Original article

Diagnosed with breast cancer while on a family history screening programme: an exploratory qualitative study

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Mammographic screening is offered to many women under 50 in the UK who are at moderate or high risk of developing breast cancer because of their family history of the disease. Little is understood about the impact of screening on the emotional well-being of women with a family history of breast cancer. This qualitative study explores the value that women at increased risk placed on screening, both pre- and post-cancer diagnosis and the impact of the diagnosis. In-depth interviews were undertaken with 12 women, aged 35–50, diagnosed with breast cancer while on an annual mammographic screening programme. Women described the strong sense of reassurance gained from screening prior to diagnosis. This faith in screening was reinforced by early detection of their cancer. Reactions to diagnosis ranged from devastation to relief at having finally developed a long-expected condition. Despite their positive attitudes about screening, not all women wanted to continue with surveillance. For some, prophylactic mastectomy was preferable, to reduce future cancer risk and to alleviate anxieties about the detection of another cancer at each subsequent screen. This study illustrates the positive yet diverse attitudes towards mammographic screening in this group of women with a family history of breast cancer.

Keywords: breast cancer, early screening programme, family history, qualitative.

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INTRODUCTION

Women with a family history of breast cancer are at increased risk of developing the disease (Pharoah *et al.* 1997; Emery *et al.* 2001). In the UK the population risk is currently between 1:9 and 1:10; this can be increased by at least threefold for those with a strong family history. Annual mammographic screening is one early detection method recommended for women from the age of 40 whose family history places them at a lifetime risk of developing breast cancer of 1:6 or greater (NICE 2004). Surveillance from the age of 35 can be carried out as part of a research programme.

Mammographic screening aims to detect tumours at an early stage when the prognosis is enhanced. While the potential clinical benefits of screening younger women at increased risk have not been established, evidence is emerging to suggest that screening younger women with a family history leads to increased survival (Maurice *et al.* 2006), and preliminary retrospective data suggest it is possible to identify impalpable breast cancer with regular mammography (Gui *et al.* 2006). Strong evidence of effectiveness in reducing mortality is important to establish if a national programme of early screening for all women at increased risk is to be introduced. The findings from a large prospective study evaluating the potential clinical benefits of mammographic surveillance in women aged 40–49 with a family history of breast cancer are expected in 2010 (The FH01 Management Committee, Steering Committee and Collaborators 2006).

It is equally important to understand the psychological impact of mammographic surveillance for women with a family history of breast cancer, particularly as a number of studies have reported increased levels of breast cancer worry and anxiety in this group of women (Lloyd *et al.* 1996; Zakowski *et al.* 1997; McCaul *et al.* 1998). The majority of women who attend screening receive an initial all-clear/normal screening result, and a small proportion will be recalled for further tests prior to their all-clear result. To date, research has focused on comparing the psychological impact of screening on women in these two screening result groups (Watson *et al.* 2004, 2005). The focus of the present paper, however, is on women who received a screen-detected cancer diagnosis while on a screening programme. It is estimated that of those with a family history who are screened every year, four women per thousand will receive a diagnosis of breast cancer (The FH01 Management Committee, Steering Committee and Collaborators 2006). To our knowledge, no studies have looked at how women react to a diagnosis of breast cancer while on a surveillance programme because of their family history, or how they feel about the breast screening programme that has detected their breast cancer. This paper presents the first qualitative data on the emotional impact of being diagnosed with breast cancer while on a screening programme in the UK.

PARTICIPANTS AND METHODS

A qualitative study was undertaken involving interviews with 12 women aged 35–50, diagnosed with screen-detected breast cancer while on a mammographic surveillance programme. Participants were identified from two sources: (1) a sample of 2321 women, at moderate or high risk of developing a familial breast cancer, who had been recruited by 21 centres in the UK to participate in a questionnaire survey (12 women) (Henderson *et al.* 2007); (2) two of the clinics identified women outside the survey who fulfilled the eligibility criteria (7 women). All women were approached with the consent of their clinical team. Six women were interviewed from each of the sources. Reasons for non-participation were (1) non-response from the women (four women) or (2) clinicians not agreeing to the women being contacted (three women). See Table 1 for biographies of the participating women.

