirely voluntary and you have the right to answer as many or as few questions as you wish. At the end of the survey there will be the opportunity to provide more detail about your experiences and/or to provide suggestions to improve the future care and support of men with breast cancer and their informal carers.

This study has been reviewed and approved by the University of the West of England Research Ethics Committee. All responses will be treated as confidential. Any personal information (e.g. name, email address) will be kept securely and separately from the survey responses. All responses will therefore be anonymous. The results of this study will be incorporated in the researcher's PhD thesis and may be published in academic journals and presented at conferences. You will not be identified in any outputs from the research. Feedback on the findings will be provided to all those participants who request this option. Participation can be stopped at any time. You also have the right to withdraw from the study up to four weeks after you have completed the survey.

Should you wish to withdraw from the study, email (beth2.herring@uwe.ac.uk) quoting your unique participant code which is generated at the beginning of the survey.

Contact information: Email: beth2.herring@uwe.ac.uk

Please click here if you would like to read the privacy notice in its entirety

1. Yes [UWE Privacy notice displayed]
2. No

If you would like to take part, please complete the consent form below.

Consent

Please ensure that you have read and understood the information provided.

If you have any questions, please contact the researcher Beth Herring (beth2.herring@uwe.ac.uk) or Professor Diana Harcourt (diana2.harcourt@uwe.ac.uk).

If you are happy to take part in the online survey, please indicate **yes**

- I have read and understood the information provided before being asked to complete this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the researcher;
- I agree that *anonymised* quotes may be used in the final report of this study (e.g. thesis) or in any subsequent publications;
- I understand that my participation is voluntary and that I am free to withdraw up to four weeks after I have completed the survey;
- I agree to take part in the research

- Yes [Continue]
- No [Skip to end of survey]

Before you proceed to the questionnaire, please complete the captcha below:

[Captcha verification displayed]

Thank you for choosing to take part in this study.
Please first create your participant identification code Your data will be stored anonymously under this code and it will enable the researcher to withdraw your data if you choose to withdraw at a later date. To create your unique participant identification, please enter the first three letters of your mother's maiden name and the date of the month that you were born, in the text box below. For example, if your mother's maiden name is Cooper and you were born on the 10th August you would enter COO10.

____

Should you wish to withdraw, email (beth2.herring@uwe.ac.uk) within four weeks of completing this study, quoting your unique participant code. This will enable us to identify all the material that needs to be deleted.

You will now be asked a few questions about yourself. It is important to know about the people who have taken part in this research. These responses will be used in our analysis, not to identify individuals.

Please remember that all your answers are anonymous.

Which best describes how you think of yourself?

○ Female

○ Male

○ Gender Variant/Non-Conforming

○ Not Listed (please state) ____

○ Prefer Not to Answer

What is your occupation?

☐ Surgeon

☐ Oncologist

☐ General practitioner (GP)

☐ Breast care nurse/clinical nurse specialist

☐ Radiographer

☐ Psychologist

☐ Social worker

☐ Counsellor

☐ Other ____

How long have you been in this profession (years, if less than one year please indicate)?

____

In what setting do you care for or support patients who have been diagnosed with breast cancer? *(Please select* *all* *that apply)*

○ National Health Service (NHS)

○ Private practice

○ NHS and Private practice

○ Other (please specify): ____

Have you ever treated, cared for or provided support to a man with breast cancer?

○ Yes

○ No

Approximately how many men with breast cancer have you supported in your career?

○ 1-5

○ 6-10

○ 11-15

○ 16 plus

In your role, what do you offer men with breast cancer?
Please select all possible responses

☐ Surgical/medical care

☐ Generic breast cancer information (e.g., leaflets, websites not specific to male breast cancer)

☐ Specific male breast cancer information (e.g., leaflets, websites specific to male breast cancer)

☐ Signpost to breast cancer support organisations/charities that are **not specific** to male breast cancer

☐ Signpost to support organisations/charities that are **specific** to male breast cancer (Please specify) ____

☐ Signpost to a **local** support organisation/group/charity

☐ Peer support (contact with other men with breast cancer) (Please specify) ____

☐ Psychological therapies such as Acceptance And Commitment Therapy (ACT), Cognitive Behavioural Therapy (CBT)

☐ Referral to clinical psychologist/counsellor

☐ Complementary therapies

☐ Other (Please specify) ____

☐ None

If you would like to provide any more detail, please use the box below:

____

Does your role involve explaining a <u>diagnosis and/or treatment</u> to men with breast cancer?

○ Yes

○ No

How difficult do you find explaining a <u>diagnosis</u> to a male breast cancer patient when compared to a female breast cancer patient?

○ It is harder to explain to a male breast cancer patient

○ It is easier to explain to a male breast cancer patient

○ It is the same

How difficult do you find explaining <u>treatment</u> to a male breast cancer patient when compared to a female breast cancer patient?

○ It is harder to explain to a male breast cancer patient

○ It is easier to explain to a male breast cancer patient

○ It is the same

Have you received any specific training in providing support for men with breast cancer?

○ Yes (please specify) ____

○ No

Do you think it would be useful to receive specific training in providing support for men with breast cancer?

○ Yes (please specify what training you think would be useful)
____

○ No

Section C. Informal Carers of men with breast cancer

Does your role involve providing support for the informal carers (e.g. wives, husbands, partners, relatives, children, friends) of men with breast cancer?

○ Yes

○ No

○

We understand Covid-19 regulations may have restricted informal carers from accompanying patients to appointments. When answering the questions below, please consider your experiences pre-Covid or when restrictions are/were lifted.

In your role, what do you offer informal carers of men with breast cancer?
Please select all possble responses

☐ Generic breast cancer information (e.g., leaflets, websites **not specific** to male breast cancer)

☐ Specific male breast cancer information (e.g., leaflets, websites **specific** to male breast cancer

☐ Signpost to breast cancer support organisations/charities that are **not specific** to male breast cancer

☐ Signpost to support organisations/charities that are **specific** to male breast cancer (Please specify) ____

☐ Signpost to a **local** support organisation/group/charity

☐ Peer support (contact with other informal carers of men with breast cancer) (Please specify) ____

☐ Psychological therapies such as Acceptance And Commitment Therapy (ACT), Cognitive Behavioural Therapy (CBT)

☐ Referral to clinical psychologist/counsellor

☐ Complementary therapies

☐ Other (Please specify) ____

☐ None

Have you received any specific training on supporting the **informal carers** of men with breast cancer?

