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The experiences of men with breast cancer in the United Kingdom

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ABSTRACT

To investigate the experiences of men with breast cancer across the United Kingdom, a multi-phase study using: (a) focus groups ($n = 4$) with men and women with breast cancer and with healthcare professionals; (b) questionnaires to men with breast cancer ($n = 161$); (c) follow-up interviews with these men ($n = 30$) and (d) reconvening the focus groups ($n = 2$) for the men and women with breast cancer. The majority of men (84%, $n = 135$) reported their symptoms early, but were shocked to receive a breast cancer diagnosis. Disclosure of the diagnosis was commonly made to partners (80%, $n = 129$) and other close family and was influenced by perceptions of embarrassment, stigma and altered body image. Very little information was available to participants; that which was available was often inappropriate as it was intended for women. Over half the sample wanted much more information (56%, $n = 90$). This study also demonstrated low utilisation of formal support services and initiatives are needed to improve the information and support provided to men with breast cancer after diagnosis and treatment. Increasing the profile of breast cancer in men generally amongst healthcare professionals and the public is also needed.

1. Introduction

Breast cancer in men is rare [1,2]. Approximately 1% of those diagnosed with breast cancer each year in the United Kingdom (UK) are men, with 245 men in England [3], 23 men in Wales [4] and 18 men in Scotland [5] newly diagnosed with breast cancer in 2001. There is a paucity of information about trends in breast cancer amongst men. Although the incidence is reported to be rising in the US [6], a review of incidence trends in the early 1990s gave no support to the existence of upward trends in Europe [7]. This is unlike breast cancer in women where incidence rates are rising in most countries throughout the world [8,9].

The most common symptom of breast cancer in men is the presence of a painless lump [10]. Clinically, there is a similarity to breast cancer in women with hormonal, genetic and environmental factors contributing to the development of the disease [11]. Risk factors can include age, benign breast conditions, testicular disease, Jewish ancestry, and chromosomal abnormalities such as Klinefelter's syndrome [12,13]. It has also been suggested that predisposing risk factors include radiation exposure, oestrogen administration, and diseases associated with hyperestrogenism, such as cirrhosis of the liver [2]. Obesity can increase the risk of breast cancer in men, possibly through hormonal mechanisms, so dietary factors and physical activity may also be relevant [14]. About 10% of

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breast cancer in men is attributed to *BRCA2* mutations [15]. Studies also suggest socio-economic correlates such as geographical location, education level and social class deserve further investigation [12,14].

Survival rates for men with breast cancer are inferior to women, despite indications that breast cancer in men is equally curable in comparable stages [16,17]. Stage of disease predicts survival rate, and men frequently present with more advanced breast cancer than women. The mean age of presentation in most studies is 60–65 years, ranging from the mid-20s to the early-90s [1,18]. Optimal management of men is unclear as the rarity of the disease precludes large randomised controlled trials. Much of our current knowledge regarding the biology, natural history and treatment strategies for breast cancer in men have been extrapolated from women [19]. The relatively common nature of breast cancer in women has resulted in high levels of awareness, yet breast cancer in men remains comparatively unknown by both healthcare professionals and the general public [20]. The objective of this study was to investigate the experiences of men with breast cancer across the UK. We wanted to explore how they felt about being diagnosed with breast cancer; what information and support had been made available to them; their feelings about living with breast cancer on a day-to-day basis, and to elicit suggestions for practical improvements to healthcare services in the UK.

2. Patients and methods

This study was divided into four phases which ran from July 2002 to December 2003 (Table 1). Phase One consisted of two focus groups of men with breast cancer ($n = 5$; $n = 4$), one group of women with breast cancer ($n = 13$), and one group of health care professionals ($n = 5$). This phase explored the experiences of men with breast cancer, comparing them to women, and with healthcare professionals who care for both groups. These results have been published separately [21].