Data were collected using in-depth, semi-structured interviews. Interviews were carried out by AC; all women chose to be interviewed in their own homes, and interviews lasted between 90 and 150 min. A flexible topic guide was used to allow exploration of issues introduced by the participants and incorporation of additional issues that arose from the data analysis. The broad topic areas included experiences of breast cancer within the family, feelings of likelihood of developing breast cancer, own screening and cancer diagnosis experiences, views of mammography, of overall participation in the programme and future management of cancer risk. Each interview was audiotaped, transcribed verbatim by a specialist transcription service, checked for accuracy and anonymized.

Analysis was undertaken by AC, BH and ST using the framework approach (Ritchie & Spencer 1993). Analysis began as soon as the first interview had been undertaken, and continued concurrently with the data collection to allow emerging findings to be included in subsequent interviews. Through detailed reading of the texts, an initial coding frame was developed, using both anticipated and emergent issues. The frame was extended and refined as new data were generated. Broad themes, such as ‘reaction to diagnosis’ were subsequently subdivided into more specific categories, for example, ‘relief’ and ‘acceptance’. Texts were re-read and data relating to each theme were arranged to allow consistency and variation to be identified both across interviews and within each interview. The coding framework, categories and themes were discussed between the three analysts to ensure the credibility and trustworthiness of the interpretation and analysis (Mays & Pope 1995). A qualitative software package (ATLAS-ti 2007) was used to help in the management of the data, in particular in the comparison of issues and experiences between participants.

FINDINGS

The findings we describe below relate to the women's reactions to participating in an enhanced breast screening programme, and the emotional impact of their cancer diagnosis. The themes presented occurred across the range of participants and the quotations represent the full range of the responses given. The bracketed number is the identifier from Table 1.

Reasons for being on the early screening programme

The reason given by most women for wanting to be on the programme of regular mammography related to early diagnosis: the sooner a cancer is detected, the greater they perceived the chance of survival to be.

> . . . that's the crucial time to catch it isn't it, is in the early stages, which is what I was very keen on, thinking well you know if I'm going to get it I want to know as soon as it's there . . . I was highly unlikely to be able to detect it myself, so I wanted someone else or some other method of being able to detect it, which was the mammograms. [2]

As can be seen from the previous quote, related to early detection was the greater faith most women had in mammograms and clinical breast examinations than in self-examination. With the exception of one woman, there was

Table 1. Biographies of women diagnosed with breast cancer at an annual mammographic screen

Participant	Age at diagnosis	Risk*	Time between interview and diagnosis	Treatment	Type of cancer as described by the women	Number of previous screens
1	46	High	8 months	Lumpectomy Radiotherapy	'Small – caught early second lumpectomy to remove precancerous cells'	None
2	37	High	17 months	Mastectomy Chemotherapy Waiting for PM	'Very small – no lymph nodes, not palpable'	2
3	45	Moderate	5 months	Mastectomy Receiving chemotherapy Waiting for PM	'Grade 3 aggressive cancer, many lymph nodes involved'	11
4	40	High	8 months	Lumpectomy Radiotherapy	'Area of precancerous cells, no lymph nodes'	5
5	48	High	4 months	Lumpectomy Radiotherapy	'Very small – no lymph nodes'	3
6	43	High	10 months	PM Chemotherapy Waiting for reconstruction	'Aggressive'	4
7	46	Moderate	12 months	Lumpectomy Radiotherapy and chemotherapy Waiting for PO	'Small grade 3 – aggressive'	4
8	47	High	5 months	Receiving radiotherapy	'Very small – no lymph nodes'	8
9	47	High	49 months	Lumpectomy Radiotherapy	'Very small – no lymph nodes'	None
10	40	High	37 months	Mastectomy	'Very mild'	None
11	37	High	27 months	PM Reconstruction	'Preinvasive cancer' (both breasts)	20
12	50	Moderate	30 months	PM Chemotherapy Reconstruction	'Very small – early stage 1 lymph node involved'	8

*Family history risk as provided by the screening clinic.
PM, prophylactic bilateral mastectomy; PO, prophylactic oophorectomy.

a tendency not to self-examine on a regular basis. The experience was described as 'painful' and 'worrying' by those with what they described as large, tender or lumpy breasts. Lack of faith in their ability to differentiate a potential cancerous lump from a harmless nodule made some prefer not to self-examine.