○ Yes (please specify) ____

○ No

Do you think it would be useful to receive specific training on supporting the informal carers of men with breast cancer?

○ Yes (please specify what training you think would be useful)
____

○ No

*The following statements are based on recent research conducted with men who have received a diagnosis and/or treatment for breast cancer, as well as their informal carers. Please read each statement and indicate to what extent you **agree or disagree** with each one:*

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Men with breast cancer feel isolated	○	○	○	○	○
There is little public awareness about male breast cancer	○	○	○	○	○
Receiving a diagnosis of breast cancer is a shock to men as they think it is a female disease	○	○	○	○	○
There is not enough information specifically for men with breast cancer	○	○	○	○	○
Men with breast cancer feel less masculine	○	○	○	○	○
Men with breast cancer have concerns about their appearance and body after mastectomy	○	○	○	○	○
There is little support for men with breast cancer	○	○	○	○	○
There is little support for the informal carers of men with breast cancer	○	○	○	○	○

Awareness campaigns portray breast cancer as a female disease	○	○	○	○	○
Men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men	○	○	○	○	○

What do you consider to be the main issues for <u>men</u> who have received a diagnosis of breast cancer?

____

____

____

____

____

What do you consider to be the main issues for the <u>informal carers</u> of men who have received a diagnosis of breast cancer?

____

To what extent do you feel current available resources in the UK meet the needs of:

	Extremely unsuitable	Somewhat unsuitable	Neither suitable nor unsuitable	Suitable	Extremely suitable	Not applicable
Men with breast cancer	○	○	○	○	○	○
Informal carers of men with breast cancer	○	○	○	○	○	○

Please use the text box below if there is anything else you would like to add:

____

____

____

____

____

Are you aware of any resources specifically for men with breast cancer and/or their informal carers?

○ Yes (please specify) ____

○ No

Finally, a number of terms are often used to refer to men with breast cancer. Please indicate what term(s) you use in your professional practice:

☐ Breast cancer

☐ Male breast cancer

☐ Breast cancer in men

☐ Men with breast cancer

☐ Chest cancer

☐ Other (please specify) ____

If you would like to receive a summary of the results of this survey, or to hear about future research that we may be conducting on this topic, please add your email address below.

Please note that your email address will only be used for contacting you regarding the study results or future related research. We will ensure that your email address is kept separately from your responses to ensure confidentiality.

☐ I am happy being contacted about future research in this area. Please provide your email address. ____

☐ I would like to receive a copy of the results. Please provide your email address. ____

Appendix 19 - Study 3 Social media recruitment posts

Instagram

Men get breast cancer, too!🙋‍♀️🙋‍♀️🙋‍♀️

👨Male #breastcancer is a rare cancer that forms in the breast tissue of men. Although breast cancer is most commonly associated with women, it can also occur in men. Approximately 400 men are diagnosed every year in the UK and men tend to be diagnosed between 60-70 years old, although younger men can also be affected.

🔍To date, very little #research has examined psychosocial aspects of male breast cancer and the impact on both patients and those close to them.

📝CAR's PhD researcher Beth Herring recently conducted research with men with breast cancer and their informal carers (wives, husbands, partners, children, friends). Results showed they experienced isolation, lack of awareness, very little gender-specific information, concerns about treatment and a poor standard of support….

❓So, what are the next steps❓

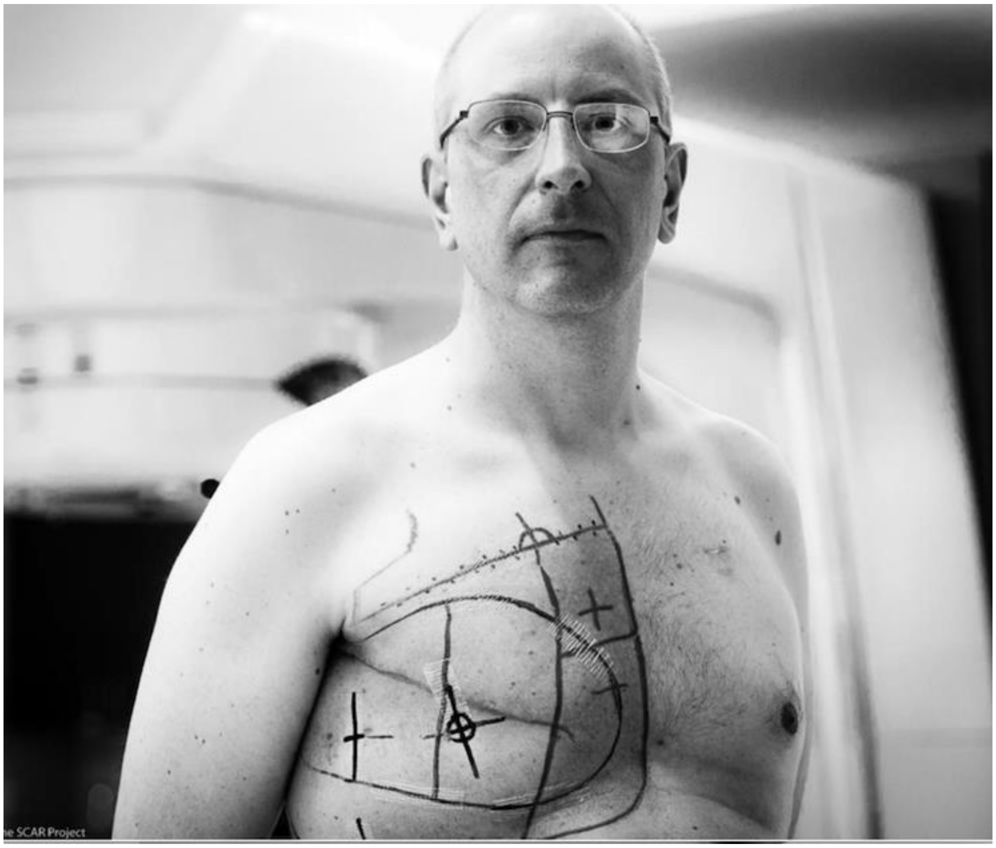
➡️ As greater awareness and more research is needed to better understand the needs and concerns of men with breast cancer and their informal carers, Beth is conducting further research in this field.