Phase Two involved a retrospective cross-sectional questionnaire to men with breast cancer across the UK identified through contacts in regional genetics centres, and the National Cancer Research Network. Eighty seven clinicians were issued with patient information sheets and consent forms, which they distributed on our behalf to men with breast cancer in their care. Some men were also recruited in response to media publicity about the study. Only once the consent form was returned and the patient agreed to participate, was a questionnaire posted to them. The questionnaire gathered demographic and clinical information from participants, and used psychological measures for general distress (Hospital Anxiety and Depression Scale [22]), cancer-specific distress (Impact of Event scale [23]) and coping (adapted COPE [24]). Open-ended questions were included asking men to elaborate on whether they wanted more information specific to men with breast cancer; whether they called their own illness breast cancer or something else, and their thoughts on causality. A total of 186 completed consent forms were received – 138 via clinicians (74%) and 48 from publicity (26%) – with 171 (92%) completing our questionnaire. Data from 10 men were excluded due to the length of time since diagnosis (>10 years); hence analyses were based on 161 participants – 82% ($n = 132$) from clinicians and 18% ($n = 29$) who self-referred.

Each man from Phase Two was asked whether he would be interested in participating in an in-depth interview to explore some of the issues for Phase Three. Fifty-seven percent of participants consented to continue ($n = 92$). This was in excess of the numbers required for data saturation ($n = 30$) so a sample of men were chosen randomly to give a good range of age, time since treatment and geographical spread. Interviews were conducted at participants' homes, lasting an hour on average and were tape-recorded.

Phase Four concluded the study by reconvening the focus groups from Phase One, reporting back results, and asking participants for practical recommendations for the future. There were two focus groups – one with men ($n = 7$) and one for women with breast cancer ($n = 10$). The focus group with healthcare professionals was not reconvened as the emphasis was on the patient experience and their perspectives on improving the quality of their care; instead the healthcare professionals were sent a short summary of the main results and asked to comment on the validity of findings.

The overall theoretical framework was developed from the literature and a previous pilot study in Wales [20] and evolved

Table 1 – Study phases

Phases	Method	Participants	Data collection and analysis
One July 2002–September 2002	Focus groups ($n = 4$)	Two groups of men with breast cancer ($n = 5$; $n = 4$) One group of women with breast cancer ($n = 13$) One group of healthcare professionals ($n = 5$)	Groups recorded and transcribed fully Analysis conducted by hand
Two October 2002–December 2002	Retrospective cross-sectional questionnaire	Men with breast cancer ($n = 161$)	Demographic and clinical information Psychometric scales and open-ended questions Data analysed using SPSS v.12.0
Three April 2003–August 2003	Interviews	In-depth discussions with men from Phase 2 ($n = 30$)	Each interview recorded and transcribed verbatim Analysis with QSR NVivo 2
Four October 2003	Reconvened focus groups ($n = 2$)	Men with breast cancer ($n = 7$) Women with breast cancer ($n = 10$)	Groups recorded and transcribed fully Analysis conducted by hand

through each phase of the study, focusing on the main themes of diagnosis and disclosure, information needs and support. Data analysis were sequential. For example, the topic guide used in the focus groups for Phase One concentrated mainly on the key themes above. However, the questionnaire in Phase Two was refined as aspects of these key themes emerged: e.g., body image, and standard psychological measures were included to capture the psychosocial impact of living with breast cancer. The survey data were analysed using SPSS 12.0 and descriptive statistics are reported here; an analysis of the prevalence and factors associated with psychological distress amongst participants will be reported elsewhere [25]. All 30 interviews were transcribed fully and analysed independently by two researchers. A framework approach [26] was adopted for this analysis to find meaning, salience and connections within the data as material was sorted into codes. Agreement on thematic categories was obtained by discussion and data were interrogated using the software package NVivo 2. Preliminary analysis of Phase Four data has involved identifying consensus in terms of practical recommendations for raising awareness about breast cancer in men. Additional analysis of this data is planned.

We acknowledge the methodological limitations of this study. Not all men with breast cancer may have been known to breast surgeons and geneticists. Due to the indirect nature of the recruitment process, it was not possible to estimate the overall number of men who were approached to participate. Furthermore, there is possible selection bias of clinicians who may have referred particular patients to the study and excluded others.

