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Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study

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ABSTRACT

Objectives: To explore the influence of overdiagnosis information on women's decisions about mammography.

Design: A qualitative focus group study with purposive sampling and thematic analysis, in which overdiagnosis information was presented.

Setting: Community and university settings in London.

Participants: 40 women within the breast screening age range (50–71 years) including attenders and non-attenders were recruited using a recruitment agency as well as convenience sampling methods.

Results: Women expressed surprise at the possible extent of overdiagnosis and recognised the information as important, although many struggled to interpret the numerical data. Overdiagnosis was viewed as less-personally relevant than the possibility of 'under diagnosis' (false negatives), and often considered to be an issue for follow-up care decisions rather than screening participation. Women also expressed concern that information on overdiagnosis could deter others from attending screening, although they rarely saw it as a deterrent. After discussing overdiagnosis, few women felt that they would make different decisions about breast screening in the future.

Conclusions: Women regard it as important to be informed about overdiagnosis to get a complete picture of the risks and benefits of mammography, but the results of this study indicate that understanding overdiagnosis may not always influence women's attitudes towards participation in breast screening. The results also highlight the challenge of communicating the individual significance of information derived from population-level modelling.

ARTICLE SUMMARY

Article focus

- Little is known about the impact that information on overdiagnosis in mammography screening might have on women's decision-making about screening.
- We used qualitative methods to explore women's responses to information on overdiagnosis in breast screening.

Key messages

- The concept of overdiagnosis was unfamiliar to many participants and there was a strong belief that women should be informed about it.
- Participants sometimes struggled to understand the concept of overdiagnosis and often regarded it as an issue for treatment, rather than screening decisions.
- Few women felt that the information they had been given would affect their future breast screening decisions.

Strengths and limitations of this study

- This is the first study to explore responses to overdiagnosis in breast screening in the UK and benefitted from the use of in-depth qualitative methods.
- The use of the phrase 'slow-growing cancer' in our explanation of overdiagnosis may have affected women's responses.

INTRODUCTION

The controversy over the risks and benefits of breast cancer screening has been played out in the public media[1] as well as the medical press.[2–5] It prompted an independent review of the research evidence on breast cancer screening in the UK[6] which reported its findings in October 2012.[7] As part of the debate, the information about breast screening provided by the National Health Service (NHS) has been criticised as being one-sided.[8] A key concern is that the risk of overdiagnosis is not adequately reflected in the information that is given to the public.[9–12] However, given the complexity of interpreting results obtained from modelling population patterns of screening and mortality, and the difficulties of applying population-level results to individual decision-making, there may be challenges in communicating this

information, particularly given the range of estimates about the risk of overdiagnosis. The UK review reported estimates between 9.7% and 29.4% across three trials,[7] depending on the denominator used, and other studies have reported higher and lower figures.[3]

At present it is unclear whether women would like to have numerical information on overdiagnosis and whether they would take it into account in making breast screening decisions. Survey results in the USA and Europe have indicated considerable enthusiasm for screening and a tendency for the public to overestimate the benefits of mammography.[13 14] Tolerance of false-positive results also seems high, with one US study finding that even among women who had experienced a false-positive mammogram, a third believed that it would be acceptable for 10 000 women or more to have false-positive results to save one life from breast cancer.[15] The issue of overdiagnosis and unnecessary treatment is probably less well understood by the public. The same US study found that only 7% of women were aware of non-progressive breast cancer, but after a brief explanation of ductal carcinoma in situ and the risk of overtreatment, 60% wanted to take this information into account when deciding about mammography screening.[15] This indicates the importance of providing information on overdiagnosis, although in the survey context only a very brief description could be given. It is possible that immediate responses to survey questions on a previously unfamiliar topic may lack ecological validity and could be thought of as 'non-attitudes' in that they do not reflect any pre-existing beliefs.[16] This problem could be addressed by creating an opportunity for women to discuss and reflect on their understanding of overdiagnosis and the potential impact of this information on subsequent screening decisions in a more considered and ecologically valid way.