She is currently recruiting healthcare professionals and breast cancer support organisations to take part in an online survey to explore their experiences, understanding and perceptions of the support needs of male breast cancer patients and their informal carers.

If you are a healthcare professional or work for a breast cancer support organisation with breast cancer patients based in the UK and would be interested in taking part in this study, please visit *[URL]* or contact **beth2.herring@uwe.ac.uk** to receive further information.

Twitter

CAR’s PhD researcher @BethCHerring is conducting a survey of UK based healthcare professionals and cancer support organisations who work with breast cancer patients and their families to explore their views and experiences: *[URL]*
Please RT.
#MaleBreastCancer#CancerResearch#MensHealth



*The above image was used in the social media posts. Permission to use image was granted from photographer for use in social media posts and to include in thesis appendices.

Facebook

Men get Breast Cancer Too!

There is minimal research with men with breast cancer and those who support them. Greater awareness and more research is needed to understand their experiences and support needs.

CAR's PhD researcher @BethCHerring is currently conducting a short online survey with UK based healthcare professionals and those who work for cancer support charities.

If you are a healthcare professional or work for a cancer support organisation with breast cancer patients based in the UK, please follow the link for more info and share:

[Insert URL to Qualtrics]

#MaleBreastCancerAwareness #CancerResearch
#MenWithCancer#MensHealth#MenHaveBreastsToo

*Permission to use image was granted from photographer

Appendix 20 - Study 3 feedback letter to participants

Centre for Appearance Research
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol BS16 1QY
United Kingdom
www.uwe.ac.uk/car

Exploring Healthcare Professionals' experiences and perceptions of the support needs of men with breast cancer and their informal carers

Why was the research conducted?

The study in which you kindly participated, was the third in a series for a PhD exploring the psychosocial impact of breast cancer in men. The researcher has previously conducted studies with men who have been diagnosed with breast cancer and their informal carers. Together with this study, the researcher aims to gain a holistic understanding of the impact of the disease. The findings will help guide the rest of this PhD and ultimately aims to help improve support for people whose lives are impacted by breast cancer in men.

This summary provides an overview of the key findings from the research.

There were two main objectives:

- To explore the experiences of healthcare professionals with experiences of working with men with breast cancer and/or their informal carers
- To elicit healthcare professionals' perceptions of the resources/support services that would be beneficial for male patients with breast cancer and their informal carers

What was done?

Sixty-two UK based healthcare professionals from a broad range of disciplines involved in the treatment and/or care of breast cancer patients and/or their informal carers took part in an online survey. The majority were breast cancer surgeons (32%) and specialist breast cancer nurses (21%).

What was found?

Healthcare professionals currently provide a variety of resources and support to men with breast cancer and their informal carers. The majority of respondents (52%) signpost men with breast cancer to generic breast cancer support organisations whilst 60% offer general breast cancer information (e.g., leaflets, websites not specific to breast cancer in men). The vast majority (81%) reported there was a lack of information specifically for men with breast cancer and 55% reported the current available resources are unsuitable and insufficient for this patient population.

Regarding the informal carers of men with breast cancer, 78% of healthcare professionals who took part in survey signpost them to generic breast cancer organisations whilst 74% offer them generic breast cancer information. The vast majority (85%) felt that the current available resources are unsuitable and insufficient for the informal carers of men with breast cancer.

Heathcare professionals reported concerns about stigma, isolation and a lack of psychosocial support for both male patients with breast cancer and their informal carers.

Implications for future support

- These findings indicate a recognised need for male-specific materials and sources of support for both patients and their informal carers in the UK
- Training for healthcare professionals on how best to support men with breast cancer and their informal carers may be beneficial
- Together, these may help male patients and their informal carers better cope with breast cancer and its treatment and reduce feelings of isolation.

This study has highlighted important areas for further research to improve the provision of support and information for male patients with breast cancer and their informal carers in the UK.

How have the results been disseminated

The results of the study were presented at The Male Breast Cancer Happens Conference (November 2022). This is the largest, non-profit male breast cancer awareness organisation based in America, which aims to raise awareness of breast cancer in men worldwide. It is planned to present the study at future conferences aimed at health care professionals and researchers. A paper on this study is being submitted for publication in an academic journal.

What do you think – any comments?

Thank you once again for participating in this research, your time is very much appreciated. To reiterate that all responses are treated anonymously. This summary provides brief details about the study which may be interesting. If you have any comments or would like any further details about the study, please do not hesitate to contact me. As the research is ongoing, your feedback may be incorporated in subsequent studies and is greatly appreciated.

Finally, the information you have shared has been fundamental in my PhD. If you would be interested in receiving information about future studies in this area, I would very much like to hear from you. Once again, my email is beth2.herring@uwe.ac.uk

With best wishes,

Beth Herring

Contact: Email: beth2.herring@uwe.ac.uk

PhD researcher – Breast Cancer in Men

Centre for Appearance Research

University of the West of England

Appendix 21 – Breakdown of statements by profession

Men with breast cancer feel isolated

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	1 (5%)	2 (10%)	12 (60%)	5 (25%)
Oncologist (n=6)	0	0	0	5 (83%)	1 (17%)
General Practitioner (n=2)	0	0	1 (50%)	1 (50%	0
Breast Cancer Nurse (n=13)	0	0	2 (15%)	7(54%)	4 (31%)
Radiographer (n=8)	1 (13%)	0	0	1 (13%)	6 (75%)
Psychologist (n=8)	1 (13%)	0	0	1 (13%)	6 (75%)
Physiotherapist (n=4)	0	0	0	1 (25%)	3 (75%)
Occupational therapist (n=1)	0	0	0	1 (100%)	0
Overall (n= 62)	1 (2%)	1 (2%)	5 (8%)	29 (47%)	25 (40%)

There is little public awareness about male breast cancer

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	2 (10%)	0	13 (65%)	5 (25%)
Oncologist (n=6)	0	0	0	1(17%)	5 (83%)
General Practitioner (n=2)	0	0	0	1(50%)	1 (50%)
Breast Cancer Nurse (n=13)	0	1 (8%)	0	3 (23%)	9 (69%)
Radiographer (n=8)	0	0	0	3 (38%)	5 (63%)
Psychologist (n=8)	1 (13%)	0	0	2 (25%)	5 (63%)
Physiotherapist (n=4)	0	0	0	0	4 (100%)

