Recalling women for further investigation of breast screening: women’s experiences at the clinic and afterwards

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Summary

Background In 1993–1994 about 66000 women in breast screening were called back (recalled) to a specialized centre for further investigation (assessment). The information requirements of these women during and after their appointment were investigated. Ninety per cent of recalled women were found not to have cancer.

Methods Consecutive women (n = 2132) from eight breast screening centres throughout the United Kingdom were asked to complete a postal questionnaire two weeks after attendance at assessment. No reminder was sent.

Results The response rate was 70 per cent. Communication was viewed by women as the most stress-relieving aspect of the recall appointment. Women from centres where nurses provided the opportunity to talk in private before further investigation were less likely to want to talk later about why assessment was needed for them (4 per cent) than women from centres not using a nurse for this purpose (30 per cent) (p < 0.0001). The former were also less likely to want more information about the tests they had had (2 per cent physical examination, 2 per cent X-rays, 3 per cent ultrasound) than the latter (6 per cent, 9 per cent and 10 per cent, respectively) (p < 0.005). Distressed/very distressed women were more likely to have wanted to talk to someone at the centre about the reason for recall (26 per cent) than somewhat distressed/not distressed women (18 per cent) (p < 0.0001). However, the former were no more likely to have spoken to staff about it than the latter (33 per cent vs 32 per cent). Ways to improve the giving of results were identified. After the appointment women commented that there was a need for more information about harmless breast conditions.

Conclusions Overall the quality of communication at assessment was viewed highly by women, but varied considerably between centres. There is scope for substantial further improvement. Breast care nurses can play an important role in this.

Keywords: breast screening, patient education, false positive reactions, communication

Introduction

In 1993–1994 about one million women aged 50–64 attended mammographic screening in the National Health Service (NHS) breast screening programme.1,2 Studies have shown that screening was not a stressful procedure3,4 for women who received a negative mammographic result. About 66000 women had an abnormal or suspicious mammographic result and were called back (recalled) to a specialized centre for further investigation (assessment).1,2 Various studies have shown that calling women back for further investigations has significant adverse psychological consequences,6–7 because the belief that they were healthy had been challenged.8 Many recalled women react as if they have already been diagnosed with cancer.9,10 These recalled women were most affected emotionally and physically while waiting at the assessment clinic. Ninety per cent were subsequently found on assessment not to have cancer.1,2 The psychological consequences of recall reduced substantially one week after the recall appointment, but were still significantly higher than for screened women who were not recalled. However, it has been noted that even when people are found to be disease free after their tests, not all of them are reassured. Anxieties may remain for months or even years.5,11,12

The attitudes and communication skills of health workers can be an important factor in determining women’s emotional response to a recall appointment and subsequent adjustment.13–15 Much is known about women’s perceptions of the initial breast screening visit,3,16–22 but information requirements of recalled women are little understood.23 We conducted a multicentre study to address this specific issue. The written information needs of recalled women before attending for their assessment appointment have been published elsewhere.24 The present paper deals with women’s experiences and information needs at the assessment clinic and afterwards. The procedure of assessment at each centre was analysed in relation to women’s perception about various aspects of the assessment procedure, in particular with regard to the
opportunity offered to women to discuss topics of concern to them with health workers at the centre.

**Methods**

Over a period of five months women attending consecutively at eight breast screening centres throughout the United Kingdom (including Scotland, Wales and England) who were recalled for further investigation (assessment) were included in the study. Excluding technical recalls, each eligible woman (a total of 2132 women) was posted a postal questionnaire two weeks after assessment (200–300 women from each centre). No reminders were sent to non-responders, to maintain a consistent time interval.

The following key topics were covered in the questionnaire:

1. women’s emotional response to being recalled;
2. communication at the centre about the reason for recall;
3. the personnel with whom women talked, including the role of the breast care nurse;
4. whether the tests undertaken (X-ray, physical examination, ultrasound) were explained to them and whether the women would have liked more information about the purpose and the nature of the tests;
5. communication about the results of the tests;
6. other aspects important to women during assessment;
7. the need for additional information during and after assessment.

Women who reported that they had discussed a topic were asked to specify in more detail what they talked about and with whom they had talked. If women were not given the opportunity to discuss a topic, they were asked whether they would have liked to talk about it. A few open questions were included in the questionnaire to encourage women to respond in their own words.

