Experiences and perceptions of men following breast cancer diagnosis: A meta-synthesis

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Abstract

Background

Men with breast cancer (MBC) experience unique physical and emotional challenges. However, a thorough understanding of these experiences including the psychosocial effects and supportive care needs have received less attention. In some settings, MBCs experience stigma within the healthcare system and their care needs are not prioritised. This influences the level of professional support offered, consequently worsening their health and well-being outcomes. This review explored the variabilities in the experiences and treatment outcomes of MBCs across different demographic contexts.

Methods

All primary study designs including qualitative, quantitative and mixed methods studies that reported on the experiences, treatment approaches and outcomes of MBC were included in this systematic review. Six databases (Embase, Medline, PsycINFO, Global Health, CINAHL and Web of Science) were searched for articles from database inception to 2021. A results-based convergence synthesis was used for data analysis and reported using PRISMA guidelines.

Results

38 studies met the inclusion and exclusion criteria. Our findings relating to the experiences and treatment outcomes of MBC are broadly themed into three parts. Theme 1 - Navigating through a threat to masculinity: describes how males experienced the illness reflecting on detection, diagnosis, coming to terms with breast cancer, and disclosure. Theme 2- Navigating through treatment: captures the experiences of undergoing breast cancer treatment/ management following their diagnosis. Theme 3 - Coping and support systems: describes how MBCs coped with the disease, treatment process, aftercare/rehabilitative care, and the available support structures.

Conclusions

Men experience a myriad of issues following a breast cancer diagnosis, especially with their masculinity. Awareness creation efforts of MBC among the general public as well as healthcare practitioners are urgently required. Considerations for training, education and development of specialised guidelines for healthcare practitioners on MBC would provide the necessary knowledge and skills to enhance their practice through the adoption of person-centred and male-specific care strategies. Professional care intervention and support for MBC should not end after the diagnosis phase but should extend to the entire treatment continuum and aftercare.

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Background

Men with breast cancer is a rare, accounting for less than 1% of all breast cancers. About 2,710 men are estimated to be diagnosed with breast cancer, with approximately 530 men projected to die from breast cancer in 2022 and have about 1 in 833 lifetime risk of being diagnosed with the disease in United State (1). Data from the Global Burden of Disease 2017 database indicate that the incidence of male breast cancer (MBC) increased from 8.5 thousand in 1990 to 23.1 thousand in 2017 with 123 countries showing a significant increasing trend in MBC incidence rates (2). Evidence suggests that men present breast cancer at an advanced stage of the disease and with relatively worse prognosis compared to women (3–7). This has been attributed to a lack of awareness of the disease among men (8–11). Similarly, knowledge of MBC remains relatively low among healthcare professionals and in the general population due to its rarity (7, 8) and paucity of research (12).

MBCs are mainly diagnosed with more severe clinical manifestations with relatively complex tumour characteristics (i.e. larger sizes and extensive lymph node involvement) (13), associated with higher proportions of positive hormone receptors, which mostly results in prolonged treatment delay, and metastasis of the disease at diagnosis compared to female breast cancer (14). However, treatment for MBC has mainly been informed by available evidence for female breast cancer (15) as a result of inadequate characterisation (16–18); hence a call for studies to investigate the suitability of female-based therapies for men (19). Some guidelines have been published for the management of MBC (20–22), however, these guidelines are rarely based on clinical trials leading to a paucity of literature on the evaluation of outcomes for MBC. Men with breast cancer face unique physical and emotional challenges. However, there is inconclusive understanding of men's experiences of the psychosocial implications of MBC as well as the supportive care needs (23, 24). They are also likely to experience stigma within the healthcare system or their complaints not seriously considered which could potentially influence the level of professional support offered to them (25).

There are variations in the incidence of MBC among countries for instance, in Thailand MBC incidence was lower than that in Israel, and the rate of variability has been attributed to population-specific factors (26). Additionally, disparities have been noted in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions in specific population groups (27). Some of these disparities have been noted in the United States, where black men are reported to have higher incidence and mortality rates compared to white men in the context of all cancer (27–29). Therefore, in this review, we explored the experiences of MBC and the management approaches across different demographic contexts.

Methods

Review objectives:

1. To report on the experiences and perceptions of MBC patients
2. To explore treatment approaches used and outcomes achieved for MBC patients.
Design

We conducted a mixed method review (30) and reported in line with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines (31).

Search strategy

We identified relevant studies through a search in six electronic databases: Global Health, CINAHL, Medline, PsycINFO, Embase, and Web of Science. Furthermore, we searched reference lists of included studies for additional studies. The search duration covered inception of these databases to December 2021.