Occupational therapist (n=1)	0	0	0	0	1 (100%)
Overall (n= 62)	1 (2%)	3 (5%)	0	23 (37%)	35 (56%)

Receiving a diagnosis of breast cancer is a shock to men as they think it is a female disease

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	1 (5%)	3 (15%)	10 (50%)	6 (30%)
Oncologist (n=6)	0	0	1 (17%)	3 (50%)	2 (33%)
General Practitioner (n=2)	0	0	0	1 (50%)	1(50%)
Breast Cancer Nurse (n=13)	0	0	0	6 (46%)	7 (54%)
Radiographer (n=7)	0	0	1 (14%)	2 (29%)	4 (57%)
Psychologist (n=8)	1 (13%)	0	0	1 (13%)	6 (75%)
Physiotherapist (n=4)	0	0	0	1 (25%)	3 (75%)
Occupational therapist (n=1)	0	0	0	1 (100%)	0
Overall (n= 61)	0	1 (2%)	5 (8%)	25 (41%)	29 (48%)

There is not enough information specifically for men with breast cancer

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	2 (10%)	1 (5%)	10 (50%)	7 (35%)
Oncologist (n=6)	0	0	1 (17%)	4 (67%)	1 (17%)
General Practitioner (n=2)	0	0	0	1 (50%)	1 (50%)
Breast Cancer Nurse (n=13)	0	0	4 (31%)	4 (31%)	5 (38%)
Radiographer (n=7)	0	0	0	3 (43%)	4 (57%)

Psychologist (n=8)	1 (13%)	0	1 (13%)	0	6 (75%)
Physiotherapist (n=4)	0	0	1 (25%)	0	3 (75%)
Occupational therapist (n=1)	0	0	0	0	1 (100%)
Overall (n= 61)	1 (2%)	2 (3%)	8 (13%)	22 (36%)	28 (46%)

Men with breast cancer feel less masculine

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	4 (20%)	8 (40%)	7 (35%)	1 (5%)
Oncologist (n=6)	0	3 (50%)	2 (33%)	1 (17%)	0
General Practitioner (n=2)	0	0	1 (50%)	1 (50%)	0
Breast Cancer Nurse (n=13)	0	1 (8%)	5 (38%)	7 (54%)	0
Radiographer (n=7)	0	0	2 (29%)	4 (57%)	1 (14%)
Psychologist (n=8)	1 (13%)	0	1 (13%)	2 (25%)	4 (50%)
Physiotherapist (n=4)	0	0	0	3 (75%)	1 (25%)
Occupational therapist (n=1)	0	0	1 (100%)	0	0
Overall (n= 61)	1 (2%)	8 (13%)	20 (33%)	25 (41%)	7 (11%)

There is little support for men with breast cancer

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	4 (20%)	5 (25%)	7 (35%)	4 (20%)
Oncologist (n=6)	0	0	0	0	6
General Practitioner (n=2)	0	0	1 (50%)	1 5(0%)	0
Breast Cancer Nurse (n=13)	0	4 (31%)	1 (8%)	4 (31%)	4 (31%)
Radiographer (n=7)	0	1 (14%)	0	3 (43%)	3 (43%)
Psychologist (n=8)	1 (13%)	0	1 (13%)	1 (13%)	5 (63%)
Physiotherapist (n=4)	0	0	1 (25%)	3 (75%)	1 (25%)
Occupational therapist (n=1)	0	0	0	0	1 (100%)
Overall (n= 61)	1 (2%)	9 (15%)	9 (15%)	19 (31%)	32 (52%)

There is little support for the informal carers of men with breast cancer

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	3 (15%)	6 (30%)	6 (30%)	5 (25%)
Oncologist (n=6)	0	1 (17%)	0	5 (83%)	0
General Practitioner (n=2)	0	2 (100%)	0	0	0
Breast Cancer Nurse (n=13)	0	2 (15%)	2 (15%)	6 (46%)	3 (23%)
Radiographer (n=7)	0	2 (29%)	1 (14%)	1 (14%)	3 (43%)
Psychologist (n=8)	1 (13%)	0	0	2 (25%)	5 (63%)
Physiotherapist (n=4)	0	0	1 (25%)	3 (75%)	0
Occupational therapist (n=1)	0	0	1 (100%)	0	0

Overall (n= 61)	1 (2%)	10 (16%)	11 (18%)	23 (38%)	16 (26%)

Awareness campaigns portray breast cancer as a female disease

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	0	1 (5%)	0	10 (50%)	9 (45%)
Oncologist (n=6)	0	0	0	1 (17%)	5 (83%)
General Practitioner (n=2)	0	0	0	0	2 (100%)
Breast Cancer Nurse (n=13)	0	0	0	6 (46%)	7 (54%)
Radiographer (n=8)	1 (13%)	0	0	2 (25%)	5 (63%)
Psychologist (n=8)	1 (13%)	0	0	0	7 (88%)
Physiotherapist (n=4)	0	0	0	0	4 (100%)
Occupational therapist (n=1)	0	0	0	0	1 (100%)
Overall (n= 62)	2 (3%)	1 (2%)	0	19 (31%)	40 (65%)

Men with breast cancer have concerns that the treatment they receive has not been sufficiently tested on men

Profession	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Surgeon (n= 20)	1 (5%)	4 (20%)	8 (40%)	4 (20%)	3 (15%)
Oncologist (n=6)	0	0	2 (33%)	4 (67%)	0
General Practitioner (n=2)	0	0	2 (100%)	0	0
Breast Cancer Nurse (n=13)	1 (8%)	3 (23%)	2 (15%)	7 (54%)	0
Radiographer (n=7)	0	1 (14%)	1 (14%)	5 (71%)	0

Psychologist (n=8)	1 (13%)	0	3 (38%)	2 (25%)	2 (25%)
Physiotherapist (n=4)	0	0	1 (25%)	2 (50%)	1 (25%)
Occupational therapist (n=1)	0	0	1 (100)	0	0
Overall (n= 61)	3 (5%)	8 (13%)	20 (33%)	24 (39%)	6 (10%)

Appendix 22 - Research outputs from this PhD

Academic publications

Herring, B., Lewis-Smith, H., Paraskeva, N. and Harcourt, D. (2022) Exploring the experiences and psychosocial support needs of informal carers of men with breast cancer: a qualitative study. Support Care Cancer vol 30, no8, pp. 6669–6676.