Meetings were held to explain the protocol to those responsible for gathering the data in each centre. During data collection all centres were visited by the researchers on at least two occasions to conduct semi-structured interviews with members of staff (including the screening office manager, radiographers, radiologists, surgeons and breast care nurses). Notes were taken about the procedures for assessment at each centre and the responsibilities of different health workers. For example, where a breast care nurse was employed, it was important to establish exactly what role the nurse had in relation to recalled women. Likewise, it was important to establish the procedure within each centre for giving women their results.

Ethical approval to participate in the study was obtained individually by each centre.

**Analysis**

Contingency tables were used for comparison and \( p < 0.05 \) (two-sided) was considered to indicate significance. As described in detail elsewhere, \(^{24}\) women were asked how they felt on receiving their recall letter and their reactions were categorized into ‘distressed/very distressed’ (58 per cent of recalled women) and ‘somewhat/not distressed’ (42 per cent of recalled women).

The notes taken about the procedures for assessment at each centre and the responsibilities of different health workers were also categorized and analysed in relation to women’s response to the questions and their additional comments. Women’s emotional response at being recalled was analysed in relation to whether they were offered an opportunity to talk about aspects of the assessment procedure. Qualitative analysis was undertaken using the method described by Potter and Wetherall \(^{25}\) for discourse analysis. This allowed responses to open questions to be categorized.

Because the service on offer differed between centres, subsets of women were used according to whether data were available to answer specific questions. For this reason different denominators were used for different questions. Some respondents did not fill in all questions in the postal questionnaire. This is a well-known phenomenon in surveys using postal questionnaires.

**Results**

Seventy per cent of women (1493/2132) completed the postal questionnaire. Postal response by study area ranged from 66 per cent to 78 per cent. Ninety-five per cent of women returned their postal questionnaire within three weeks.

**Communication about why women needed assessment and the tests women had**

Sixty-eight per cent of women (985/1439) reported having the opportunity to talk about the reason for their assessment. Twenty-three per cent of women (326/1439) would have liked to talk about this. Overall, 93 per cent of women reported having their tests explained for their physical examination (1273/1362), for their X-rays (1282/1375) and for their ultrasound (581/635). Five per cent of women (66/1342) would have liked more information about the physical examination they had, and 7 per cent of women would have liked more information about the X-rays (94/1347) and ultrasound they had (45/610).

The need for communication at the assessment centre was related to women’s emotional response to being recalled (Table 1). The percentage of women who would have liked to talk about the reason for recall with health workers was significantly higher for women who felt distressed/very distressed (26 per cent) than for women who felt somewhat/not distressed (18 per cent) (\( p < 0.0001 \)), even though similar percentages of both groups reported not having had the chance to talk about this (33 per cent vs 32 per cent, \( p > 0.1 \)). The need for more explanations about the tests they had was also higher for the former than for

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\[^{25}\] Qualitative analysis was undertaken using the method described by Potter and Wetherall for discourse analysis. This allowed responses to open questions to be categorized.
RECALLING WOMEN FOR BREAST SCREENING

Table 1 Communication at the assessment centre and level of distress (percentages, with numbers given in parentheses)

<table>
<thead>
<tr>
<th>Communication</th>
<th>Distressed/very distressed women</th>
<th>Somewhat/not distressed women</th>
<th>Significance (p value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women who had not talked with somebody at the centre about the reason for recall</td>
<td>33 (275/835)</td>
<td>32 (191/597)</td>
<td>not significant</td>
</tr>
<tr>
<td>Women who would have liked to talk about the reason for recall</td>
<td>26 (214/835)</td>
<td>18 (108/597)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Women who thought they were not given enough information about the physical examination they had</td>
<td>6 (46/757)</td>
<td>4 (20/563)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Women who thought they were not given enough information about the X-rays they had</td>
<td>9 (72/773)</td>
<td>4 (22/553)</td>
<td>&lt;0.0005</td>
</tr>
</tbody>
</table>

the latter; 6 per cent vs 4 per cent for information about the physical examination they had (p < 0.05) and 9 per cent vs 4 per cent for the X-rays they had (p < 0.0005).