3. Results

This section presents an overview of key results from male participants in Phases Two, Three and Four of the study, including their demographic and clinical characteristics. Results from these phases are reported together as the participants were the same, and so for example, survey evidence could be illustrated by verbatim quotations from interviews. The dominant themes in each phase were consolidated by a process of repeated review and included diagnosis and disclosure, information needs, support and raising awareness about breast cancer in men (Table 2).

3.1. *Demographic and clinical characteristics*

The total study sample of men with breast cancer was 161. The demographic and clinical characteristics of participants are displayed in Table 3 which includes the male participants from Phase Four. The average age was 67 years with a mean time since diagnosis ranging from 2 to 120 months. Most men were married or living with a partner ($n = 125$, 78%) and were educated to at least secondary school level ($n = 102$, 64%). Almost one fifth ($n = 29$, 18%) of the sample had no children. Frequently, presenting symptoms included a lump ($n = 118$, 73%) and/or changes to the nipple ($n = 68$, 42%). Most men ($n = 135$, 84%) reported their symptoms to a GP within 3 months, many encouraged to do so by wives or partners. Around half the sample ($n = 87$, 55%) were still being treated for breast cancer and 49% ($n = 79$) were cur-

Table 2 – Dominant themes

Theme	Illustrative quotations
Diagnosis and disclosure	*“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.083] *“I was surprised more than anything. . . Women it’s an ever present threat . . . Men – never occurs to them”.* [I.035] *“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 don’t think I had heard of and the fact that it was cancer”.* [I.108] *“When I first knew I didn’t want everyone knowing, because I didn’t want everyone coming round sympathising”.* [I.025]
Information needs	*“. . . 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”.* [I.023]. *“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”.* [I.005]
Support	*“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”. [I.046]* *“What I personally would like to see besides information leaflets is . . .. .some money pumped into forming a men’s help group . . .. But I would happily spend time on a switchboard . . . to talk things through with other men in a similar position or men who might even be worried about it”. [I.043]* *“ . . .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”. [I.35]*
Raising awareness	*“By their expression they don’t believe me. You can tell they think I am conning them you know, lying to them or whatever”.* [I.005] *“Yes they were incredulous and then . . .a couple of them laughed”.* [I.022] *“I mean men know about testicular and prostate cancer but not breast cancer . . . why not?”. [I.023]* *“I guess every article you ever read is about women with breast cancer . . . And nothing ever says ‘oh by the way chaps you can get it too’. . .I don’t think raising awareness about it would be difficult it would just be about including men”. [I.044]*

Table 3 – Demographic and clinical characteristics of participants (n = 161)

Variable	
Age (years)	
M	67.30
SD	11.93
Range	27–88
Relationship status, *n* (%)	
Married or living with a partner	125 (78%)
Single (never married)	13 (8%)
Divorced or separated	10 (6%)
Widowed	13 (8%)
Education, *n* (%)[a]	
Less than secondary education	57 (36%)
Secondary education or above	102 (64%)
Number of children, *n* (%)[a]	
None	29 (18%)
1–3 children	115 (72%)
4 or more children	16 (10%)
Time since diagnosis (months)	
M	34.84
SD	31.04
Range	2–120
Presenting symptoms, *n* (%)[b]	
Lump	118 (73%)
Inverted nipple	43 (27%)
Discharge from nipple	25 (15%)
Pain	16 (10%)
Other	14 (9%)
Time taken to report symptoms	
Less than one week	78 (49%)
Less than 3 months	57 (35%)
Between 3 and 6 months	15 (9%)
Between 6 and 9 months	6 (4%)
More than 9 months	5 (3%)
Treatment, *n* (%)[b]	
Radical mastectomy	130 (81%)
Lumpectomy	38 (24%)
Radiotherapy	87 (54%)
Chemotherapy	43 (27%)
Hormone therapy, e.g. Tamoxifen	126 (78%)
Current breast cancer treatment, *n* (%)[a]	
Yes	87 (55%)
No	71 (45%)
Treatment side-effects, *n* (%)	
Yes	79 (49%)
No	82 (51%)

a Valid percentages are reported in cases where data were missing.
b Numbers and percentages are reported per category for variables where there were multiple response options.