A combination of the following keywords was used for search strategy i) ‘Men’ OR ‘Male’ OR ‘Father’ OR ‘Husband’ AND ii) ‘Breast cancer’ OR ‘Breast carcinoma’ OR ‘Breast neoplasm’ OR ‘Breast tumour’ AND iii) ‘Experiences’ OR ‘Perceptions’ OR ‘Perspectives’ OR ‘Opinions’ AND iv) ‘Treatment’ OR ‘Approaches’ OR ‘Outcomes’. Multiple variations of the keywords were used including the truncations based on database requirements to broaden to capture all relevant studies.

Inclusion and exclusion criteria

This review included all primary studies of any design (including qualitative, quantitative or mixed methods) that report on male breast cancer, studies reporting on the experiences, perceptions and treatment approaches and outcomes achieved for male breast cancer patients as well as studies conducted and reported in English based on the resources available to the researchers. Studies reporting on cancers in men other than breast cancer and transgender men were excluded including studies that did not report on MBC experiences and perceptions as well as those reported in other languages other than English.

Data extraction, synthesis, and analysis

The search results were imported to Endnote version 20 reference manager by the first reviewer (MA-O), duplicates were removed, and titles with abstracts screened. Studies remaining after title and abstracts were screened against inclusion/ exclusion criteria, by three reviewers (MA-O, JB, OA) and any study for which inclusion was unclear was discussed and resolved by reviewers (YS and TA). Full texts of studies were obtained if abstracts did not have enough information to determine the relevance of an article. We extracted variables such as authors, countries where studies were conducted, aims/objectives, study design, sample size and characteristics, experiences of MBC with verbatim quotes, MBC treatment approaches with outcomes and conclusions drawn to a common table (see Table 1).

We used a convergent design (32). We initially separately synthesised qualitative and quantitative findings, then the findings from the two designs were in a final synthesis (see Fig. 1). This allowed us to synthesise quantitative results regarding treatment modalities of MBC and qualitative or mixed methods results on the experiences of MBC.
Descriptive statistics was used in reporting the number of published studies and presented in a PRISMA flow diagram in Fig. 2. We synthesised the descriptions of MBC experiences and treatment approaches reported across the included studies. Qualitative, quantitative, and mixed method studies were descriptively analysed. To synthesise the data regarding the experiences of men with breast cancer, verbatim quotes reported in the qualitative studies were extracted by two authors (JB & TA). Employing an interpretive and inductive stance, the verbatim quotes were reviewed to generate codes (see Table 2). Similar codes were aggregated to generate subthemes following which higher order themes were formulated. For the quantitative data regarding the treatment modalities, we focused on describing the reported modalities in terms of words rather than numerical representation. At the end of the analysis, both the qualitative findings and descriptions from the quantitative studies converged as one dataset. The themes generated from the initial process and the descriptions obtained from the quantitative studies formed the basis of undertaking a narrative synthesis.

The quality of included studies was assessed using the QATSDD tool (33), a tool designed for use in mixed methods reviews and quality reporting in reviews that included qualitative, quantitative, mixed- and multi-methods research.

**Results**

**Study characteristics**

Following extensive search and screening, 38 studies were retained with publication years ranging from 2000 to 2020. The majority of the studies (n = 10) emerged from the USA (34–43). Other settings include Germany n = 6 (44–49), UK n = 5 (9, 19, 50–52), Canada n = 2 (53, 54), India n = 2 (55, 56), Turkey n = 2 (57, 58), Israel (59), Brazil (60), Italy (61), Egypt (62), South Africa (63), Nigeria (64), China (65), Netherlands (66), Hong Kong (3), Burkina Faso (67) and one multinational study across multiple countries/sites (Denmark, Finland, Geneva, Norway, Singapore and Sweden) (22). Twenty-six studies employed varied quantitative designs and 6 studies each employed qualitative and mixed-method designs. Although most of the studies (n = 34) included only MBC, two retrospective studies compared males and females with breast cancer, and only the data reported on males were included in this review (37, 65).

**Objective 1: Experiences of males with breast cancer**

As shown in Table 2, three themes and nine subthemes emerged from the data which encapsulate the experiences of males with breast cancer.

**Theme 1: Navigating through a threat to masculinity**

This theme describes how males experienced the illness reflecting on detection, diagnosis, coming to terms with the disease, and disclosure. The subthemes are 1) emergence and awareness of a foreign illness 2) coming to terms with a gendered disease and 3) opening up/ coming out of the illness closet.
Emergence and awareness of a foreign illness

Males generally perceived breast cancer as a feminine illness which cannot affect their bodies (46, 50). In fact, most males had not previously heard about breast cancer in males which made them rule out any possibility of ever living with it (19, 50). This perception and the emerging non-specific symptoms often delayed early health seeking as the symptoms were interpreted as irrelevant or not requiring urgent attention (19). Some men had to be ‘pushed’ by their wives or partners to seek medical attention to rule out the possibility of breast cancer; a condition they felt was out of their scope (19, 52). A breast cancer diagnosis was met with varied emotions including been dumbfounded, shocked, surprised, debilitating stress, and a feeling of housing a feminized illness in a masculine body which threatened their sense of masculinity and personhood (9, 19, 46, 50).