Overall, 24 per cent of women (349/1426) reported having talked with a doctor or radiologist, and 23 per cent with a nurse or counsellor (331/1426) about the reason for recall. Radiographers also have an important role in discussing the reason for recall with women. However, who women talked to at assessment about the reason for recall or the tests they had, depended very much on the screening unit’s policy. Women from centres where nurses provided the opportunity to talk in private before their further investigation were more satisfied with the information communicated to them than women from centres where there was no breast care nurse (BCN) or where the BCN did not routinely provide an opportunity for talking before starting the tests (see Table 2):

1. the former (women from centres where a BCN provided routinely an opportunity to talk beforehand) were more likely to have talked with 'some health professional' about the reason for recall (93 per cent) than the latter (58 per cent) (p < 0.001); in particular, they were more likely to have talked with the BCN about it (60 per cent) than the latter (9 per cent) (p < 0.0001);

2. after assessment they were less likely to have wanted to talk about the reason for recall (4 per cent) than the latter (30 per cent) (p < 0.0001);

3. the former were less likely to want more information about the tests they had (2 per cent physical examination, 2 per cent X-rays, 3 per cent ultrasound) than the latter (6 per cent, 9 per cent and 10 per cent, respectively) (p < 0.005).

Some women received a recall letter before assessment which

Table 2 Communication at the assessment centre and the role of breast care nurses (percentages, with numbers given in parentheses)

<table>
<thead>
<tr>
<th>Communication</th>
<th>Centres where women were not systematically provided with the opportunity to talk immediately before tests</th>
<th>Centres where the breast care nurse provided women with the opportunity to talk in private immediately before tests</th>
<th>Significance (p value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women who had talked at the centre about reason for recall:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With 'somebody' at the centre</td>
<td>58 (611/1055)</td>
<td>93 (374/401)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>With a doctor or radiologist</td>
<td>31 (323/1035)</td>
<td>7 (26/391)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>With a nurse</td>
<td>9 (87/1035)</td>
<td>60 (234/391)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Women who would have liked to talk about reason for recall</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women who stated that the tests they had were not explained to them:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical examination by a doctor</td>
<td>8 (82/981)</td>
<td>2 (7/381)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>X-rays</td>
<td>9 (88/966)</td>
<td>1 (5/379)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>9 (39/413)</td>
<td>2 (5/212)</td>
<td>&lt;0.005</td>
</tr>
<tr>
<td>Women who wanted more information about the tests they had:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical examination by a doctor</td>
<td>6 (59/964)</td>
<td>2 (7/378)</td>
<td>&lt;0.005</td>
</tr>
<tr>
<td>X-rays</td>
<td>9 (86/971)</td>
<td>2 (8/376)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>10 (39/401)</td>
<td>3 (6/209)</td>
<td>&lt;0.005</td>
</tr>
</tbody>
</table>
Table 3 Quality issues during the recall appointment (representative comments of women)

- Centres should pay attention to the facilities
  'Pleasant surroundings helped to provide a soothing effect.'
- Staff should know the content of the recall letter or leaflet sent to women and act upon it
  'I asked the radiographer about the X-rays being 'unclear' [mentioned in the recall letter]. She told me the original X-rays were clear. I therefore deduced that something was wrong and became very anxious.'
  'Your leaflet says you will know the results before you leave the centre. I had to wait ANOTHER WEEK for the result.'
- Staff should maintain the high quality of communication provided at the centre
  'I was made to feel I counted as a human being who needed reassuring; this means so much to woman.'
  'All the staff were friendly, reassuring and efficient on both my visits.'
- Staff should try to improve any weaknesses in communication that still exist
  'I would have liked a chance to chat with someone before the X-rays about why I had been recalled.'
  'I was so excited about the result that I forgot what the doctor told me.'

mentioned that the reason for recall would be given at their appointment. At assessment, however, it turned out that those women (who had received such a letter) were just as likely to talk about why assessment was needed (55 per cent, 212/384) as those who had not been promised this in the recall letter (60 per cent, 399/671) \((p = 0.1780)\). However, those promised were more likely to have wanted to talk about it when the opportunity was not provided (36 per cent, 136/376) than those who had not been promised this (26 per cent, 174/663) \((p=0.0008)\). Both previously mentioned groups came from centres where there was no nurse, or the nurse did not provide a counselling service.

After women had undergone assessment, those who had received a leaflet before assessment with explanations about the tests were less likely to have wanted more information about 'how uncomfortable the tests might be' (20 per cent, 121/606) than women who received no explanations about the tests (30 per cent, 254/847) \((p < 0.0001)\).

Other aspects important during or after assessment, including the giving of results

In some instances, important factors during and after assessment were revealed through spontaneous comments. These observations were hard to quantify, because they reflected women's responses to very specific information or situations, e.g. explanations or phrases which health workers at the centres had used, or specific words in the recall letter or leaflet. Those qualitatively adjudged\(^{25}\) to be most important or recurrent are included in Tables 3–5 to make them available for health workers. An attempt should be made to quantify them in future studies.