> . . . if I hadn't have been screened, well I just dread to think what would have happened, because I did breast checks infrequently. *Interviewer* (*I*): *You weren't checking regularly?* No because it just made me feel sick doing it. In case there was . . . and I know it's stupid, but in case there was anything there. [3]

What early screening gave the women – feelings before the cancer diagnosis

The value that the women placed on being in the early screening programme was striking. There was variety in the understanding that women had about the effectiveness of screening – some women felt that if a cancer was there, it would be detected; others knew that not all cancers could be picked up and that screening for women under 50 years old was generally less effective than for older women. There was, however, no difference in the reassurance described by the women in terms of the reassurance that screening offered. 'Relief', 'peace of mind', 'safety net' were very common descriptions of the women's feelings about what screening meant to them. One woman reflects this in her description that mammography gave her:

> . . . the confidence and reassurance that I could just forget about it (*fear of developing breast cancer*) now until the following year. [6]

The security offered by mammography was also described in the following way:

> I don't think the mammography so much was the anxiety, it was the fact that you sit down in front of the doctor and who goes through your genetic tree and says your risk is, and that's the frightening bit. and the mammography was the safety aspect to it. [3]

For one woman, having regular and early screening took away the worry of developing cancer. She felt that if cancer was detected, the outcome would be far more positive than it had been for her relative.

> We always thought if any of us had breast cancer, because we were part of the screening programme, we would never be in the same situation that our sister was in, we were never going to be that bad. She was one side and we were the other. *I: In terms of the potential outcome, do you mean?* Yes, the severity of the disease would be nothing like my sister had. It was very aggressive. It was a very aggressive cancer . . . *I: Do you know what it was that made you feel it would be very different for you . . .* 'Early detection. If you're having them every year they would be detected at a much earlier stage'. [12]

Reaction to diagnosis

There was a marked difference in women's reactions to their cancer diagnosis. For several women, the diagnosis brought with it a sense of relief. A relief that finally the cancer had been diagnosed. As the following two quotes show, this reaction can be understood in the context of having for years lived with the fear of developing breast cancer.

> . . . it was like an expected, something we were expecting, so once it had turned up it was like okay we can deal with it now, whereas like before we were thinking oh when's it going to be and you know is it going to turn up, isn't it going to turn up, and you're almost living – not living on the edge but . . . you have that, so it probably sounds really weird doesn't it, saying it was almost like a relief . . . [2]
>
> Initially it was quite a shock. I felt quite shocked by it. and I have to say, it was a really strange feeling, and it probably sounds horrible, but I was almost relieved when I was diagnosed. Because I thought this dark cloud, that I've always been waiting for, is finally here. I don't have to wait for it any longer. I can deal with it now and get it over and done with. I know it sounds really strange but there was almost a feeling of relief. I mean obviously initially not, I was shocked. [11]

For some, there was nothing positive about the diagnosis. One woman described herself as being absolutely devastated when she developed breast cancer; for her, the diagnosis was completely traumatic. Having been told she had a one-in-four chance of developing breast cancer, she had interpreted this as:

> . . . my stakes were pretty high really on not getting it, and it never really affected my life . . . I managed to get through life thinking I was never going to get it and that's how I coped with it. [6]

While some women did not describe a sense of relief, they did describe resignation, an acceptance of the diagnosis, and a feeling of knowing that what they had felt was inevitable had finally happened and they would now deal with it.

> . . . no, I certainly wouldn't have liked to have thought right I want to have it just so that then I can move on. No, not at all . . . *when you were younger and . . . more at risk?* No. No. My anxieties were please don't let me get it, not right just give it to me and I can move on. No not at all. Yeah. You're not shock, shocked when you get the phone call, because you know you're at risk, but you are instead shocked that well this is it, it's happened now . . . [3]

Feelings about mammography after the detection of cancer

Perhaps not surprisingly, all the women were overwhelmingly positive in their attitudes to having had a mammogram. Their diagnosis had come early enough for treatment to be beneficial. This was most noticeable for women whose cancers could not be felt even when seen on the mammogram, although women whose cancers were at a more advanced stage still felt mammography had given them the opportunity for curative treatment.

> *I: How do you feel about accepting the offer that they made of being on the screening programme?* Elated! (laughs) Because as I say the way I look at it, if I hadn't been on that screening I'd be dead, because it being a grade three, I wouldn't have found that lump possibly for a couple of years, by which time it would be too late for treatment basically because by that time, with it being a grade three, it would have gone through my body and it would have been elsewhere and that would have been a horrible prognosis I think, definitely. So I'm eternally grateful for being on it. [7]

Anticipated reactions to future screening

Despite the overwhelmingly positive reaction to mammography, there were differences between the women's reactions to the ongoing management of their cancer risk. Not all women wanted to continue with surveillance by yearly mammography. Some described wanting to rid themselves of the anxiety that they felt regular screening would provoke, and in preference selected bilateral mastectomy as their treatment of choice.