In a recent UK survey of the public's preferences for information on cancer screening (in this case it was colorectal cancer), most people, responding on a scale of 1–10, said they would like all available information about risks of screening as well as benefits.[17] However, when asked more detailed and open questions in qualitative research, the UK public can be critical when risk information is included in colorectal screening information leaflets; arguing that if the NHS thinks people should go for screening, they should give unambiguous messages and not 'frighten people off' with stories of rare risks and the complexities of follow-up.[18] Some studies have also found women to be suspicious about the motivation behind questioning the benefits of mammography.[19] To take forward new approaches to the provision of breast screening information, it is crucial to gain an understanding of women's perspective on the idea of 'overdiagnosis'. Information must be provided in a manner that is understandable and not likely to undermine equality of access.

Within the current debate about overdiagnosis, the voice of the users of the screening programme, women themselves, has been largely silent. The one study to date examined Australian women's responses to detailed information on overdiagnosis and a range of estimates of its prevalence, using focus group methodology.[20] The results showed that although women generally lacked prior awareness of the issue, they were able to understand it when information was provided in the form on an audiovisual presentation. The impact of the information on future screening intentions varied widely between women and was also different depending on the prevalence of overdiagnosis presented.

The present study aimed to use qualitative methods to elicit British women's reactions to the notion of overdiagnosis and examine the effect they felt it might have on their decision-making about mammography participation. The UK context is important first, because of the media attention there had already been to the overdiagnosis issue at the time of this study[1 21–23] and second, because of the on-going and high-profile criticism of the information provided to women in the UK about the breast screening programme.[5 8 24] We focused on the impact of relatively brief information on overdiagnosis, to reflect the kind that might be provided in a screening information leaflet.

METHODS

Methodological approach

Focus groups were used to explore women's existing knowledge and experience, and elicit dynamic responses to potentially new information on overdiagnosis in the context of a structured discussion.[25] It is acknowledged that focus groups are well suited to exploring 'public' topics, such as public health interventions[26] and are a good way to identify 'group norms and cultural values'.[25] We used focus groups rather than individual interviews for this study to try to gauge the public response to information about overdiagnosis in the context of a national screening programme, and to provide participants with the opportunity to question each other and to reflect and respond to one another's comments. A qualitative analysis allowed us to identify common themes.

Participants

Six focus groups were conducted with women in the mammography screening age range (50–71 years). All women spoke fluent English, none had a personal history of cancer and none worked in occupations related to cancer or cancer screening. Women living in and around London were recruited from a specialist participant recruitment agency, community groups, mailing lists and adverts circulated by email to achieve a sample with a range of ethnicities, and marital and socioeconomic status. Ethical approval was obtained (UCL Research Ethics Committee: ref 3162/002).

Data collection

Groups were conducted in March and April 2012 at UCL or a suitable community venue in London, and

facilitated by an experienced qualitative researcher with a second researcher acting as observer. In designing the discussion guide, emphasis was placed on constructing open-ended, non-directive questions and using a funnelling approach with questions moving from the general to the more focused (see online supplementary material for the discussion guide).[27] The aim was to generate discussion and elicit views on overdiagnosis. To open the discussion, participants were invited to discuss their own experiences of decision-making about mammography. They were asked to read the relevant pages of the current NHS breast screening leaflet[28] to remind them of the information currently provided about benefits and risks of screening, which includes a statement on overdiagnosis ('Screening can find cancers which are treated but which may not otherwise have been found during your lifetime'). We then read out brief information on overdiagnosis (see box 1) and women were asked to discuss it and to consider how it might affect their views of breast screening. The information was repeated if participants requested this.

The description of overdiagnosis presented to the focus groups was developed in consultation with experts. We used 8 of 1000 cancer diagnoses as a starting point, as this information is currently included in the NHS leaflet.[28] The range of 1–3 overdiagnoses of 8 cancers detected corresponds to a rate of overdiagnosis of 12.5–37.5%, broadly consistent with the conclusions of the UK review.[7] The wording was designed to be understandable to women of all educational backgrounds. We used the term 'slow-growing cancer' rather than overdiagnosis because it is familiar to the public and has been used in previous overdiagnosis research.[13] It also makes it very clear that overdiagnosis relates to the detection of cancers and is therefore different from false-positive results, as well as being distinct from the treatment of benign conditions due to medical errors. We chose to use brief information rather than a more lengthy presentation, to reflect the level of detail women might be given in a written leaflet.