This publication can be found in appendix 24 and at the following link:

https://pubmed.ncbi.nlm.nih.gov/35508668/.

Paper and Poster Conference Presentations

August 2020. **The Male Breast Cancer Coalition Conference** (online). *Exploring the psychosocial impact of breast cancer in men.* Oral Research Presentation.

February 2021. The Male Breast Cancer Virtual Meet up (VMU) (online). Oral research presentation of the PhD and outlined the Study *"Exploring the experiences and psychosocial support needs of informal carers (wives, husbands, partners, family members or friends) of men with breast cancer - A qualitative study."*

August 2021. **The Male Breast Cancer Coalition Conference** (online). Oral research presentation, *"Exploring the experiences and psychosocial support needs of informal carers (wives, husbands, partners, family members or friends) of men with breast cancer - A qualitative study."*

April 2022. The British Psychological Oncology Society Annual Conference (online). Poster presentation *“Exploring the Experiences and Psychosocial Support Needs of Informal Carers of Men with Breast Cancer; A Qualitative Study.”*

June 2022. The British Psychological Society Division of Health Psychology Annual Conference, Bristol. Poster presentation *“Exploring the Experiences and Psychosocial Support Needs of Informal Carers of Men with Breast Cancer; A Qualitative Study.*

November 2022. Male Breast Cancer Happens Conference (online). *“Exploring the psychosocial impact of breast cancer in men and their informal carers.”* An overview of the PhD.

November 2022. International Men’s Day Research UWE Showcase (online). Presented an overview of the PhD; *“The wider impact of men’s health. Breast cancer in men and the experiences and support needs of informal carers of men with breast cancer.”*

Podcast episode

August 2022. CAR Podcast Summer Shorts Series (No 2) [Audio podcast episode]. Herring, B. & Thornton, M. *"Exploring the experiences and psychosocial support needs of informal carers of men with breast cancer: a qualitative study", Supportive care in cancer, vol. 30, no. 8, pp. 6669-6676.*

Soundcloud. **https://soundcloud.com/appearance-matters/summer-short-series-male-breast-cancer-and-informal-carers?utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing**

Upcoming presentations

June 2023. UWE Postgraduate Research Conference, Bristol. Theme: Making a difference to Health, Science and Society. I will be presenting an overview of the PhD.

November 2023. I have been invited to present at The Male Breast Cancer Global Alliance Conference (Online).

Appendix 23 – Impact of social media posts as of 1 March 23

Date of post	Content of post	Instagram	Facebook	Twitter
January 2020	Survey male breast cancer (embedded link to survey)	n/a	n/a	1,990 impressions (views) 34 engagements 4 link clicks 3 likes 5 retweets
8 June 2020	National Cancer Survivors Day post	n/a	1 like	825 impressions 4 engagements 1 like
20 October 2020	Recruitment post (Photo of the late Bill Becker by David Jay)	126 impressions (views) 117 accounts reached 35 likes 1 comment 2 saves 4 profile visits 2 follows	n/a	n/a
October 2020	Male Breast Cancer Awareness Week - findings of online study (On IG, the post features photos from Brent Stirton)	1396 impressions 1168 accounts reached 137 likes 7 comments 12 saves 29 profile visits 2 follows	6 likes & 1 share	1,147 impressions 2 likes 1 retweet
26-27 February 2021	Recruitment post (Incorporated photo of the late Bill Becker by David Jay in Canva post)	191 impressions 169 accounts reached 29 likes 3 saves 2 profile visits 2 follows	3 likes & 1 share	1,317 impressions 25 engagements 1 like 1 quote tweet 1 retweet

22 April 2021	Recruitment post	n/a	2 likes	2,338 impressions 37 engagements 3 link clicks 5 likes 1 quote tweet 2 retweets
June 2022	DHP conference (poster on male breast cancer)	n/a	n/a	653 impressions 46 engagements 13 likes 5 retweets
22 June 2022	Recruitment post	212 impressions 184 accounts reached 10 likes 1 comment	(1 July 22) 2 likes & 1 share	n/a
8 July 2022	Summer Shorts Podcast Episode on Male Breast Cancer	375 impressions 291 accounts reached 23 likes 2 comments 3 profile visits	0 likes	n/a

Appendix 24 Ethics approval letters have been removed as they contain personal information

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Appendix 25 Published journal article

Supportive Care in Cancer (2022) 30:6669–6676
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ORIGINAL ARTICLE

Exploring the experiences and psychosocial support needs of informal carers of men with breast cancer: a qualitative study

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Abstract

Purpose The provision of practical and emotional support for men who have been diagnosed with breast cancer in the UK falls primarily on their partners, close family members or friends. However, informal carers' experiences are omitted from the research literature. Therefore, the present study aimed to explore the care-giving experiences of informal carers (ICs) of men with breast cancer in the UK and identify psychosocial support needs and preferences.

Methods Semi-structured interviews, conducted on the telephone or via online video calls, explored ICs' experiences of providing support, the psychosocial issues they faced and the impact of the illness on themselves and their relationship with the patient. They were also asked about any support previously offered to them, in addition to their support preferences. Twelve ICs participated (11 females, 1 male), and 9 were spouses. Interview transcripts were analysed with reflexive thematic analysis using NVIVO software.

Results Four key themes were identified: "The impact of caring", "Lack of awareness", "Isolated and alone" and "Making a difference".

Conclusions The physical, emotional, financial and social impact of providing emotional and practical care and support for a man diagnosed with breast cancer can be considerable. ICs may experience significant levels of distress and often feel isolated. Greater awareness and more research is needed to better understand the psychosocial impact and support needs for ICs of men with breast cancer. There is an evident necessity to address their information needs and offer sources of support throughout the cancer journey.