> I don't want to have any more screening done, because you're looking for something again aren't you, you know. So if I've had my breasts removed there's nothing left for anybody to screen . . . I just want to get rid of the anxiety now, of having to go back for regular . . . it was like a reassurance before, whereas like now I'm thinking I don't want you to look, just remove whatever you need to remove . . . [2]

> . . . if I hadn't have had my other breast off, I think I would have had fear then, every time I had a mammogram I would have been more fearful . . . So I had bilateral mastectomy which, I had no difficulty making that decision at all. I just didn't want to live under the cloud every year of having mammograms on the other breast. [12]

> Another woman who no longer wanted to continue with screening also selected bilateral mastectomy as her treatment of choice, as she wanted a minimal chance of the cancer returning. Her mother had experienced two recurrences following her initial breast cancer, and she herself had suffered a very powerful emotional reaction to her chemotherapy regime. [6]

Those who felt that they would carry on with screening described an anticipation of feeling more anxious at the time of the next mammogram, fearful that a second diagnosis might be made. Despite this, the first diagnosis was translated into a positive reason to maintain screening. If a further cancer did develop, the women had faith that it would again be detected by mammography.

> I think if I got called up again, and they found another one I'd be fed-up obviously, you know if they said "Sorry Mrs xxx we've found another one in here", I'd just say 'Right well take it out.' You know what else can you do? [5]

Women had not always anticipated their reactions to future management. One woman, who had felt a strong sense of relief at the point of diagnosis, had initially decided to undergo bilateral mastectomy. This was based on her feeling '. . . how much of my life do I want to spend thinking I'm going to get cancer?'. She subsequently changed her mind about treatment and decided to continue with screening, having become aware that her worries about dealing with cancer were now less than they had been prior to her diagnosis.

> I hope I'm right in thinking this, but in another year or two if they tell me they've found something else I do feel as though I'll probably be a lot more sort of oh okay, right what happens next? I think I'll deal with it better than I thought I would in the first place you know. As I say I've dealt with it all right actually this time . . . much better than I thought I would . . . [8]

DISCUSSION

This study has highlighted both commonalities and diversities in the women's reactions to mammographic surveillance and to a cancer diagnosis. The perceived value of early detection gave women a strong sense of reassurance during the time they were receiving screening, and the detection of their cancer at a sufficiently early stage to warrant potentially curative treatments confirmed their faith in the screening programme. Specific reactions to the diagnosis varied, from a sense of relief that finally the wait was over, to intense shock. Despite the positive attitudes towards mammography, both pre- and post-diagnosis, not all women wanted to continue mammographic screening, preferring bilateral mastectomy both to reduce risk and to alleviate continuing concerns.

When asked to reflect back on their feelings about the screening programme before their diagnosis of breast cancer, most women described the security afforded by the screening programme and their belief that any cancers would be detected at an early stage. While some women highlighted issues to do with effectiveness of screening for younger women, this seemed not to influence the relief they obtained from receiving an all-clear result. The faith in mammography held by women has been highlighted in another qualitative study exploring beliefs and expectations of women under 50 years old regarding screening mammography in the general population (Nekhlyudov *et al*. 2003). In both this and our study, all women had positive attitudes towards screening mammography; the perceived risks of mammograms were seen to be minimal, and the women's feelings did not reflect the current controversy about the value of screening in women under 50 (Moss 2004).

While repeated regular self-examination is not currently advocated, breast awareness involves being responsive to potential changes, which may be seen or felt ('Be Breast Aware' leaflet 2006). A number of women in our study voiced concerns about examining their own breasts, a finding which has also been reported in other qualitative studies (Salazar & Carter 1994; Persson *et al*. 1997). Some questioned how reliable self-examination is as a means of detecting breast symptoms, and also described being inhibited from touching their breasts through fear of detecting a symptom. It may be that these apprehensions increased the trust placed in early screening. This finding is slightly at odds with a study of adherence to self-examination in women with a family history of breast cancer (Brain *et al*. 1999) in which an association between increased general anxiety and cancer worries, and hypervigilant self-examination was seen. It may be beneficial for women to have detailed discussions with their care teams to ensure that any concerns they have are understood, and where possible barriers to maintaining breast awareness are diminished.