“...there is no reason why I shouldn’t have cancer, I’m only the same as anyone else. I’m just a bit disappointed really about where it got me. it’s not right on a man, is it? (50) (p.467).

“From others at work, I always (hear) ‘admit it, you’re just trying to find excuses. You’re not a real man, or you wouldn’t have such an illness’. (46) (p.8).

‘I suppose the fact that it was breast cancer surprised me. The fact that it was cancer I suppose was a shock... So, I suppose a combination of both. You know the fact that it was breast cancer which I do not think I had heard of and the fact that it was cancer” (9) (p.336).

Receiving the diagnosis was challenging which some men kept to themselves or only informed family/close friends (52). The notion of breast cancer been a feminine illness made men to view the disease as foreign or exotic to their bodies (19). The growing awareness of the disease made the men feel a sense of oddity and shame for having a feminine illness alongside a feeling of losing one's manhood to an illness not considered masculine (19, 50). Worry, anxiety, and uncertainty also marked their increasing awareness of the disease particularly regarding how the disease could distort the shape of their ‘masculine chest’ (9). Despite the varied emotions, some males felt extremely lucky that the cancer was located at a site not considered ‘vital’ in terms of masculinity (68).

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?” (46) (p.8).

“Now when I first knew that I had got it, I thought to myself ...well how the Dickens did I get breast cancer. I’m not a woman. I’m a man. I was surprised more than anything... Women it’s an ever-present threat ... Men – never occurs to them. ”When I first knew I did not want everyone knowing, because I did not want everyone coming round sympathizing”. (9) (p.336).

Coming to terms with a gendered disease

Following the breast cancer diagnosis, males were faced with the reality of living with a condition they did not expect to have. Coming to terms with a feminized disease was gradual and a lonely journey for the
affected men. In fact, some wished they could give their condition another name instead of breast cancer. The fear of being stigmatized made some men to keep their diagnosis to themselves (9, 45). Others also felt a sense of awkwardness discussing such sensitive issues and would avoid (9). Taken together, men with breast cancer often concealed or attempted to re-label their diagnosis to manage their sense of stigma, shame, and oddity as they navigated through coming to terms with living with a “feminine disease” in their masculine bodies (9, 45, 54):

“I told the guys I played golf with that I’d got cancer; I do not think. I necessarily told them it was breast cancer”. (9) (p.337)

“...but if I did, I would talk about it as chest cancer. I wouldn’t use breast cancer. So that would be the term I would use, and, in the conversation, I would say that it is the same as breast cancer. It’s exactly the same thing; it’s just it’s in my chest.” (54) (p. 964).