rently experiencing side-effects. Some participants describe the discovery of their symptoms below:

> *"I was literally showering and suddenly became conscious about a lump and I hadn't noticed it before…I wasn't self-examining or anything……I just merely discovered it…" [I.018]*

> *"The first indications I've got of anything wrong whatsoever was the nipple started to invert…Firstly I assumed that was just age……thought this is what happens, as you get older…your body changes, so I thought ignore that. I'll just carry on"*. [I.074]

3.2. *Diagnosis and disclosure*

For 86% of participants ($n = 138$) the diagnosis of breast cancer was given by a surgeon. These men were not surprised to get cancer per se, but many were shocked at receiving a breast cancer diagnosis, particularly as it was perceived to be a gendered illness. Only 40% of participants ($n = 64$) had heard of the condition prior to their diagnosis.

Most men disclosed their diagnosis to spouses/partners ($n = 129$, 80%) and other close family and friends, with less disclosure to extended family and work colleagues ($n = 60$, 37%). A small number of men ($n = 6$, 4%) disclosed to no one. As well as not wanting sympathy or to be stigmatised, other reasons for non-disclosure included a perceived lack of awareness about breast cancer in men and awkwardness amongst others in discussing a sensitive condition:

> *"I told the guys I played golf with that I'd got cancer, I don't think I necessarily told them it was breast cancer"*. [I.002]
> *"It's the sort of thing friends don't like to raise. You know they feel embarrassed about it"*. [I.033]

Only 16% of participants ($n = 26$) stated they had experienced some embarrassment relating to their breast cancer, with very few men ($n = 4$, 2%) stating they would rather their condition was called something other than breast cancer. The issue of embarrassment emerged as significant to participants during the interviews as they expanded on their feelings about body image:

> *"I don't feel a complete person either, because I've got something missing haven't I?….. My nipple's 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"*. [I.005]

Altered body image seemed to affect younger men more; generally the older the men were, the less concerned they were about their appearance and more aware of their own mortality. There was some acceptance of altered body image when it was related to how much worse breast cancer is for women:

> *"But as time goes on, as I get older it becomes less important because I know I've got to die of something sometime so you get a little bit more relaxed…"* [I.021]
> *"No I am at the age where I think I got it, I got to put up with it"*. [I.056]
> *"I didn't have the traumas that women [have] … clearly for them the problem is the loss of their breasts ….My daughters says "Oooh it looks like you've have had a fight with a shark Dad. It makes you look really hard." No it doesn't. It's very nice of you to say so but 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".* [I.109]

3.3. Information needs

There is a paucity of information for men with breast cancer. The most common source of information for participants was verbal (*n* = 148, 92%), with 71% (*n* = 114) receiving leaflets and 53% (*n* = 85) receiving booklets; in addition, 20% (*n* = 32) had used the internet, while 12% (*n* = 19) saw a photograph prior to their surgery. Information was primarily delivered by healthcare professionals working in hospital settings, but much of what was available in written form was inappropriate, covering topics such as menstruation, breast reconstruction, and bra fittings. Over half of participants (*n* = 90, 56%) wanted much more information.

A photograph of a man after a mastectomy, and information about the side effects of treatments, were consistently cited as being the most useful pieces of information as they would enable men to better prepare for what lay ahead and could adjust their expectations accordingly. Some participants argued for leaflets specifically aimed at men; whereas others argued to simply include additional information about men within existing information packages. However, leaflets to raise awareness generally about breast cancer in men in primary care settings were also considered important:

> *"Well you'd look at that and think "Oh wow … I'm going to end up looking like that".* [I.033]
> *"The photo idea would be a very good idea – says much more in a picture…"* [I.023]
> *"I mean men are only just admitting to prostate cancer aren't they …they have always been a bit slow about talking about things like that ……and I think that, perhaps because it is called breast cancer they don't want to admit to it. But if they saw a leaflet that was actually aimed at men, not women and men, but men specifically …"* [I.022]

3.4. Support

Although partners provided emotional and social support, this study demonstrated low utilisation of formal support services. Only 19% of participants (*n* = 31) spoke to other men who had breast cancer, but 27% (*n* = 43) would have liked that opportunity after their diagnosis. Most were not interested in talking to men with other cancers either individually or in a group, or to women with breast cancer and the vast majority would not attend a mixed support group. However, there was some agreement from the men who were interviewed that it had been personally beneficial to have talked with an independent other about aspects of their condition.