Group discussions were digitally recorded and transcribed verbatim. Participants also completed a short questionnaire assessing demographic characteristics and screening history.

Box 1 Description of overdiagnosis (read aloud to participants during group discussion)

It's been suggested that some of the breast cancers that get diagnosed through breast screening are so slow-growing that they would not have caused any problems. But because we can't yet tell which kind of cancer is the slow-growing kind, the woman receives the usual treatment for breast cancer (eg, surgery). Of all women who go for breast screening, about 8 in 1000 are diagnosed with cancer. It's very hard to know what proportion of cancers diagnosed in the screening programme are of the slow-growing type and the experts disagree at the moment. The estimates have varied from one in eight of women who are diagnosed to three in eight.

Analysis

Verbatim transcripts were analysed thematically using guidelines outlined by Braun and Clarke.[29] Two researchers read all the transcripts independently and generated initial codes. These were then collated into potential themes. A thematic map of the analysis was produced by each researcher and these were refined through group discussion with all authors. All transcripts were then re-read using the final thematic map and adjustments were made following further group discussion. We used NVivo V.9 to code the data, and analysis continued into the write-up stage using the themes and verbatim examples to produce a narrative of women's experiences of the topic. Only sections of the analysis concerned with overdiagnosis are reported here. Demographic data were analysed using SPSS V.15.

RESULTS

A total of 40 women took part in six discussion groups; the number of women per group ranged from four to nine. Demographic characteristics of the sample are shown in table 1. Focus groups lasted an average of

Table 1 Demographic characteristics of the sample

	N (%)
Age (mean (SD); range)	58.5 (5.4); 50–71
Ethnic group	
White	27 (67.5)
Black	6 (15.0)
Asian	5 (12.5)
Mixed	1 (2.5)
Other	1 (2.5)
Marital status	
Married/cohabiting/civil partnership	15 (37.5)
Single/never married	12 (30.0)
Divorced/widowed	13 (32.5)
Highest level of education	
University degree	21 (52.5)
A-levels/ONC/BTEC/other further education	11 (27.5)
O-level or none	7 (17.5)
Missing	1 (2.5)
Time since last mammogram	
3 years or less (as recommended)	29 (72.5)
4–9 years	4 (10.0)
10 years or more	3 (7.5)
Never screened	2 (5.0)
Screened, but time since last screen missing	2 (5.0)
Ever called back for further tests?	
Yes	5 (12.5)
No	33 (82.5)
N/A—never had a mammogram	2 (5.0)

75 min (range 51–93 min, depending on group dynamics and how much women had to say about the issues being discussed).

Themes emerged relating to women's previous experiences and beliefs about breast screening, and their attitudes to false-positive results. As these issues are well documented in the existing literature,[15 30 31] we focus here specifically on responses to the overdiagnosis information (ie, Question 6 in the discussion guide—see online supplementary material). Two main themes were identified: (1) 'Making sense of the concept of overdiagnosis' and (2) 'Implications of overdiagnosis information' (see box 2).

Making sense of the concept of overdiagnosis

In the initial discussions of mammography screening, overdiagnosis was mentioned in four of six groups, but there was only one group in which most women were familiar with the concept. The few women who had heard about the issue tended to find it somewhat discouraging and one said that negative information about breast screening in the media, including on overdiagnosis, had influenced her intentions to attend.

> I just haven't felt like going again … I read everything and there hasn't been very good reports that I've read recently, in the past five years basically, so I haven't been again. (P5)

After reading the information on the risks and benefits of breast screening in the NHS leaflet, some women recalled seeing it before while others had little recollection of it and were unaware of the risk information. The analysis here focuses on responses to the information in box 1, which encompassed a number of themes.