“I think among old men they almost consider it to be a stigma, they almost don’t want to tell people, you know, it’s some kind of, I don’t know, a black mark, but I never looked at it that way...I think people younger would just view it a little differently, you know it’s cancer, it’s something they have to deal with, it doesn’t really matter what type of cancer it is.” (68) (p.37).
<table>
<thead>
<tr>
<th>Codes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>• Living with a women's disease</td>
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<td>Navigating through a threat to masculinity</td>
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<td>• Living with an exotic disease</td>
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<td>• Threat to oneself</td>
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<td>• Living with it like “any other disease”</td>
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<td>• Breast cancer perceived as a ‘feminine’ disease</td>
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<td>• Feeling like an outsider/ stigmatized as being the only male patient with breast cancer at the hospital/ gynaecological units</td>
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<td>• Left in the cold after receiving diagnosis of cancer</td>
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<td>• Hair loss from chemotherapy</td>
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<td>• Mastectomy scars</td>
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<td>• Benefits of breast cancer treatment (and some procedure) were developed with women in mind. So, taking the same hormone therapy medications such as Tamoxifen as females which felt frustrating.</td>
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<td>• Being treated as a woman</td>
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<td>• Experiencing side effects of the medications (hot flushes, sweating and decreased libido/ lowered sexual potency, describing themselves as “menopausal women”)</td>
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<td>• Men with breast cancer felt health care practitioners did not know much about their disease and treatment regimen; lacked sensitivity and did not take the patients seriously</td>
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<td>• Difficulties with finding a doctor to treat them due to reimbursement issues (the GPs felt their specialty was women’s practice and did want to attend to the men with breast cancer)</td>
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<td>• Generally, they were satisfied with the medical care; some felt the services and procedures at the hospital failed to consider their needs)</td>
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<td>• Some men were unconsciously addressed as ‘Mrs’ in waiting rooms or in their letters.</td>
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<td>• Receiving emotional support from wives and partners</td>
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<td>• Attending support groups (although others were skeptical about joining)</td>
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<td>• Other coping strategies included physical activity, acupuncture, psychosocial services at the hospital</td>
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<td>• General lack of male-specific psychosocial support and information tailored to their needs</td>
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<td>• Until diagnosis, most men did not know about MBC (which delayed the timing of seeking healthcare/ diagnosis)</td>
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<td>• Some men or their wives had to persist before being referred to the consultant surgeon</td>
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<td>• Shock and needing emotional support at the cancer diagnosis</td>
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<td>• Unwilling to discuss MBC diagnosis with other family members/ close friends; but they did not feel embarrassed</td>
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<tr>
<td>• The myth that breast cancer is “a woman's disease”</td>
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<td>• Living with mastectomy scars/ body image changes</td>
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<td>• Feeling that exposure to environmental toxins had caused the cancer</td>
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<td>• Questioning about the cause of the cancer</td>
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<td>• Lack of information specifically about breast cancer</td>
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<td>• Being put on medication originally prescribed for females with breast cancer (Tamoxifen)</td>
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<td>• Healthcare professionals’ inadequate knowledge on how to manage MBC.</td>
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<td>• Support from female friends</td>
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<td>• Postoperative support and advice was lacking</td>
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<td>• Not surprised to be diagnosed with breast cancer, but the men were shocked at receiving a diagnosis of breast cancer as it is considered a gendered disease</td>
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<td>• Some men disclosed to close family and friends and others did not disclose to anyone</td>
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<td>• Not wanting sympathy or to be stigmatized</td>
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<tr>
<td>• Lack of awareness as perceived about breast cancer among men</td>
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<td>• Feeling awkward while discussing sensitive issues</td>
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<td>• Wishing their condition were called something else, rather than breast cancer</td>
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<tr>
<td>• Younger men affected by altered body image than older men</td>
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<tr>
<td>• General lack of information about breast cancer and the treatment process in males</td>
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<td>• Support received from wives and partners</td>
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<tr>
<td>• Most were generally not interested in talking to other men with other forms of cancers</td>
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<td>• Participants did not describe delay in seeking healthcare</td>
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<td>• Wives/ partners played a key role in pushing for early health seeking</td>
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<td>▪ Men reacted stoically following breast cancer diagnosis</td>
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<td>▪ Men reacted stoically following breast cancer diagnosis</td>
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<td>▪ Healthcare professionals were less sensitive and “matter-of-act” attitude</td>
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<td>▪ Healthcare professionals were less sensitive and “matter-of-act” attitude</td>
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<td>▪ Not fully open about their diagnosis</td>
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<td>▪ Not fully open about their diagnosis</td>
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<td>▪ Some men were concerned about their appearance (some would stare at their scars; unable to remove their shirts during outdoor events)</td>
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<tr>
<td>▪ Some men were concerned about their appearance (some would stare at their scars; unable to remove their shirts during outdoor events)</td>
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<td>▪ Receiving support from their partner</td>
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<td>▪ Receiving support from their partner</td>
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<td>▪ Disappointed at the lack of information on breast cancer specific to men</td>
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<td>▪ Disappointed at the lack of information on breast cancer specific to men</td>
<td></td>
<td>▪ Men showed pictures of females who had undergone mastectomy and not male mastectomy</td>
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<tr>
<td>▪ Men showed pictures of females who had undergone mastectomy and not male mastectomy</td>
<td></td>
<td>▪ Majority of men would appreciate a chance to discuss with another man with breast cancer on basis</td>
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<td>▪ Majority of men would appreciate a chance to discuss with another man with breast cancer on basis</td>
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<td>▪ Receiving the cancer diagnosis as a lightning strike</td>