One of the unexpected findings from this study was the positive reaction by some women to their cancer diagnosis, describing feelings of relief, while other women seemed accepting of their situation, and only one woman described the emotional devastation the cancer diagnosis had brought to her. One suggestion for these findings is the reduction of uncertainty in the threatening situation of being at risk of developing breast cancer. Individuals vary in their need for certainty (Frenkel-Brunswick 1949; Kruglanski 1989), and this has been shown to be related to motivations to undergo genetic testing (Croyle *et al*. 1995; Henderson *et al*. 2006). It could be that the women who describe feeling relieved at their diagnosis prefer the certainty of the situation compared to the ambiguous one of being at risk. A further potential explanation is that the years during which the women have been at risk have enabled them to prepare psychologically for their diagnosis of breast cancer. The diagnosis is therefore not as shocking or devastating as it may be for women without a family history because their expectations have been confirmed.

The highly positive views that women held of mammography after their diagnosis of cancer are comparable to those of other women diagnosed with screen-detected cancers (Farmer 2000; Miles *et al*. 2003), who seem to have lower levels of psychological morbidity compared with women with symptomatically detected cancer. Farmer demonstrated that women with screen-detected breast cancer received more reassurance by doctors that their cancer had been caught at an early stage, which in turn led to a minimization of the significance of screen-detected cancer.

While all women described their full appreciation of the screening programme, prior to and following the detection of their cancer, not all wanted to continue with annual mammography, with some preferring bilateral mastectomy as their management choice. It is possible that the surveillance and care offered by the programme conferred a high level of psychological protection as long as no cancer was detected. For some women, once the diagnosis was made, and regardless of their reaction to it, surveillance was no longer sufficient. Greater security could be gained from reducing the risk of recurrence as far as was possible, even if this meant undergoing more radical surgery than was clinically warranted. It may also be that for some of these women, their diagnosis would have confirmed they were likely high-risk gene mutation carriers, and their risk of a contralateral breast cancer may have exceeded their previous counselled risk of breast cancer. Previous work has shown that many women in this situation who have been properly counselled about this future risk have opted for risk-reducing surgery (Evans *et al*. 2005).

The value of qualitative research lies in the depth of understanding gained from detailed descriptions of specific experiences. For this reason, the number of participants in a qualitative study is necessarily small. Although it was the restricted number of women available to us, rather than data saturation that determined our sample size, the views of the 12 women included in this study are a valuable addition to the scarcity of literature regarding women who are diagnosed with breast cancer while on a family history screening programme. One limitation to the study is that the views of the women who declined, or were not approached to participate, may have added even more to our understanding, particularly as they may have been more adversely affected by their diagnosis and their cancers may have been diagnosed at a more advanced stage. It may be useful in future work to attempt to determine specific reasons for non-participation, to estimate how far the findings from this study can be translated to other women in the same situation.

Several clinical implications arise from this study. Not all women diagnosed with breast cancer while on a family history screening programme will have a pronounced negative reaction to their diagnosis; indeed a number may feel relieved that they have finally developed the condition that has been long expected. The period while they are under threat of developing the condition may be a time of psychological preparation for the women, which helps them adjust more readily to their diagnosis. We have also identified that women may select bilateral mastectomy as their treatment of choice, although clinically, their cancer may warrant a less radical approach. Surgeons need to be aware that women may have a need to reduce, as far as is possible, the risk of a future cancer, or alleviate totally the fears associated with future screening. Although women place significant emphasis on the early detection of cancer, self-examination, as part of maintaining breast awareness between annual mammograms, is often not practised. It may help to identify women who may be averse to self-examination, to see if the reasons for avoidance can be overcome. We have shown that being diagnosed with cancer for the women in this study has not been solely a negative experience. It may therefore benefit asymptomatic women, who are particularly distressed about their likelihood of developing breast cancer, to be involved in a mentoring system with those who have experienced the process of diagnosis and treatment in order to improve their perceptions of their ability to cope with a potential diagnosis of cancer.

Extending this work with a larger number of women could enable an exploration for patterns within psychological reactions to screening and diagnosis, and pragmatic reactions to risk management. Future work also needs to explore the experiences of women who have put their faith in a screening programme but whose cancers have not been detected by an annual mammogram, or whose cancers are at a much more advanced stage at the point of diagnosis.

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