Keywords Informal carers · Breast cancer in men · Oncology

Background

Although rare, the prevalence of breast cancer in men (BCiM) is increasing worldwide [1, 2] and approximately 400 men are diagnosed annually in the UK [3]. However, there is often a lack of awareness about BCiM among both the public and health care professionals [4], and it is frequently overlooked in research [5]. Cancer affects not only the patient but also the lives of family members and close friends [6]. The role of support of BCiM patients falls primarily on partners, close family members or female friends who have had breast cancer [7].

The term "Informal Carers (ICs)" commonly refers to someone who actively participates in sharing the patient's illness experience on a practical and/or emotional level [8]. It does not include those who provide professional paid or voluntary care, such as healthcare professionals working or charity volunteers. ICs typically face caring responsibilities with little or no formal training and additional support [6]. The physical, emotional, financial and social impact of caring for an individual with cancer can be considerable; they may experience anxiety and depression, concerns about the future and losing the patient, financial worries and strain in family and marital relationships [6]. ICs may also experience poor physical health, including sleep difficulties and fatigue, cardiovascular disease, poor immune functioning, and increased mortality [8]. However, to the best of our knowledge, no research has focussed on ICs of BCiM patients. This study therefore aimed to address this neglected area of research. A qualitative study was conducted using

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semi-structured interviews with ICs of men who had received a diagnosis of breast cancer. The study aimed to as follows: (a) explore the care-giving experiences of ICs of men diagnosed with breast cancer; (b) identify psychosocial support needs; (c) establish preferences for support.

Methods

Due to the lack of research in this field, a qualitative approach was deemed the most appropriate method to elicit participants' experiences and perspectives and is well-suited to health research [9]. Eligible participants were men or women in the UK, aged over 18 years, who currently, or had previously, provided practical and/or emotional support for a man who had received a diagnosis for breast cancer and were able to take part in an interview conducted in English without the need for an interpreter. There were no exclusion criteria relating to treatment or stage of disease, and bereaved carers were included.

Participants from a previous study conducted by the lead researcher were invited to share information about the current study with those they identified as their ICs. Social networking sites and websites of the authors' research group, cancer charities and support groups such as Breast Cancer Now, Maggie's Centres and The Male Breast Cancer Virtual Meet Up ("The Men's VMU") advertised the study. Snowball sampling also occurred, whereby ICs forwarded details of the study to other ICs.

Study adverts directed potential participants to the secure on-line platform, Qualtrics, which was used to host the study information, obtain consent, and collect sociodemographic data including age, gender, ethnicity, relationship status, sexual orientation, relationship to the patient and employment status. Potential participants' email addresses were collected to arrange the interview. The researcher's email was provided to answer any questions. Feedback was sought from an IC of a BCiM patient on the interview guide. Semi-structured interviews were conducted by the first author. All data collection took place during COVID-19 restrictions, between January and June 2021. Consequently, participants were given the option of Microsoft Teams or telephone, rather than in-person interviews.

Data analysis

Interviews were transcribed verbatim by the first author and all identifying details were removed. A reflexive thematic analysis (Reflexive TA) [10] of the data was conducted by the first author using NVivo software, with supervision throughout the analytic process and agreement on the final themes from the last author.

As the aim of the current study was to explore the experiences, meaning and subjective reality of ICs of patients with BCiM, an inductive orientation to the data was chosen, considering the semantic meanings generated from the data rather than a pre-determined theoretical foundation [10]. An experiential qualitative framework aimed to capture participants' perspectives, meanings and experiences. Finally, a critical realist ontological approach endeavoured to focus on the participants' assumed reality and truth encapsulated within data [10].

Analysis followed the six phases of Reflexive TA, conducted in a recursive process: (1) data familiarisation; (2) coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining, defining and naming themes; and (6) writing up [11]. In accordance with the central component of reflexive TA, the researcher's experiences, pre-existing knowledge, and social position and how these aspects influence and contribute to the research process and potential insights into the data were acknowledged [10]. A reflective journal was kept throughout which reflected on any assumptions that may have underpinned their reading of the data. These included being female, not having personal experience as an IC nor having experienced breast cancer. They also reflected on their previous qualitative research conducted with men who have received a diagnosis and treatment for breast cancer.

Results

Twelve informal carers (11 female, 1 male; mean age = 54 years [range = 25–77 years]) participated. Interviews, lasting an average of 55 min (range = 28–71 min), were conducted via online video calls (Microsoft Teams $n = 8$) or telephone ($n = 4$). The sample had a range of experiences as ICs, including caring for men in the early stages of treatment, mid-treatment and many years after diagnosis. One participant was caring for a man in palliative care and two were bereaved carers of men who had died of breast cancer.

The majority were married to the patient ($n = 9$), one was the daughter of a BCiM patient, one was an ex-partner who had been in a relationship with the patient at the time of diagnosis and treatment and one was a close friend (see Table 1 for details of the sample).

Thematic analysis identified four key themes: "The impact of caring", "Lack of awareness", "Isolated and alone" and "Making a difference". These are discussed using exemplars from the interviews along with pseudonyms. Table 2 provides participant details.

Table 1 Sample characteristics ($n = 12$)

Characteristic		n	%
Age	Mean = 53.42 yrs ($SD = 15.23$)		
Range = 25–77 years			
Gender	Male	1	8.33
	Female	11	91.76
Ethnicity	White	12	100
Relationship status	Married	9	75
	Relationship or civil partnership	1	8.33
	Widowed	1	8.33
	Single	1	8.33
Sexual orientation	Heterosexual or straight	10	83.33
	Bisexual	2	16.67
Relationship to BCiM patient	Wife	8	75
	Husband	1	8.33
	Ex-partner	1	8.33
	Daughter		
Friend	1		
1	8.33		
Employment status	Employed	4	33.33
	Self-employed	2	16.66
	Retired	4	33.33
	Student/artist	1	8.33
	Unable to work due to disability	1	8.33

Table 2 Participant details

Pseudonym	Age (years)	Gender	Relationship to BCiM patient	Year of diagnosis	Cancer stage
Dee	52	Female	Widow	2004	Deceased
Anna	31	Female	Wife	2008	Palliative care
Ambellina	25	Female	Daughter	2011	Deceased
Mia	52	Female	Wife	2007	Secondary
Andora	77	Female	Mother	2005	Secondary
Nico	51	Female	Wife	2012	Not provided
Ragdoll	73	Female	Wife	2021	Not provided
Bouquet	70	Female	Wife	2011	Not provided
Becksbud	47	Female	Friend	2007	Secondary
Raine	48	Female	Ex-partner	2018	Secondary
Jeremiah	66	Male	Husband	2015	Not provided
Freya	49	Female	Wife	2021	Secondary

