Breast cancer survivors' perspectives on whether clinical staff should ask breast cancer patients about childhood abuse

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ABSTRACT

INTRODUCTION Recent studies have shown that women who recall childhood abuse are at increased risk of emotional problems following a breast cancer diagnosis. How services should respond is unclear given the risk of compounding the emotional trauma of cancer with questioning about abuse. Our aim was to present the research findings to women with experience of breast cancer so as to obtain their perspective on how this evidence should influence clinical practice.

METHODS Participants were women who had been treated for breast cancer at one of the study units and women with a history of breast cancer who were members of a local patient support group. Three focus groups were conducted (with six, five and three participants respectively). The interview transcripts were analysed qualitatively.

RESULTS Participants emphasised the importance of the research findings for cancer care. The consensus was that abuse and its consequences for patients being treated for cancer should not be a 'taboo' area, and that patients should be given the opportunity and choice to disclose abuse as part of a holistic programme of care.

CONCLUSIONS Services should examine how to include prompts about abuse as part of routine holistic assessment by clinical staff, who will need to be trained in eliciting and managing disclosures of abuse.

KEYWORDS

Breast cancer – Childhood abuse – Patient and public involvement – Support

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About a fifth of adult women report childhood sexual abuse,^{1–3} with physical and emotional abuse being even more common.⁴ Despite this, abuse remains a 'taboo' subject. Health practitioners are often unwilling to address it, fearing making things worse by 'saying the wrong thing'.^{5,6} Ethics committees are cautious about researching this area owing to concerns that patients might be offended or retraumatised.⁷ In reality, people who have been abused often welcome sensitive enquiries about it, finding these less intrusive than the reminders presented by daily life.^{7,8}

Long-lasting effects of abuse include depression, anxiety, personality disorders, substance misuse, eating disorders and relationship difficulties.^{9–11} In mental health settings, abuse is assessed and addressed explicitly.¹² In physical health, its importance has been less appreciated. It is particularly prevalent in the history of patients with functional problems¹³ including irritable bowel syndrome^{14,15} or fibromyalgia.¹⁶ However, its widespread psychosocial sequelae should be expected to compromise patients' response to physical illness and treatment more generally.

We therefore investigated adjustment to breast cancer in 355 women whom we also assessed for childhood abuse. It

has been found that recalling sexual, physical or emotional abuse increases the risk of emotional problems compared with those not reporting abuse.¹⁷ Abused women are also more likely to blame themselves for cancer and to feel ashamed of their bodies, and they find it harder to trust practitioners.^{17,18} We and others have since replicated these findings.^{19,20} In addition, women choosing breast reconstruction following a mastectomy were more likely to report childhood abuse than those choosing a mastectomy alone.²¹

These findings underline the importance of research that addresses this taboo subject. Nevertheless, it remains unclear how clinical practice should be influenced. Given the sensitivity of the topic, this question has ethical and professional implications; empirical research alone cannot resolve it. Patient and public involvement is advocated to ensure that patients' perspectives are considered alongside research evidence.^{22,23} However, breast cancer survivors' views on whether and how abuse should be addressed are not yet known. We therefore presented our findings to women with experience of breast cancer in focus groups and asked them how this evidence should influence clinical practice.

Methods

Participants were women with a history of breast cancer who were members of a local patient support group or who had been treated in the last ten years at the study hospital and had volunteered to be consulted around patient needs and clinical care. After approval by the Liverpool Research Ethics Committee (reference 04/Q1502/92), the (female) researcher (LC) visited the patient support group and described the study to approximately 20 women. Eleven agreed to take part, forming the first and second groups (six and five participants respectively). Ten patients on the volunteer list were mailed a copy of the information sheet. Three of these agreed to participate and formed the third group. Participants provided written consent. They were aged 40–73 years and had been treated for breast cancer 2–10 years previously.

Discussions were facilitated by the researcher and a breast care nurse. The discussions lasted 60–90 minutes and followed accepted procedures for focus group research. 'Ground rules' for confidentiality were agreed first. It was then explained that discussions were not intended to be 'therapeutic'; participants should not seek help with emotional or other difficulties through participation and should not disclose personal experiences unless they felt comfortable doing so.

The groups were led non-directively according to a discussion schedule. Participants were briefed about the main research findings on the effects of childhood sexual, physical and emotional abuse in women treated for breast cancer.^{17,18} They were asked to suggest processes that might explain the findings and to discuss how the findings could improve care. The main discussion points from each group were fed into the next group discussion. Discussions were audio-recorded and transcribed anonymously. At the third focus group, no new information arose, confirming 'theoretical saturation'.