Confusion

Some women found the statistical information on overdiagnosis (box 1) difficult to understand. The challenge of making sense of the numerical information was implicit in some participants' responses but was also mentioned explicitly. In one group, participants struggled to respond to the information that had been read to them:

Box 2 Thematic structure

1. Making sense of the concept of overdiagnosis
   - Confusion
   - How do they know?
   - Emotional responses
   - Cynicism
   - Referring to experts
2. Implications of overdiagnosis information
   - Erring on the side of caution
   - Right to know
   - Overdiagnosis as a treatment issue
   - Impact on screening decisions

> P11: It's hard to say really.
>
> P10: I don't know what to say about that.
>
> P7: Yeah, it feels a bit, well, it's only some, so, well, that's good because it's only five [that need treatment] but I don't know. (Group 2)

Other women did demonstrate good understanding though. In this group, one participant explained the concept to another who was confused:

> P15: I don't understand
>
> P19: No I don't think she understands it a hundred per cent.
>
> P14: 8 women have cancer.
>
> P15: Yes
>
> P14: But maybe three, one two three … don't have dangerous cancer. It doesn't matter, they wouldn't have died. They would not have died without an operation. (Group 3)

Emotional responses

Some women expressed shock at the level of overdiagnosis and the implications for overtreatment, with women in two of the groups voicing more concern about unnecessary treatment than had been evident at earlier stages of the discussion. Some said they would be angry to discover that they had been unnecessarily treated for cancer ('I'd have their guts for garters' (P7)). Others highlighted the side-effects of treatment they had witnessed in friends and family and expressed dismay at the prospect of anyone having to go through that unnecessarily. There was also concern for the financial cost to the NHS and for the wasted time and energy of NHS staff.

> P27: I don't know, but four out of ten! As you say one out of ten is quite a lot. Four out of ten is horrendous.
>
> P22: Scary!
>
> P21: And I also think about the waste of funds and resources when they could be used for people that genuinely need it … I'm quite shocked at what you've told me today. (Group 4)

Cynicism

In five of the six focus groups, some cynicism was expressed about the statistical information.

> Well, I'm very sceptical about statistics generally because I've seen them manipulated to prove what the person using them wishes to prove. (P2)

In particular, some women feared that statistical data supporting the risks of mammography could be used to justify a cost-cutting exercise in which the NHS Breast

Screening Programme might be restricted or withdrawn. Many women became protective of the screening programme at this stage in the face of what was perceived to be a threat to the service.

> I would hate to see funding for screening of breast cancer being removed because, even though I might not go for it, it's a choice and it's good to have the choice, and I think that choice is very, very important and such a vital thing you know. (P3)

Referring to experts

Once women had an understanding of the concept of overdiagnosis they began to refer to experts in two ways: first to question how scientists know that this phenomenon exists and then to express their trust in health experts.

Women often questioned the statistical information they had been given.

> How do they know? How have they arrived at those figures, then? Because is it just literally at the end of chemo, they go 'Yeah, it's still there, or no, it's…?' (P22)

When it was explained that an individual woman would not know that her treatment had been unnecessary, participants began to question the basis of the information. Where women asked these questions, facilitators explained that statistical modelling is used to estimate levels of overdiagnosis. Not surprisingly, many participants found this difficult to understand.

> I mean if this is all done on modelling, what's it modelled on? Is it that when they remove things they find different things within it, but you have to have it removed to know that? … Or is it that it's all coming through post-mortems and things? (P27)

Some participants wondered if doctors would choose not to treat a suspected slow-growing cancer, alluding to an implicit fear of undertreatment.

> Because doctors aren't infallible are they? … Some will be more cautious than others, some will want to err on the side of not doing very much surgery and only doing as little as they can get away with until there is an indication that more is needed. (P37)

Others felt that surgeons 'like to wield their knives' (P19) and might be inclined to operate rather than try alternative approaches.

However, there was also widespread trust in health experts, which was expressed in all groups. There was trust in doctors, scientists and the NHS breast screening programme to utilise new knowledge or improved technology to ameliorate the risk of overdiagnosis and unnecessary treatment in the future.