The impact of caring

Participants' accounts described how, from the beginning of the cancer journey, they played an integral role in supporting the BCiM patient. Initially it was often the IC who urged the men to see a GP, which ultimately led to receiving the diagnosis, and they frequently portrayed themselves as a "gate-keeper" to medical appointments, healthcare providers and professionals. Many gave clear examples of the support they provided, and often expressed bearing the pressures and responsibilities of providing for the physical and emotional wellbeing of the patient as well as offering practical support. The impact of caring for a man with breast cancer affected many aspects of their lives:

> You are literally living with cancer, and you are drawn into it day after day, and you can't get away from it. (Raine)

Demands often increased during chemotherapy and radiotherapy as the patient experienced the side-effects of treatment. Many patients also suffered with long-term comorbidities, such as anxiety, depression and diabetes, which ICs helped them to manage:

> He was physically unable to do anything… I was helping him get up, helping him dress, I was making him food, everything and driving because he couldn't drive, I was helping him walk round the house, everything.
> (Anna)

Some ICs were forced to reduce their work hours or took leave to provide care. This impacted both their income and household finances and provided additional stress and anxiety. The ripple effect of the disease on their social life and family, especially children, was frequently reported. Participants often felt they had to be "strong", "positive" and to try to "maintain normality". As well as assuming the responsibility of caring for the BCiM patient, many participants also took on running the household and completing all domestic chores, as well as looking after and supporting their children:

> I was looking after him and also looking after the family … for most of the time I felt like a single parent because he was so poorly.
> (Dee)

For some, the impact of providing emotional care and practical support was overwhelming. Often, participants expressed how they neglected their own needs. They described how this eventually took a toll on their physical and mental health:

> It really impacted me, and I went through, like self-harm, and just feeling really low.
> (Ambellina)
> I had a nervous breakdown.
> (Mia)

Some participants described how taking on the responsibilities of an IC changed their relationship with the patient, with many feeling that they had become more of a carer than a wife or partner:

> I had to almost divide myself in two, so I had me as his girlfriend and carer…., it's impossible to have a loving, close, physical relationship… you end up purely being a carer for that person.
> (Raine)

However, for some, the change in their roles had a positive impact on their relationship:

> It's made us both stronger, definitely, you know, a deeper respect …. getting to do things like this for your partner has made us closer and better friends and I think it's just made our relationship better.
> (Anna)

Lack of awareness

This theme encapsulates lack of awareness of BCiM among both the general public and healthcare professionals. Only two ICs had previously heard of BCiM prior to becoming a care-giver, and most reacted to the diagnosis with shock, disbelief and distress. For some, this led to uncertainty about how best to discuss the diagnosis and support a man with what is commonly perceived as a female disease:

> Not even knowing how to speak to a man about it …..you talk about breasts with a man and at times it can become, not a sexual thing, but you don't normally talk about boobs with a man. So, there is that whole concept there as well as that, I am talking about boobs with my best mate but its disjointed…so you have to try and get over that and I found that quite difficult.
> (Becksbud)

All the participants found it difficult to access information about BCiM and described how available literature invariably portrayed it as a female disease, written for women and not representing men. This often left ICs feeling uncertain about how the illness impacts men and how they should best support the patient:

> It was really hard, 'cause it was a man whose got breast cancer and everything they talked about, all the pamphlets were bras and mastectomy bras and wigs and reconstruction.
> (Mia)

Participants expressed how some healthcare providers appeared to be unaware of BCiM and that they failed to treat and provide suitable care and support for the male patient or them as ICs. They described hospital staff assuming the breast cancer patient to be female, with presumptions that the accompanying female IC was the patient:

> When we went for appointments most people assumed it was me who had breast cancer, if you went for a clinic appointment, I was asked how I was and I was like… well, I'm fine but I'm not the patient.
> (Dee)

One participant explained her husband receiving a letter from a healthcare trust for a hospital appointment which was written for a woman and suggested suitable clothing to wear:

> The letters weren't adjusted to be for a man. For the mammogram it said it would be better to wear a blouse and skirt.
> (Bouquet)

The focus on female breast cancer and the lack of research conducted with male patients resulted in some ICs describing their mistrust of medical decisions. Many were extremely concerned about the medical treatment prescribed for men, and in particular, the hormone therapy, tamoxifen. They worried about men being prescribed a female hormone drug and about changing parameters of the length of prescription. This all led to uncertainty and lack of confidence in their medical treatment:

> He was told 'take it for two years', then 'oh no, you need to take it for five years', and then, 'oh no, you need to take it for ten years.' So, the goal posts kept changing, and I said to him I felt that he was starting to feel like a guinea pig because there isn't any research on the effects of Tamoxifen on men because it is a female drug, for female hormones.
> (Nico)

The adverse, sometimes long-term, side-effects associated with tamoxifen, posed significant challenges to the quality of life and well-being of patients. This consequently also impacted the lives of their ICs. Reported side-effects often included loss of libido and erectile dysfunction and ICs described how this consequently impacted their intimate relationships:

> He's lost all of his sex drive for a start, which is a big thing.
> (Jeremiah)

Several participants felt unprepared for the long-term impact of cancer and its treatment on the physical and mental health of the patient. Due to the lack of support either available or offered to ICs, some expressed feeling ill-informed and uncertain about how the illness impacts men.