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<td>▪ Receiving the cancer diagnosis as a lightning strike</td>
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<td>▪ Being scheduled for mammography or being told of having a lump led to feelings of being men with breasts</td>
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<td>▪ Being scheduled for mammography or being told of having a lump led to feelings of being men with breasts</td>
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<td>▪ Feeling dumbfounded with a cancer diagnosis and its location</td>
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<td>▪ Feeling dumbfounded with a cancer diagnosis and its location</td>
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<td>▪ Feeling of having breasts, not only a chest</td>
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<td>▪ Feeling of having breasts, not only a chest</td>
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<td>▪ Feeling like a freak because of the gendered status of the disease</td>
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<td>▪ Feeling like a freak because of the gendered status of the disease</td>
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<td>▪ Living with visually disturbing mastectomy scars</td>
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<td>▪ Living with visually disturbing mastectomy scars</td>
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<td>▪ Feeling lucky of having the cancer at a part not considered “vital”</td>
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<td>▪ Feeling lucky of having the cancer at a part not considered “vital”</td>
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<td>▪ Concerns about the wound, but not the so significant gendered part</td>
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<td>▪ Concerns about the wound, but not the so significant gendered part</td>
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<td>▪ Men concerned about their body image and upper-body mobility following affecting mastectomy</td>
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<td>▪ Men concerned about their body image and upper-body mobility following affecting mastectomy</td>
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<td>▪ Mastectomy re-sculptured their muscles necessitating a need to amend their masculinity</td>
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<td>▪ Mastectomy re-sculptured their muscles necessitating a need to amend their masculinity</td>
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<td>▪ Support from wives and partners</td>
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<td>▪ Support from wives and partners</td>
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<td>▪ Living with a disfigured chest</td>
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<td>▪ Living with a disfigured chest</td>
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<td>▪ Living with the side effects of the adjunct hormone therapy (sudden mood alterations, hot flushes, emotional explosions, PMS, altered sexual lives, loss of erections etc.)</td>
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<tr>
<td>▪ Living with the side effects of the adjunct hormone therapy (sudden mood alterations, hot flushes, emotional explosions, PMS, altered sexual lives, loss of erections etc.)</td>
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<td>▪ Younger men more concerned about their physical bodies than older men</td>
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<td>▪ Younger men more concerned about their physical bodies than older men</td>
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<td>▪ Managing breasts and masculinities</td>
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<tr>
<td>Codes</td>
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<tr>
<td>• Having troubles with scheduling mammography (feeling like the only male in the sorority)</td>
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<td>• Embarrassing to interact with healthcare staff about MBC</td>
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<td>• Feeling out of place/ alone at clinics</td>
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<td>• Lonely process in coming to terms with the reality of the diagnosis/ having breasts</td>
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<td>• Concealment a life-threatening cancer and its location to manage their sense of oddity</td>
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<tr>
<td>• Amending or reformulating their masculinities (men with breasts and cancer, seeking emotional support from close friends and partners, opening up to others about their cancer experiences)</td>
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<td>• Not seen as gendered malignancies like testicular cancer which participants could lay a legitimate claim of ownership</td>
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<td>• Giving the illness a gendered status</td>
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<td>• Associating the illness more closely with femininity than masculinity</td>
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<td>• Body image changes/ sexuality concerns</td>
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<tr>
<td>• Some surgical procedures following MBC impacted on their masculinity, and in some instances, their sexual orientation</td>
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<td>• Public information regarding male breast cancer is scarce</td>
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<td>• Distress because of living with inaccurate information on the disease and misunderstandings</td>
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<tr>
<td>• The experience of loss of libido and erectile dysfunction following tamoxifen therapy. This impacted on their masculinity.</td>
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<td>• Seeking refuge by concealing their diagnosis (the period of concealment offered some form of respite for the reality of the illness to be rationalized and accommodated); others also experienced struggles between maintaining secrecy and self-declaration which disrupted their inner and idealized outer world</td>
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<td>• Healthcare staff were excellent but were often unaware of the specific information and psychological needs of men</td>
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<tr>
<td>• Feelings of being marginalized in the clinics (as HCPs attempted to conceal them from the female clients by asking them to wait in other parts of the clinic or use alternate entry/ exit routes)</td>
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<td>• Surprised at the breast cancer diagnosis</td>
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<td>• Seeing the physician promptly once the problem was detected</td>
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<tr>
<td>• Some men experienced reluctance in sharing their unusual problem or disclosing their problem</td>
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Codes | Sub-themes | Themes
--- | --- | ---
• Trying the find the right name for the disease (chest cancer, cancer on the chest etc.) |  |  
• Feelings that it is a woman's disease |  |  
• Support from wives, and family |  |  
• Need to speak to men with similar experience of MBC. |  |  
• Role strain reported by younger men as they were worried about their inability to provide for the family during the period of receiving chemotherapy |  |  
• Worry about having to rely on others |  |  
• Feelings of permanent stigma associated with the mastectomy scars |  |  
• Although dealing with the disease had been difficult, younger men reported gaining new insights in life and changing their views and life priorities |  |  
• Mixed reactions of the physicians (some referred immediately, and others did not express suspicion about a cancer diagnosis/ wait and see attitude which led to late delays with diagnosis) |  |  
• Difficulties in accessing gynecological care (rejection by some healthcare centres due to billing issues) |  |  
• Some men were satisfied with in patient care and did not differ from routine care; some men felt being in a special position such as receiving more attention from healthcare professionals whilst others did not feel comfortable with it as being the only male in a room for a procedure whereas the women were divided into the rooms |  |  
• Stigmatization during hospitalisation |  |  
• Treatment with tamoxifen was associated with uncertainty and side effects |  |  
• Being the only man among women during rehabilitative care (some experienced positive experiences as they got the chance to share with the women) |  |  
• Feeling exotic and excluded from the group during the rehabilitative/aftercare phase |  |  