Most information which was considered by women to be particularly reassuring related to the written information received with the recall letter, as described elsewhere.\(^{24}\) During the recall appointment women mentioned communication with the staff as the most stress-relieving aspect at the centre (6 per cent). Mention of this varied between 2 per cent and 11 per cent dependent on the centre. Qualitative analysis revealed additional categories of information which seemed important to women during the recall appointment (Table 3).

The great majority of women (90 per cent, 1311/1449) had talked with one or more health professionals at the centre about the result of their tests. Seventy-two per cent of women (1022/1414) reported talking with a doctor or radiologist, 10 per cent (144/1414) with more than one person and 5 per cent with a nurse or counsellor (76/1414). Qualitative analysis showed how some common mistakes in giving results may be avoided and the quality of giving results can be optimized (Table 4). Six per cent of women (85/1436) would have liked to talk about their results but were not given the chance.

Table 4. Quality issues about communication of results (representative comments of women)

<table>
<thead>
<tr>
<th>Comment</th>
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<tbody>
<tr>
<td>Give women their results first, then explain</td>
</tr>
<tr>
<td>'The doctor talked of technicalities interesting to her but not to me before she told me I was OK.'</td>
</tr>
<tr>
<td>'Good news first then explain.'</td>
</tr>
<tr>
<td>Often women do not take in their results because they are nervous:</td>
</tr>
<tr>
<td>'Once I start to worry I do not listen with concentration, sometimes things needs to be repeated.'</td>
</tr>
<tr>
<td>Make sure that women understand their results before they leave</td>
</tr>
<tr>
<td>'It was helpful to have the talk at the end with the nurse to make sure you understood.'</td>
</tr>
<tr>
<td>Women should be given the opportunity to disclose their fears</td>
</tr>
<tr>
<td>'I did not get the chance to discuss whether the cysts would reappear.'</td>
</tr>
<tr>
<td>'Was it really necessary to have another X-ray?'</td>
</tr>
</tbody>
</table>
The categories of information that are problematic for women who were found to have a clear result on assessment following their initial abnormal mammogram are shown in Table 5.

**Discussion**

This study was undertaken to evaluate the information requirements of women who are recalled for further investigation of breast screening. This paper deals specifically with their needs during and after assessment. Unlike previous studies, which investigated consumer views in breast screening in local areas, the eight participating assessment centres in our study covered a wide geographic area (including Scotland, Wales and England). It is hoped that this makes our results more generally applicable to the United Kingdom as a whole.

We chose to use a cross-sectional observational survey. This enabled us to extract the most important elements influencing women's satisfaction or distress at the clinic. However, whether the associations found are causative needs to be determined in other forms of study, such as randomized controlled trials.

Our study did not attempt to elucidate the influence of personality and pre-existing levels of anxiety on satisfaction and distress with assessment. Though doubtless important, they are not amenable to alleviation by procedural improvement.

Recall for further investigation significantly affects the emotional and psychological well-being of women. This effect is most apparent while waiting at the recall assessment clinic. It can still be detected up to one week after the appointment. Overall satisfaction with communication at the centre was high, as it also had been in the Leicester breast screening centre. Many women in our study took the opportunity of the questionnaire to express their gratitude for the personal attention they received. However, there was considerable variation in satisfaction from centre to centre.

The attitude of the staff at the initial breast screening visit for mammography was also identified as one of the main predictors of satisfaction.

The information provided in the written information before assessment may influence women's expectation at assessment. We highlighted a number of instances where the recall letter or leaflet stated or promised something particular which did not materialize during women's appointments. This happened through misunderstanding because the staff clearly were not familiar with the content of the written information, or because health workers failed to realize the importance women attached to this continuity. After assessment, comments indicated that this was very unsatisfactory to women and sometimes enhanced anxieties. Ensuring that expectations are matched with experience at the centre is clearly an area amenable to improvement. A first step would be to ensure that all health workers are completely familiar with the written materials sent to screened women.

It has been reported that doctors frequently fail to identify psychosocial problems experienced by people. Our results in the context of further investigation are consistent with this. Around 33 per cent of distressed/very distressed women had not been provided with the opportunity to talk about the reason for recall at the screening centre. These women were significantly more likely to have wanted to talk about the reason for recall than somewhat/not distressed women. Improving communication skills of health workers could clearly ameliorate this situation.