Isolated and alone

Social lives and relationships were often impacted as ICs had less time to spend outside the house, which led to feelings of isolation and loneliness. Participants described how the support of the patient's friends and family, although initially present, often dwindled and they were left as the sole carer. This increased the amount of support they provided the patient and intensified their caregiving role:

> A lot of his friends actually disappeared
> (Raine)

Several participants felt unprepared for the long-term impact of cancer and its treatment on the physical and mental health of the patient. Due to the lack of support either available or offered to ICs, some expressed feeling ill-informed and uncertain about how the illness impacts men. Almost all participants expressed a distinct lack of formal practical or emotional support. As a result, they felt they did not have the opportunity to talk about their concerns with others in a similar situation or discuss things they may not feel able to talk about with family or friends. Consequently, many did not know about rights, financial benefits or support available to all ICs:

> Throughout all of this I have never received any support at all, no support has ever been offered.
> (Nico)

It appeared that formal support was provided only when the BCiM patient was in palliative care at home. ICs in this position spoke highly of the benefit of the services and support they received which included counselling, financial information regarding benefit entitlement, specialist breast cancer nurses, and charities who helped with household chores. Additionally, they provided emotional support and helped ICs to prepare and cope with the death of a loved one, as well as how to support and prepare children for loss:

> She (specialist nurse) went above and beyond…she delivered medication to the house for us, just these little things, that's made a massive difference…she's reached out to charities who work with families who are dealing with a terminal illness.
> (Anna)

Isolation was further negatively impacted by the COVID-19 pandemic which necessitated a number of BCiM patients to shield, and government restrictions that prevented households meeting. Consequently, many ICs were unable to see their family and friends and faced distinctive challenges which compounded isolation.

Making a difference

Many ICs reported becoming advocates and spoke passionately about the need to raise awareness of BCiM, to share their stories, and to improve the support for future patients and their ICs. Examples included challenging an insurance company's discriminatory provision of care for male and female breast cancer patients, holding meetings with the director of a hospital, and challenging media which discussed breast cancer without the inclusion of men. One participant set-up a BCiM awareness campaign.

All participants recognised the need for support for ICs of men with breast cancer. One (the only male interviewee) felt they did not personally need support but recognised the potential benefits for others. Perceived benefits included emotional support, practical tips, sharing medical experiences and practical information as well as advice on treatment and managing side-effects. Several participants suggested that an online peer support group or forum for ICs would potentially foster a sense of community, improve confidence and increase ability to cope and provide the best care for the patient:

> It would be invaluable just to speak to someone going through the same.
> (Anna)

However, potential barriers to ICs accessing support were identified. Several felt guilty and reluctant asking for support and respite care. They felt a sense of responsibility to look after and care for the patient, who they felt was more deserving of support than themselves:

> I didn't really go looking for support, because I thought… well, why should I be looking for it, it should be him looking for it, he's the one who's sick and needs the support.
> (Dee)

Some were concerned that seeking support would be perceived as not coping, and some saw themselves as supporting the patient but were reluctant to identify as a carer:

> This is what I promised to do, I'm his wife.
> (Anna)

Discussion

The themes illustrate similarities, shared experiences, challenges and psychosocial support needs of ICs to BCiM patients. Details of the daily provision of care and practical tasks were consistent with literature on ICs with more common cancer in men [12]. The impact of caring varied according to the stage of illness; ICs of men who had recently been diagnosed had a very different experience to those of men who had undergone surgery and were experiencing the ongoing effects of treatment. These findings support previous research conducted with the ICs of a person with cancer (not specifically BCiM) [13], as well as the results of a systematic review exploring overburden among informal carers in general [14]. For some, being an IC impacted their own physical and emotional health, and participants reported neglecting their own needs, and the subsequent toll on their wellbeing. This is in line with reviews of the issues faced by caregivers of people diagnosed with cancer (15–16). In this study, ICs often felt they had to be strong for others, especially children, and to maintain a sense of normality. Similar results were reported in the care-giving experience of ICs of differing cancer patients [15].

Many participants raised the general lack of awareness of BCiM. Similar to findings from a study of BCiM patients [4], some ICs raised concerns about the feminisation of breast cancer, which they felt reinforced gender misconceptions. Lack of BCiM awareness by hospital staff was typified by assumptions that appointments were for the female IC rather than the male they were accompanying, thus mirroring previous research conducted with men with breast cancer [16]. Most ICs were concerned with the lack of gender-specific information for BCiM patients, which is evident in research with BCiM patients themselves [4, 17–19]. For some ICs, the paucity of research in BCiM resulted in a mistrust of medical decisions and treatment. These concerns, coupled with the negative impact of treatment related side-effects, such as sexual dysfunction and loss of libido, supports previous research conducted with this patient group [20, 21].

The data was gathered during the COVID-19 pandemic which may have further contributed to the loneliness and social isolation which were prominent concerns for most ICs. Similar to the social consequences described by ICs of advanced cancer patients [22], the paucity of services contributed to additional caregiver burden. This had a significant impact on their ability to work, sometimes resulting in additional financial pressures. Finally, the absence of services, lack of support and consequent isolation rendered many of the ICs vulnerable to marginalisation.

Strengths and limitations

To the best of our knowledge, this is the first study to be conducted with ICs of BCiM patients. However, the retrospective design of the study warrants consideration. To control for the limitation of recall bias, future research could focus on and follow ICs from the time of diagnosis. Second, all the ICs in this study identified as white. Future research should explore ways of engaging participants from ethnically diverse populations in order to better understand how cultural context may influence the experiences of ICs of BCiM patients.

Clinical implications

These findings indicate an urgent need for the provision of support specifically for ICs of men with breast cancer. Potential modes of support suggested by participants include online IC peer support groups and forums. Due to the rarity of BCiM, in-person meetings of ICs may not be feasible whereas online support could reach geographically dispersed populations [23]. Peer support may help to reduce isolation, increase wellbeing, quality of life and potentially improve outcomes for ICs [24].

Conclusions

The provision of emotional and practical support for a man who has received a diagnosis of breast cancer falls primarily on family and friends, and this can be demanding and enduring. The findings from this study highlight key issues and unmet needs of ICs to men with breast cancer and emphasise the need for further research including prospective longitudinal studies following ICs from the time of diagnosis. Increasing awareness of the experiences and support needs of these ICs could inform support packages tailored to their needs, which may help to mitigate future issues and better enable them to provide care and support to men with breast cancer.

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Author contribution All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by BH and DH. The first draft of the manuscript was written by BH and all authors commented on versions of the manuscript. All authors read and approved the final manuscript.

Data availability Research data are not shared due to privacy or ethical restrictions.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of The University of the West of England (29th January 2021, reference number: UWE REC REF No: HAS.20.12.059).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication The authors affirm that informed all participants provided informed consent for publication of the data gathered in the study.

Competing interests The authors declare no competing interests.

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