**Opening up/ coming out of the illness closet**

As the men gradually came to terms with living with the “foreign or exotic disease”, they were able to talk to their families and close friends about their diagnosis (9). This required a lot of courage to navigate through such sensitive issue. Interestingly, the men noted that the process of openly discussing their diagnosis in social spheres and coming out to others offered them an opportunity to reassert the meaning of masculinity, particularly as they recognize how fragile their masculine bodies are (50):
“When I spoke to people about it, they thought I was telling fairy tales ... that was really the worst thing about it.” (46) (p.8).

“I want to prove to everybody that MBC is not a women’s disease and that a normal man can have MBC.” (50) (p.468).

**Theme 2: Navigating through treatment**

The theme captures the experiences of undergoing breast cancer treatment/management following their diagnosis. The subthemes are 1) navigating through feminized treatment pathways and 2) living with the effects of care/ongoing treatment.

**Navigating through feminized treatment pathways**

Despite the reality of breast cancer among males, the care pathways and healthcare payment frameworks across various healthcare systems are significantly tailored to the needs of female which reinforces the notion of the disease as a feminine in nature (50, 52). A study from Germany highlighted the difficulty that these men experience in finding a physician as the practitioners felt their breast care specialty targeted women and would lose on reimbursement (46). Even in facilities where they were given satisfactory care, the men felt the services and procedures still failed to consider their unique needs as men with breast cancer (50, 52, 66). Some men were mistakenly addressed as females on the assumption that only females experienced breast cancer (46). Male-specific psychosocial support and information were generally lacking across the studies. Information leaflets mostly contained pictures of female breast cancer patients which made the men feel excluded (46). In fact, they felt the service was not designed for them:

“My GP said: ‘I don’t know what to do any more, it’s not my specialty area. I’ll have to refer you to someone else’. And the other doctor said, ‘This is a women’s practice (...) and we can’t get reimbursed for men, we don’t want men here.’” (46) (p.9).

“. . . but I think as a male the information that I was given was female orientated and it could have been better presented for me and . . .I know that every case is different, but it was lacking in that respect”. (9) (p.336).

Further to the above, some men had several challenges in scheduling for therapeutic regimen such as mammography (68). Interactions with healthcare providers were often considered awkward as the providers often did not know what to say to the men with breast cancer. Subsequently, most men with breast cancer undergoing treatment often felt like outsiders, out of place, marginalized, and alone:

‘No information. Nothing at all. It was like men; you are on your own. I daresay women aren’t left like that. . .On leaving after the first operation the nurse gave me a leaflet, a piece of paper with women on it doing exercises you have to do and that was it”. (9) (p.336).
“I find that dealing with the mammograms and the technical staff to kind of tiptoe around you and put you in certain places because they don't expect a male to be there, right, so they got women walking around in their gowns, so they don’t want you in those areas... they kind of shunt you into an isolated, a more isolated area so you’re not seeing the women walking by.” (54) (p.967).

**Living with the effects of care/ ongoing treatment**

Men undergoing treatment for breast cancer felt their lives were impacted by the treatment regimen. The clinical management process of the disease, in fact, further heightened the gendered essence of the disease. For men who underwent surgical intervention, the mastectomy scar served as a permanent reminder of the disease impacted on their masculinity (54). Others felt their chest had deformed due to the scar (52). The typical exposure of the male chest at leisure activities such as the beach was considered a no-go area to conceal the scar from public view. The scars also evoked a sense of perceived stigma among these men (45):

“I've been abroad and sunbathed. People do look, they do look” (52) (p.1835).

“I don’t feel a complete person either because I’ve got something missing, haven't I? ... My nipples not there anymore. Sometimes I look in the mirror... I don’t like doing that. It's gone... There's a scar across there... Doctor said I look like a patchwork quilt. So, I don't bother taking my shirt off now. And something else ... yes you ought to have a tattoo as a nipple”. (9) (p.337).

For men who underwent hormone therapy, it was observed that the side effects of the various medications threatened their notion of being a male. Experiencing erectile dysfunction and loss of libido were really challenging for these men as they felt they had lost their sense of masculinity or what made them men (46, 69). Hair loss from chemotherapy was also challenging and frustrating for them (46). These men felt as though they had been transformed to ‘menopausal women’ (46).

“We're candid and honest with one another … male sexual potency has gone.” (46) (p.9).

“This has killed my sex life; I can no longer get an erection. I'm on this Tamoxifen which I've got to take for 5 years. You know it's driving me mad. I get free Viagra but there is nothing there. There are no feelings or anything like that and it's terrible. I couldn't get an erection or nothing. I don't know what it was, I just felt so no, no (silence) I just felt so embarrassed.” (50) (p.467).