The psychological impact of being a man with breast cancer varied considerably. The prevalence of clinically significant distress was low in this sample with 1% (*n* = 2) reporting depression and 6% (*n* = 9) reporting anxiety, although 23% (*n* = 35) reported a high level of cancer-specific anxiety in the form of intrusive thoughts about breast cancer and avoidance of such thoughts [25]:

> *"I can't think about it you know. Just hoping it won't come back. That's all I think about".* [I.002]
> *"Well you hear of so many people going in and finding things wrong and then they say oh it's all over their bodies … gone within weeks yes. So every little ache and twinge you get you think, it's going to happen to me like. Has it gone before I can catch it sort of."* [I.071]
> *"Yes that's right. That's what I felt. It felt as if you lost your sexuality and your awareness of your own person. I thought this is not right. In fact it made me feel worse about myself to the point I think, if I had carried on with it, I think I would have been suicidal. It seemed to kill all my spirit and to me I didn't want that".* [I.074]

Higher distress was associated with factors such as fear and uncertainty about the future, poor body image and having unmet information needs. Those with higher distress were more likely to express a desire for formal support in order to be able to voice their physical and emotional concerns.

3.5. Raising awareness about breast cancer in men

A partial explanation for the lack of awareness about breast cancer in men that exists in society was the belief that many people simply do not believe it is possible for a man to be diagnosed with breast cancer. Raising awareness about breast cancer in men for both professionals and the public was perceived to be crucial, particularly in relation to breast or nipple symptoms. One man pointed out that providing information about breast cancer in men in oncology units does nothing to raise awareness amongst men generally:

> *" …of course they are all the people who have got it ……But all the information …about whatever cancers you like … is in the oncology unit. That's not really the place it needs to be".* [I.018]

Box 1 details a number of suggestions made by participants in the male focus group in Phase Four about how to improve awareness about breast cancer in men. These suggestions focused on practical service improvements as well as general initiatives that would highlight the issue of breast cancer in men to men in their everyday lives.

Box. 1 Practical recommendations for raising awareness about breast cancer in men

- General information on symptoms, side effects and survival rates.
- Photos of men after mastectomies.
- Local matching schemes.
- A national register of men with breast cancer.
- A telephone help-line for male cancers.
- Health promoting TV ads and health promotion messages on beer mats.
- Posters about breast cancer in men in places where men go (e.g., pubs, gyms, garden centres).
- Devise a storyline about breast cancer in men in a soap opera.

4. Discussion

Breast cancer in men is an unusual and challenging condition and as far as we are aware this is the first psychosocial study of a large sample of men with breast cancer in one country. The men in this study had a range of reactions to, and experiences of, their diagnosis depending on their previous knowledge and contacts with the health services. There was a clear desire for more information, alternative sources of support specific to men and initiatives to raise awareness about the condition generally, that were cognisant of men's mixed views on such issues as masculinity, embarrassment, stigma, isolation and stoicism.

Studies have shown that men with breast cancer can delay visiting their GP between 6 and 9 months [13]. In one study in Morocco, the mean delay to consultation was 27 months [18]. However, most men in this study (*n* = 135, 84%) reported their symptoms to a healthcare professional within 3 months. A significant factor accounting for this decrease may be wives and partners encouraging their men to seek medical advice sooner. This study demonstrates that the expectations and influences of significant others (e.g. spouses, but also children) can determine medical help-seeking behaviour for men. Delayed presentation may have serious consequences for the patient's prognosis. Delays are associated with lower survival rates, so understanding better the factors influencing symptom reporting will enable the development of strategies to reduce delays in presentation for both men and women.

