

Women with false positive screening mammograms: how do they cope?

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Abstract

Objectives—To assess the long term psychological impact on women who were recalled for further investigation after mammography screening and to find any factors that might predict coping ability in order to identify those subjects who require additional support at an earlier stage.

Setting—Counties of Västerbotten and Västernorrland, Sweden.

Methods—A prospective design was used in which 252 recalled women completed questionnaires twice—once within a week of having received the all-clear and again at follow up six months later. A group of 1104 randomly selected, screen negative women were followed up in the same way for comparison. The questionnaire included the Psychological Consequences Questionnaire (PCQ) and basic socio-demographic data. The main outcome measure was the total score on the PCQ at six months.

Results—Of the 252 women, 235 (93%) completed both questionnaires. In the control group, 987 (89.4%) women responded. Six months after the all-clear, recalled women were still significantly more anxious ($p < 0.001$) than those who had been screened but not recalled. The strongest predictor of psychological distress at six months was the PCQ score at the first measurement. Other predictors were a low level of education, living in high density urban areas, and having only one child or no children at all. Widows appeared to cope better than other women.

Conclusions—It is possible to define a group of women with false positive results who are already at risk of coping less effectively at the time of recall. Offering these women counselling or other types of support should be considered.

(*J Med Screen* 1999;6:89-93)

Keywords: mammography; false positive

In the wake of rapidly expanding programmes for the prevention and early detection of disease and risk factors for disease, the psychological distress caused by these various screening procedures has attracted increasing interest.¹⁻³ For breast cancer screening, the main concern has been the adverse psychological impact on women who receive false positive results.⁴⁻⁶ One of the main aims has therefore been to try to reduce the false positive rate to a

minimum. The recall rate in Sweden in 1992 varied between the different mammography screening centres within a range of 1.0-6.3 %, with an average of 2.9%.⁷ This is low by international standards, but it still means that some 17 000 women receive false positive results every year in this country alone, with a population of about 8.5 million people.

Key messages box

- Fifteen per cent of false positive women still have from increased levels of anxiety six months after assessment.
- Poorly educated women living in high density urban areas are at increased risk.
- A group of women with an increased risk of coping less effectively can already be defined at the time of recall.

Psychiatric morbidity increases among women who are recalled for further investigation,⁸ and five per cent of the recalled women consider this to be “the worst thing they ever experienced”.⁴ Some women need professional psychological support.⁹ These findings were supported by a pilot study of our own, in which we found that some women still had increased anxiety related to the experience of mammography six months after the recall investigation.¹⁰

The aims of the present study were (a) to assess the short and long term psychological impact on women who are recalled for further investigation before they are declared free of breast cancer and (b) to find any factors that may predict poor coping ability among these women, in order to identify those subjects who require professional counselling and support at an early stage. We therefore followed up a cohort of women with sociodemographic and anxiety measures immediately after the “all-clear” and again after six months.

Methods

SETTING

The study was conducted in two counties in the northern part of Sweden in 1995-96. In Västernorrland County, where mammography screening started in 1990, women aged 40-74 are invited for a mammogram at an interval of 20-22 months. The attendance rate was 89% in the first round, and 85% in the following rounds. The study period coincided with the fourth round of screening. In Västerbotten County mammography screening was started early in 1995. Women aged 50-69 are invited to take part. The interval is 18-24 months. The attendance rate during the first round was 85%.

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Accepted for publication
18 March 1999

Table 1 Items and layout of the Psychological Consequences Questionnaire (PCQ)

Items from the PCQ	Over the past week how often have you experienced the following because of thoughts and feelings about breast cancer:			
	Not at all	Rarely	Some of the time	Quite a lot of the time
Had trouble sleeping	0	1	2	3
Experienced a change in appetite	0	1	2	3
Been unhappy or depressed	0	1	2	3
Been scared and panicky	0	1	2	3
Felt nervous or strung up	0	1	2	3
Felt under strain	0	1	2	3
Found you have been keeping things from those who are close to you	0	1	2	3
Found yourself taking things out on other people	0	1	2	3
Found yourself noticeably withdrawing from those who are close to you	0	1	2	3
Had difficulty doing things around the house that you normally do	0	1	2	3
Had difficulty meeting work and other commitments	0	1	2	3
Felt worried about your future	0	1	2	3

SCREENING PROCEDURE

Invitations to mammography screening in Sweden are based on the national population register. All women within the age range, apart from those who have explicitly stated they do not wish to take part and those who have recently had a clinical mammogram, are invited. First time mammography is always performed with two projections. In following rounds one or two projections are performed, depending on breast tissue density. Independent reading by two radiologists is standard.

In both counties eligible women were invited according to defined geographical areas (parishes, blocks, and villages) so that women from the same neighbourhood were given appointments for breast screening during the same week, often even on the same day. Screening results were sent to the women two to eight days later. Recall investigations were performed on average one week after the screening had taken place. As a rule, the women were contacted by telephone and given an appointment one or two days later.

SAMPLES

Sample 1 comprised 252 women who were recalled and found not to have cancer during the study period 1995–96. In Västernorrland, 172 randomly selected women (of a total of 345) and in Västerbotten all 80 women who were recalled were included. Sample 2 consisted of 1104 randomly selected women in the two counties (Västernorrland 592, Västerbotten 512), during the same period as above, in whom no suspicious lesions were found at screening.

DESIGN

Sample 1—recalled women

At the end of the recall investigation, when the women had been informed that there was no longer any suspicion of breast cancer, they were given a questionnaire and were asked to complete it at home within a week (T1) and send it back in a reply-paid envelope. A second questionnaire was sent to non-responders about three weeks later.