Further to the above, some men felt they were a burden to others as they had to rely on others to have their needs met. Younger males felt their traditional roles as providers of the family was threatened as their dependence increased with a slow return to work and had to be supported by their spouses (48):

“You start to receive only sickness benefits and when all of a sudden, you have over 500 euro less, you have to first see how you manage with that. And for me [...] it was even more because I only have a 60% part-time job and work as a freelancer on the side. And that I couldn’t do any longer either.” (48) (p.6).

**Theme 3: Coping and support systems**
The theme describes how men with breast cancer coped with the disease, treatment process, aftercare/rehabilitative care, and the available support. The subthemes are 1) active coping strategies 2) family support and 3) support from healthcare providers and other support groups.

**Active coping strategies**

Although the breast cancer diagnosis was considered threatening with intense emotional stress, some affected men remained optimistic and hopeful of improved outcomes. Affected men often worked towards accepting the disease which made the navigation process less challenging (60). The treatment process and aftercare phase offered the affected men an opportunity to amend or reformulate their notion of masculinity (68). Although dealing with the disease was difficult, the men reportedly gained new insights in life which helped to reshape their worldviews and life priorities (10).

“I was kind of self-conscious the first year or so but um, I’m in pretty good shape, I’m relatively muscular, not super muscular, but I’m toned, I’m in shape, and I think a lot of times unless I’m really up close to people, I think a lot of times they don’t even see it... I’m not self-conscious. I go on vacation or go swimming at the beach, I don’t feel like people are staring at me.” (68) (p.38)

“Breast cancer, for me, means a whole complex of experiences, of realizations. It's like being in the military, you know. You meet somebody who's been in the military, you don't have to say anything. But if you meet someone who hasn't, there's not a way in the world to describe what it's like.” (68) (p.38)

**Family support**

Spousal support was identified as a significant resource to seeking healthcare in the first instances as some wives had to push their partners to seek medical care (44, 50). Spousal and family support also helped men to navigate through the breast cancer diagnosis, coming to terms with the disease (19, 44). Family support was also an essential resource during the treatment and aftercare phase as family members offered emotional and practical support (60):

“My wife was my support – she and I talked about everything. At the beginning we talked about it and agreed that I would have her as my support and she would have her family to support her through. It worked well and I also got support from her family. .. mine were useless”. (9) (p. 338).

**Support from healthcare providers and other support groups**

Although men with breast cancer felt their needs were not always met, they acknowledged the support received from healthcare providers regarding diagnosis, information, treatment options, and aftercare support (19, 44). A mixed finding was however observed regarding the support groups. Whereas some men appreciated the opportunity to talk to other men with breast cancer on one-to-one basis (46, 52), other men did not prefer this and were satisfied with the support offered by the healthcare providers (9):
“...none of the guys wanted to have self-help groups ... I don’t think they need the psychological support that perhaps women do, and women tend to congregate and talk about these things anyway. I think this is, of course ... research I know ... but actually quite therapeutic in a way”. (9) (p.338).

“To be honest, I don’t know how I would be managing if I had never had (the support group). They gave me back the will to live and I will always be grateful for that.” (46) (p. 9).

Objective 2: Types of treatment for male breast cancer

Five key therapeutic modalities were reported across the included studies: surgery, radiotherapy, chemotherapy, hormonal therapy, and palliative care. The surgical interventions included mastectomy (3, 46, 49, 53, 55, 57, 61, 65), lumpectomy (34), lymphadenectomy (36), and sentinel/ axillary lymph node biopsy (36).

Discussion

Breast cancer is generally perceived to be a disease common among women albeit incidence among men is rising, creating a need for health systems to be responsive to their needs. To this end, this review sought to develop a comparative understanding of the experiences of men with breast cancer and the treatment options available to them across different demographic settings. The review findings highlight the embodiment of breast cancer as a ‘feminine’ disease which is incongruent with what it means to be a ‘man’ and hegemonic masculinity discourses. Throughout the trajectory of the disease (that is, from diagnosis to aftercare), the review findings underscore the gendered nature of the disease with a lack of health system preparedness to support men who develop a disease perceived to be ‘feminine’. Though the treatment pathways were similar to those observed in the management of female breast cancer patients, they may not necessarily meet the unique needs of MBC across the disease trajectory warranting urgent attention considering the increasing prevalence of the disease among men. Male-specific treatment pathways and professional support are also required.