Women diagnosed with cancer tend to confide in several people [27]. Our study shows that initially men with breast cancer confide in single individuals, and then to close family and friends. Some men avoid disclosure about their cancer completely [28] and may use silence as a way of retaining self-control [29]. Factors relating to limiting disclosure are fear of stigma, low perceived need for support, and the desire to avoid burdening or embarrassing others. The greater potential for stigma for men diagnosed with breast cancer than for any other cancer was frequently noted. Men can feel constrained from discussing their health openly with others [30,31], a problem compounded by the fact that this disease is associated with women.

Additionally, the rarity of this condition amongst men left many participants isolated, particularly if their doctor had never treated a man with the condition before. Although most men did not consider breast cancer a threat to their masculinity, additional concerns about body image emerged as the study progressed, which suggests that it may be possible to underestimate the real impact of breast cancer on men and worthwhile to conduct in-depth studies exploring unmet information and support needs with larger groups of men over longer periods of time. An advantage of the mixed method approach to data collection used in this study is demonstrated by the fact that considerably more embarrassment about breast cancer was revealed in the interviews than had been suggested by the responses to the survey.

The men in this study reported high levels of need for information following their diagnosis, a factor which was associated with increased levels of distress. Theoretically, men should receive the same standard of information as women [32], to enable them to choose the most appropriate forms of treatment [10]. Participants received very little non-verbal information specific to breast cancer in males. It is interesting to note however, that whilst these men acknowledged the cost of developing completely new information sources for a comparatively rare condition, they believed that supplementary gender-specific sections within existing material, such as photographs of men and treatment side-effects for males, should be a first step.

A variety of coping mechanisms and support strategies were employed by the men in this study to enable them to deal with their condition. Men in breast cancer families often use avoidance as a coping strategy [33] and generally men and women cope differently, as both cancer patients and caregivers [26,34]. In recent years, disease focussed self-help and support groups have flourished, with the growth of cancer support groups for patients and their families being particularly noteworthy [35]. Although support groups are offered to most patients with cancer, the majority choose not to participate. The rationale for a support group is to give emotional, informational and practical support, as well as a sense of comradeship. Men are less likely to join support groups than women [36], but of those who do join they cite essentially the same reasons as women for joining, namely to learn more about their diagnosis, share their concerns, and to compare their physical and emotional progress with others. Generally, men in support groups have a tendency to seek information and knowledge about their illness, whilst women prioritise intimacy, confidential discussion and shared emotion [27,36].

It has been found that support given to women with breast cancer has a positive effect on their reactions to the illness and may even prolong their survival [37]. Experiences with support groups for men, such as the Man-to-Man prostate cancer support groups, demonstrate that healthcare professionals play a key role in informing newly diagnosed cancer patients about the availability of formal sources of support in their communities [38]. Some men in this study might have benefited from increased psychosocial support, for example by using matching schemes, registers or telephone help-lines, to supplement the traditional support group approach. Earlier referral could also enhance patients' access to shared experiences and facilitate more informed treatment decisions. Changing the theme of support groups to one of information-giving might improve take-up.

Breast cancer in men is an under-researched area in comparison to a range of other cancers and to breast cancer in women. Awareness and knowledge about breast cancer is variable in specific population groups and ignorance about this condition militates against informed decision-making [39]. Despite the growing profile of men's health, the extent of ignorance about breast cancer in men is a cause for concern. The risk of breast cancer for most men is low, but neither individual men nor their doctors regularly examine men's breasts, so men will continue to present with more advanced cancers than women. Many people in this study were surprised to learn that men can "get" breast cancer. Considerable work is needed to raise the profile of breast cancer in men amongst the general public, some of which ought to be performed in places where men congregate such as pubs, gyms and clubs. Men's health needs to be examined in context, with an understanding of the diversity of men's experiences and recognising multiple masculinities [40]. We also need to develop more innovative ways to facilitate men with expressing their healthcare needs in the future. This study illustrates that given the time, opportunity and support, men have valuable and constructive things to say about the way their breast cancer care should be delivered. Future prospective studies of representative samples are needed to explore the experiences of men as they progress through every stage of their diagnosis, treatment and care.

Conflict of interest statement

None declared. Ethical approval for this study was obtained from the Multicentre Research Ethics Committee for Wales.

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