> P5: I think that my having heard all this now, I mean [I am] more educated about it and I would say now that I just have a trust that the NHS wouldn't haul us all out if statistically there wasn't some evidence that, by and large, some people get saved, you know, and that not many people get disadvantaged.
>
> P4: I have some trust to some extent because I think it's evidence-based treatment, isn't it? (Group 1)

Implications of overdiagnosis information

Erring on the side of caution

As women discussed the implications of the information about overdiagnosis, a broad consensus emerged that overdiagnosis and false positives were strongly preferred to any risk of underdiagnosis. Some women saw overdiagnosis and false positives as evidence that the screening programme was thorough in its detection of cancer. False positives in this context were considered to be acceptable despite the short-term worry of being recalled, of which some women had personal experience. In contrast, women were extremely concerned about false negatives and the risk that cancer might be missed or treatment delayed.

> Well for me it's life or death, really, so there is no question that I would want to go for screening and have treatment as appropriate, because there are unknowns. We don't know if it is fast growing or slow growing. So I would want to have treatment with advice and stay alive basically. (P37)

Right to know

There was, however, a strong belief that women should be given information about overdiagnosis. Participants felt the information should be 'part of my decision' to attend for screening and, in the event of a breast cancer diagnosis, to be part of their decision about treatment. One participant talked about informed decision-making:

> Yes but it's a question of … awareness. It's a question of giving us the information … And letting us process it ourselves and letting us make an informed decision. The facts. (P19)

Another recognised the variation in the amount of information that different people might want:

> You can't deny people who want to know just because others don't. (P26)

Overdiagnosis as a treatment issue

Many women struggled to see information on overdiagnosis as relevant to their decision-making about screening. Much of the discussion was around treatment decisions for screen-detected cancers. Women were concerned about unnecessary treatment but were also keen to treat cancer.

> I mean, just think, they would say to you 'You've got it but we don't think it's going to come to anything and so you don't have to have treatment if you don't want to'. That doesn't make sense to me. If someone says 'You've

got a cancer', you say 'Right, let's do something about it.' (P34)

In general, the risk of undertreatment of cancer was seen as much greater than the risk of overtreatment.

Impact on screening decisions

At the end of the groups, most women retained their initial perspectives on attending screening. Previous attenders maintained that 'I'd still have a mammogram, yeah'. The reasons cited included reassurance that they do not have cancer, a desire to know if cancer is present and to increase the chances of an earlier diagnosis and more successful treatment. The information on overdiagnosis did not seem to have affected their core beliefs about screening.

I would still go, you know, it's better knowing than not knowing… At least I know that, it gives me time to plan … things or what to do next. So I would rather have it done. It wouldn't change my view at all. (P17)

Despite the majority of screening decisions being unaffected, a few women did describe a change in attitude. One participant who initially described mammograms as 'very good' and 'very important' responded to the overdiagnosis information by saying 'That puts you off going at all doesn't it?' and later 'I find that very worrying, to have an operation when you didn't need to' (P12). Another who had recently attended for screening said

I'm in the clear at the moment [because of just having been screened] and I'm wondering whether I do want to go again actually. (P40)

Women who had never attended screening or had ceased to attend also tended to maintain their view although, perhaps surprisingly, one woman thought that following the discussion, she would consider attending in future.

As I said, I haven't had an invitation for so many years that it is something that you don't even think about really … so I, you know, will gather … more information and make another informed decision about whether I will or not go. I mean it's my choice at the end of the day so no one can force me to go there … I will have another think about it seriously. (P19)

DISCUSSION

In this qualitative study, we identified widespread lack of awareness of the risk of overdiagnosis in breast cancer screening among screening-eligible women. When provided with information about the range of risks of overdiagnosis and unnecessary treatment, they were often shocked and surprised, initially. After these initial emotional responses, many women went on to question the basis of the estimates of overdiagnosis, sometimes expressing scepticism but usually trusting health professionals to make appropriate decisions. Most of those who had previously participated in screening maintained a positive attitude to the programme, preferring the risk of overtreatment to the risk of undertreatment. Given that no individual would know that her treatment had been unnecessary, women expressed an overwhelming preference to err on the side of caution. Some also regarded the information as relevant to choices about treatment rather than screening. In a few cases, however, women were put off by the information and felt that it might deter them from future screening attendance. Our findings are strikingly similar to a recent Australian study,[20] despite differences in the way that information on overdiagnosis was presented. This suggests that similar communication challenges will be faced across countries where breast screening is offered.