The breast is seen as a symbol of femininity, and as incongruent with being male, together with the significant public health emphasis on the prevention of breast cancer among females (70, 72) have further championed the perception that breast cancer is a feminine illness (49, 68). Thus, it was not surprising that the finding regarding being out of sync with one’s body resonated across the included studies. The breast cancer diagnosis which commenced the illness trajectory was really challenging for the men and filled with varied emotions. Despite the difficulty, the professional support available was often gendered and unsuitable to their needs. Thus, they mostly had to rely on their spouses and close families/ friends if they were able to open up to them, which may take some time. Coupled with the hegemonic masculinity ideology that a man must always be in charge and not demonstrate any emotions which can be perceived as weakness, it is likely that men will navigate through these on their own which can make the journey very lonely for them. Agreeing with a previous study, depressive symptoms, anxiety, and traumatic stress symptoms were common occurrences following the breast cancer diagnosis (51). The culture of silence around the issue can lead to utilizing avoidant coping
mechanisms which may delay support seeking among men. Taken together, the findings highlight a need for tailor-made, individualized counselling support service for men before, during, and after breast cancer diagnosis. The need for healthcare professionals to consider the impact of the MBC on men cannot, therefore, be overemphasised.

Commencing treatment and aftercare/rehabilitative support is an equally challenging phase for men living with breast cancer. A previous study has observed that gender impacts on the experience with breast cancer treatment (11). The review findings highlighted the ‘feminized’ nature of the treatment pathways with some practitioners not even knowing how to support the affected men. Information leaflets and other educational materials were generally noted to be filled with images of females which made the men feel out of place. Overall, these can serve as structural barrier which potentially deter men from seeking help even when required (46). Undoubtedly, breast cancer affects more females than males. However, healthcare service delivery should be tailored to the unique needs of men to overcome the feeling of marginalization or being left out. The impact of the therapeutic regimen should also be highlighted particularly as they can lead to loss of libido or erectile dysfunction which further diminishes one’s sense of being a man in relation to societal norms. Surgical procedures can lead to scars which serve as permanent reminders of the illness which can have life-long impact on men. Professional support should therefore not end after the diagnosis phase but should extend to the entire treatment continuum and aftercare. There is also a need to raise awareness of male breast cancer among healthcare practitioners to improve their approach to individual through person-centred and male-specific care strategies. It may be worth reiterating the recommendation by Nguyen et al., (46) suggesting a guideline targeting men with breast cancer to support healthcare practitioners in the health and social service delivery process.

The need for support was reiterated throughout the review, and this is corroborated in previous study where family and spousal support was critically important for men with advanced prostate cancer (71). Interestingly, mixed findings were observed regarding the need for male-specific support groups. Although this may be based on individual preferences, it may also emanate from the hegemonic masculinity ideology (72, 73) as men may appear ‘stoic’ in the presence of such difficult moments and may not want to seek help (46). Despite this, it is still cogent to understand their lived experiences and advocate for male support groups, if they would like to join one, as they navigate through the diagnosis, treatment, and aftercare pathway.

This study presents the synthesis of multicultural evidence to highlight the cross-cultural similarity in the reaction and lived experience of men when faced with the diagnosis of breast cancer. The interesting findings notwithstanding, there some limitations that needs to be highlighted. Firstly, we included only studies published in English. Thus, studies in other languages which may have reported on the experiences of men with breast cancer were excluded. Secondly, we acknowledge that younger and older men may have unique experiences while navigating breast cancer diagnosis and treatment. These nuances were not captured in the current review and may be worth exploring in future studies.
Conclusion

Men experience a myriad of issues following a breast cancer diagnosis, underscored by their ideology of masculinity. Our findings suggest the need for healthcare professionals’ training and education on managing interactions with MBC in a way that does not propagate a sense of awkwardness and otherness in a feminised support structure. Additionally, policy must address the structural barriers to treatment access for MBC including healthcare finance reimbursements that limit access to gendered specialist breast cancer treatments. Awareness creation efforts of MBC among the general public as well as healthcare practitioners are urgently required.

Professional care intervention and support for MBC should not end after the diagnosis phase but should extend to the entire treatment continuum and aftercare. Preserving sexual function is an important finding highlighted from this review. Research will be needed to develop and test testosterone-preserving treatment modalities or tweaking existing therapies in a way that is relevant to the priorities of MBC. This will also require the development of specialised guidelines for healthcare practitioners on MBC to optimise care and treatment for MBCs in a person-centred manner. In order to develop such individualised support frameworks, it is imperative to understand the specific needs, priorities, and support preferences among MBC.

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Competing interests

The authors have declared that no competing interests exist

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Authors' contributions

This review was conceived and designed by JB, MA-O, YS, OA and TA. The first reviewer imported all search results to Endnote reference manager version X9, de-duplicated, then all authors screened titles
and abstracts of all identified studies, any article for which inclusion was unclear were discussed and if necessary adjudicated by YS and TA. All authors critically appraised and contributed to the manuscript.

Acknowledgements

Not applicable

References


Tables
Table 1 is available in the Supplementary Files section.

Figures

Figure 1

A flow diagram on the results-based convergent design
Figure 2
Flow chart of study search and selection process

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table1DataextractionontheexperiencesandmanagementapproachesofMBCfromincludedstudies.docx