Qualitative data analysis²³ followed a constant comparative approach led by LC and PS (clinical psychologists), who referred periodically to CH (consultant surgeon) and JF (breast care nurse). Findings are illustrated below by quotations from specific patients, identified by group and patient numbers. The ellipsis (...) indicates omitted text. Explanatory comments are in square brackets.

Results

Discussion was enthusiastic with all participants contributing. One woman disclosed an incident of childhood abuse; when asked later, she declined support.

Childhood abuse can make adjustment to breast cancer more difficult

Participants readily discussed the continuity between previous life experiences and responses to breast cancer. They saw life experiences as the basis of resilience to new challenges such as cancer and they attributed acquired resilience to having overcome problems throughout life:

Most of the women who've had breast cancer who are 40 and over, we've all gone through traumas in our

lives and we've all learned to overcome those traumas. So by the time we're diagnosed with breast cancer most of us have coping skills. (G3, P3)

No participant, however, thought that abuse could confer resilience; instead it would always impair coping with cancer. They suggested possible reasons, based on similarities between the experiences. Some mentioned the sense of isolation associated with both:

I can remember when I [was] first diagnosed and although you think you're in the right place, you're having the right things done, you're still on your own... If you've had child abuse, I could imagine you felt very alone then, and that's the kind of thing that it brings back, all those feelings. (G1, P1)

Some participants cited the sexual significance of breasts as a link specifically between sexual abuse and cancer:

If it was a sexual abuse, they might think this is a sexual part of my body. It's not lung cancer or brain cancer, it's, they are sexual, aren't they? (G1, P3)

In other words, they saw breast cancer rekindling memories of abuse. Participants also linked abuse to how women would respond in clinical relationships, specifically by impairing trust:

They probably don't trust a lot of people because of what's happened in the past. (G2, P2)

Patients should be enabled to disclose abuse

When discussing whether services should ask about abuse, one participant speculated that it might be better not to:

Is it that they've buried it, well and truly buried it, many years ago and to open it up now is just a no-go area... they are quite happy in their little shell to sort of come, have the treatment, don't want to talk about? (G1, P4)

All others, however, thought that patients should have the opportunity to disclose abuse:

I really do think it should be brought in the open and for them to be given the choice. You know: 'Do you want help about this?' (G1, P6)

If people didn't want to talk about it, they don't have to answer but at least they'd be giving people the opportunity. (G1, P3)

Should abuse be disclosed, participants were adamant that support must be in place:

There should be an absolute solid package of support where that person is just really carried, really supported, and not sort of 'OK. We'll pass you on to here', and they get to there and there is nothing there for them. So I think if there is support offered, it should be absolutely rock solid. (G3, P1)

Indeed, one participant suggested that if support structures were not in place, disclosure might be damaging:

The research could help if [patients were] offered the correct counselling after disclosure of abuse. Otherwise it's just causing more disturbance. (G2, P4)

Participants also emphasised that clinical staff should be taught about the consequences of abuse:

We could start by promoting awareness in the medical profession of what they might encounter... Just be aware. (G2, P2)

Do not ask about abuse 'out of the blue'

Despite advocating that services enable patients to disclose abuse, participants emphasised the importance of *how* this was done. To be asked out of the blue was seen as intrusive; patients would feel 'uncomfortable' (G3, P2) or even 'shocked' (G2, P5). Participants explained that abuse could not be explored in the same way as clinical information:

It's funny, isn't it? It's sort of, like, acceptable to ask any physical thing that's happened to you and we all accept that. But emotional things seem like an invasion. (G1, P6)

There was also concern that if not approached carefully, prompting about abuse could elicit feelings of guilt and self-blame:

There are people who might be hesitant to tick on the box because they might then inwardly blame themselves and think because they allowed this sexual abuse, they've got themselves breast cancer. (G1, P5)

The participant who disclosed abuse agreed explicitly with being given the opportunity to disclose to practitioners who were trained to manage disclosures. However, she described her initial reaction to reading about the project as one of anger:

I thought you was trying to say that because of this, that's why I've got this cancer. And I was so angry. (G2, P1)

Ask about abuse as part of routine assessment

Instead of direct questions out of the blue, participants emphasised that services should explore abuse sensitively. This meant making questions 'part of the ongoing treatment for breast cancer' (G1, P1). Several emphasised the need to make assessment for abuse, as part of broader psychological assessment, a routine part of a holistic approach in which it would parallel clinical assessment:

You've got your professionals, your oncologist who diagnoses your type of cancer... and then you've got somebody who works alongside them to assess... your emotional side, and as you get all these questions from the medical side of it, you could ask [about abuse history] when you're going through to tick the boxes, you've got someone alongside doing the same with the emotional side of it. (G1, P4)

Methods suggested for incorporating this assessment varied. One participant suggested sensitive questioning beginning with an open question:

'How do you feel you've coped with things?' And that's an open door, isn't it? Because you're not asking them direct. (G1, P6)

Others suggested eliciting information on abuse in a questionnaire while gathering wider information. Participants described how gathering this kind of information initially could help to normalise further questioning or the offer of support later in the cancer journey:

Perhaps you could touch on it in the sense, like, say you went 3 or 4 years down the line and say 'I've just been looking at your questionnaire and... then mention that part as 'Now, you've ticked that you had childhood abuse so how do you feel about that now?' And then leave the ball in their court. (G1, P6)

Discussion

When presented with research linking history of childhood abuse to difficulties in adjustment to breast cancer, women who had experienced breast cancer recognised the validity and importance of the findings, and suggested processes to account for them. Although participants recognised the need to avoid upsetting patients further, they emphasised that abuse and its consequences should not be the taboo that it has been, and that patients should be given the opportunity to disclose it as part of a holistic programme of care.

Study limitations

As a qualitative study of a small sample from a single site, the findings cannot be generalised. Participants were recruited until theoretical saturation was reached on the main findings. However, more (and larger) groups or individual interviews might expose greater diversity of viewpoints, particularly in terms of suggestions on how to ask about abuse and manage disclosures. Participants were necessarily self-selected as willing to discuss the study topic. Further research using interviews or questionnaires with representative samples could explore the generalisability of the findings. Nevertheless, the views of our participants were broadly consistent with previous research.

Findings in relation to the literature

There is little evidence to support the widespread fear that asking people about abuse could retraumatise those who have been abused.⁷ In general, people who have been abused value being asked about it, particularly by practitioners, because this challenges the taboo, which leads to them being doubly victimised: first by the abuse and then by the 'conspiracy of silence' surrounding it.^{4,8} In one study of female survivors of abuse, 96% stated they would like to have been asked about abuse by their healthcare practitioner.²⁴ In cancer care, specifically, patients treated for breast, lung or

prostate cancer welcomed written information about emotional problems that included difficulties associated with abuse.²⁵ Consistent with this evidence, in the present study, almost all participants favoured routine assessment for abuse.

Despite this, participants were concerned that in the context of breast cancer, insensitive questioning could feel intrusive. Moreover, consistent with evidence that patients can blame themselves for breast cancer,²⁶ participants warned that questioning about abuse could elicit guilt and self-blame – that abuse somehow caused their cancer. They therefore advocated that patients are given the *opportunity* and *choice* to disclose abuse as part of routine, holistic assessment and are not asked out of the blue, and that support should be available for those needing it.

Processes that participants suggested to account for the research findings were also consistent with previous evidence. The suggestion that abuse creates a sense of isolation and difficulty trusting others echoes findings that survivors of abuse find it harder to build trusting relationships generally^{27,28} and in breast cancer care specifically.²⁰

Conclusions

Participants indicated ways for breast cancer teams to balance the need to enquire about abuse with the need to avoid intrusive questioning. The key was for enquiries to be seen as routine, using 'tick box' questionnaires or questions about coping in general. Such procedures could be incorporated into routine care: patients could have the opportunity to disclose abuse during assessments in clinic or in home visits by breast care nurses. However, this will be premature until staff can support patients who choose to disclose abuse.

In the UK, breast care nurses are central to supporting patients through treatment for breast cancer and they can support distressed patients better than other practitioners.²⁹ They therefore potentially have a key role in supporting patients who disclose abuse. Many abused patients will have experience of previous disclosures (including to family or people in authority) being disregarded; some will have felt blamed for the abuse.^{30,31} Against this background, training breast care nurses or other practitioners to accept disclosures, and to provide basic support and reassurance will be sufficient for many patients. Nevertheless, some are likely to need specialist psychological intervention and referral routes must be in place. Practitioners at all levels will need to be alert to the possibility that emotional difficulties after diagnosis of breast cancer can arise from experiences, such as abuse, that predate cancer.

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