In cervical screening it has been reported that women with an abnormal smear welcomed a counselling service before further investigation. Our study supports this view in the context of recall for breast screening. Thirty per cent of recalled women from centres not providing pre-investigation counselling would have liked to talk to someone about the reason for their recall. Failure to do so led to anxieties about the initial mammography result and uncertainties about the final result, even when the final result showed no sign of cancer (as happens to about 90 per cent of recalled women). Satisfaction with the information communicated to them was significantly higher for centres where a breast care nurse provided women with the...
opportunity to talk in private before further investigation if they so wished.

In the period between receiving the recall letter and attending the assessment appointment, breast care nurses (BCNs) proved to play a very important role as a person to contact. The present paper shows the role of the BCN at the assessment clinic and afterwards. In December 1993, draft guidelines for nurses in the NHS breast screening programme were published, which spelled out the role that nurses should play in breast cancer screening. The guidelines defined the BCN as somebody who ensures that each woman (1) is provided with appropriate information, (2) has the name and contact number of a BCN when after initial screening she is referred by post for assessment, (3) is monitored for signs of anxiety when attending the assessment centre, and (4) is able to make informed choices after diagnosis, if she so wishes. Our findings confirm the importance of these roles and additionally (more specifically) suggest that the BCN should:

1. give a counselling service on arrival at the centre, explaining to women why they were called back for assessment, explain the tests that will be carried out and provide psychological support;
2. help to ensure that women's results were understood after their rounding off discussion with the doctors (some women do not take in what the doctor tells them because they are too nervous to concentrate);
3. give her name and telephone number after assessment and handle women's questions in case they telephone.

Table 6. Implications of the study

- All staff should be familiar with the content of the written information sent to women and make sure that all women receive the service which was promised in the letters or leaflets.
- All women should be offered the opportunity to talk in private about their reason for recall and the tests before further investigation.
- Each centre should have a breast care nurse who is experienced in communication skills; these nurses should be allowed to use their skills at specific stages of assessment:
  - To give a counselling service on arrival at the centre
  - To make sure that women understand their results
  - To handle women's questions in case they telephone after assessment, and serve as an intermediate to doctors at the centre
  - To support women diagnosed with cancer.
- The good overall quality of communication at the assessment centre should be maintained.
- Giving of results to women could be improved by using the following specific and general verbal techniques:
  - First give women's results, then explain
  - Simplification of the language
  - Explicit categorization
  - Repetition
  - Use of specific rather than general statements
  - Make sure that women understood explanations
- Confirm women's results in writing.
- After women's rounding off discussions at the centre it would be a good idea to give all women with a false-positive result a leaflet which serves as back-up material to what has been said; the leaflet could contain information about:
  - Why the great majority of women with a 'suspicious' initial mammogram turn out to have normal breasts after assessment
  - The harmless breast conditions one can have
  - How to obtain further information, in case women feel anxious about anything when they are at home.

Research studies into other screening procedures have demonstrated that after an abnormal initial screening result, a clear final test result will not always bring reassurance. In breast screening, despite being found to have nothing wrong (about 90 per cent of recalled women) a substantial number of women in our study had lingering doubts after assessment that they may be at a higher risk of developing breast cancer or wanted more information about their harmless breast condition. This was consistent with breast screening findings in the United States. Women need to be told their results in ways that they can understand and remember. Achieving this has been shown to increase satisfaction. Our study suggested ways of improving result-giving specific to the situation of recall in breast screening:

1. Give women their results first, and then give explanations and further details. This study observed that women who are nervous take in their results better this way.
2. After giving the result, somebody (e.g. the BCN) should make sure women understand their results. Other techniques to improve understanding include stressing the importance of content, simplification, explicit categorization, repetition and use of specific rather than general statements.
3. Confirm the results in writing to give women a chance to absorb information. Medical research studies of memory have shown that information is most effectively understood when given orally by health professionals and supplemented by written information.
4. Produce written materials specifically for the situation of women who received a clear final result on assessment after...
an initial abnormal mammographic result. This could include information about the features of an initial X-ray that can give rise to a false positive result, reassuring information, and information about harmless breast conditions.

5. Provide a telephone number that women could ring after assessment if they still had anxieties about any aspect when they returned home. In the context of screening for familial ovarian cancer this was found to be a satisfactory approach.34

The overall implications of this study for breast screening programmes are summarized in Table 6. The questionnaire of this study can be obtained by contacting the authors at the CRC [Telephone: Oxford (01865) 310457].

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