The study benefitted from the inclusion of women within the breast screening age range, around 70% of whom had been screened within the last 3 years, which is broadly in line with national coverage data.[32] Women willing to attend a discussion group on mammography may generally be more proscreening than the general population and this may be a limitation of our study, although this concern is mitigated by the fact that our groups included women in the screening age range who had never attended or were overdue for screening. The use of focus groups allowed the complex issues surrounding overdiagnosis to be explored and discussed within a group context, enabling us to understand more about likely public responses to information within the screening programme than would be possible using individual interviews. However, individual interviews may have been more informative in understanding women's individual responses and the way that information might be integrated into women's screening histories and experiences. Larger-scale work will be needed to establish the generalisability of the findings. In common with most qualitative research, we used non-random sampling, recruiting women using a range of methods. This, and the fact that women were recruited in and around London, may also limit the generalisability of our findings.

Our participants sometimes found it difficult to understand the brief explanation of overdiagnosis that we provided, and there is an urgent need to develop clear and concise methods of conveying both the concept and its prevalence in a written format to provide to women. The difficulties of communicating risk estimates to the lay public are well documented[33] but may be particularly challenging where epidemiological, clinical and lay perspectives differ[34] and where there is such wide disagreement between experts.

We chose to use the term 'slow-growing' to describe cancers that are overtreated in the screening programme as this has been used in previous survey work.[13] There is on-going debate about how best to communicate the concept of overdiagnosis to a lay audience. The citizen's jury carried out as part of the current review of NHS information materials found that women preferred the

term 'overtreatment' to 'overdiagnosis',[35] while the recent Australian study[20] used 'overdetection' (both these were published after our study had been completed). To our knowledge, no empirical data are available on the impact that using these different terms has on responses to the information. However it is possible that the image of a slow-growing cancer could have led our participants to think about receiving a cancer diagnosis and may have caused them to focus on treatment rather than screening decisions. The terms 'overdetection' and 'overdiagnosis' may make it easier to consider the concept in more abstract terms. But we felt it was important for women to realise that the cancers being overdiagnosed in the screening programme do represent malignant disease, as distinct from false-positive results. Further research is needed to identify the best way to describe the phenomenon.

The themes we identified included some that have been described before. We found that women had a desire to be provided with all the available information on risks,[17] although this was tempered by concern that risk information may put 'other people' off screening.[18] The theme of viewing others as being more risk averse or easily deterred has been found in other qualitative studies[18] and it is unclear whether this is a coded way of expressing personal concern or a reflection of broader identity beliefs that tend to represent the self as stronger than others in many respects. There is evidence that people evaluate risk differently when considering themselves and when considering others, tending to be more risk averse when considering other people.[36] It is possible, therefore, that women in our study were cautious of anything that might deter others from attending screening. Some women also expressed scepticism about any suggestion of shortcomings of mammography, which is consistent with the finding that even women with interval cancer diagnoses tend to maintain trust in the screening programme and to see their own cases as exceptions to an otherwise effective programme.[37]

The finding that women generally preferred to be overdiagnosed than underdiagnosed is consistent with previous survey findings of high tolerance levels of false-positive results[15] and a fear of false-negative results identified in qualitative work[38]; in other words women appear to value sensitivity over specificity, which has been found in qualitative studies in other screening as well as diagnostic contexts.[39 40] But this is the first study, to our knowledge, to have explicitly explored the notion of overdiagnosis in the UK breast screening context.

The study has two broad implications. First, it highlights the difficultly of communicating the concept of overdiagnosis to non-statisticians. Confusion was common and women found the idea that the estimates of overdiagnosis are based on statistical modelling extremely difficult to understand. Further work is needed to develop ways of conveying this type of information clearly, especially given moves towards a policy of informed choice in screening.[41] Second, although women felt the information was important, it generally had little impact on their beliefs about screening and their future intentions to participate. More work will be needed to see whether this finding could be generalised to the wider population and whether the impact of information on overdiagnosis differs across socioeconomic groups.

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