Sample 2—screened women

The screen negative group received the same questionnaire by mail two to three days after receiving the result (T1). They were asked to

return the completed questionnaire using a reply-paid envelope within a week. If they failed to do so, a reminder was sent three weeks later.

A follow up questionnaire (the PCQ only) was sent six months later (T2) to all those who responded to the first questionnaire in both samples, again with a reminder to non-responders.

With a response rate of 90%, there would be data from about 990 women in the screen negative group and 225 women in the recall group. From previous studies and our own pilot study we estimated the standard deviation of the measurements of the PCQ to be 0.5 in the screen negative group and 1.0 in the recall group. This would enable us to detect a size difference between the two groups of approximately 0.22 with the level of significance $\alpha=0.05$ and the power $1-\beta=0.90$.

INSTRUMENTS

The postal questionnaire included the Psychological Consequences Questionnaire (PCQ), which is a measurement tool developed in Australia specifically for breast cancer screening¹¹ (table 1). We also used a questionnaire on sociodemographic factors with items on age, number of children, marital status, education level, employment and, if not employed, reason for this (unemployed, retired, and so on).

The PCQ was originally designed to have three separate subscales. Factor analysis performed in a British study from 1997 identified only one scale with an eigenvalue of 7.7.¹² Factor analysis in our own study also failed to separate the three subscales—that is, emotional, social, and physical symptoms, and we therefore used the PCQ as a single scale.

STATISTICAL ANALYSIS

Some of the variables had non-normal distributions (age and PCQ questionnaire). As the sizes of the two samples were large, the central limit theorem allowed us to use an ordinary *t* test to compare the means for independent samples and paired samples.

In sample 1 a stepwise multiple regression analysis was performed with the mean score for the 12 item PCQ at six months as the dependent variable.¹³ The independent variables were all six sociodemographic background variables

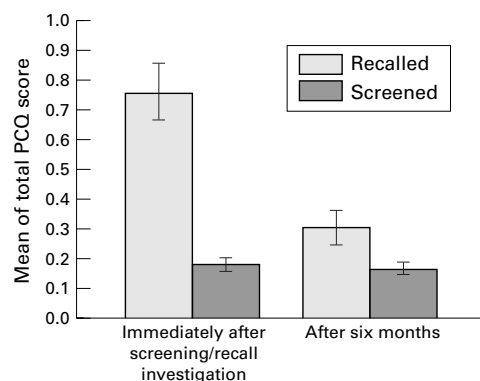


Figure 1 Mean of total Psychological Consequences Questionnaire (PCQ) immediately after screening/recall investigations and after six months. Confidence interval 95%.

and the mean score for the first PCQ measurement. One of the factors was “marital status”. As this is a variable at nominal level, it was dummy coded (four categories implying three dummy variables). We therefore had nine background factors to work with. A backward stepwise regression procedure with these nine independent variables was performed, removing unimportant variables one at a time until all those remaining contributed significantly. The final model included five significant background variables.

Results

Of the 1356 women who were invited to participate, 1222 (90.1%) returned both questionnaires, 987 (89.4%) in the screen negative group and 235 (93%) in the recall group.

The median age was two years lower in the group of recalled women than in the screen negative group, 55 *v* 57 years. There were no significant differences in level of education, marital status, number of children, or employment between the two groups.

Figure 1 shows that women who were recalled experienced significantly ($p < 0.001$) more distress during the time they were recalled than those who were only screened. Six months later, although the mean level of distress was lower, it was still significantly ($p < 0.001$) higher than that of the screen negative women. The size differences that it would have been possible to detect, with the standard deviations obtained in the two samples, between the groups at T1 and T2 were 0.16 and 0.10 respectively ($\alpha = 0.05$ and $1 - \beta = 0.90$). The group that was only screened had a low level of

Table 3 Multiple regression analysis

Variable	B	Significance (p value)
Mean PCQ* score (1 st measurement)	0.288	0.000
Marital status†	-0.196	0.013
Educational level‡	-0.106	0.000
Type of accommodation§	-0.06	0.006
Number of children	-0.06	0.028

Dependent variable: mean score PCQ (2nd measurement).

*PCQ = Psychological Consequences Questionnaire.

†Categories: unmarried, married, and divorced (coded as 0), *v* widows (coded as 1).

‡Categories: primary, secondary O level, A level, university (coded as 1, 2, 3, 4 respectively).

§Categories: rural area, small towns, low density urban, high density urban (coded as 1, 2, 3, 4 respectively).

distress on both occasions and there was no significant difference over six months.

The reactions of the recalled women were studied in more detail (table 2). Three main patterns of reaction were identified: (A) 54% of the women who appeared to cope well and reported only mild or no distress just a few days after they had received the results; (B) 30% of the women who reacted with moderate or severe distress during the time around and after the recall examination but who gradually became relieved, showing only little or no distress at six months; and (C) about 15% of the women who experienced moderate or strong reactions immediately after the recall examination and who seemed to have a poor coping ability, with about the same or only a slightly reduced level of psychological distress six months later. There were also three women (D) with only mild or no distress immediately after recall who reported worse symptoms at six months.

The cut off point between “none or mild” and “moderate or severe” psychological adverse effects was chosen in order to include those women who had a wide spectrum of reactions (nine or more), albeit mild, as well as those who reported high levels of distress on a limited number of items. The cut off point is very close to the one chosen by Ong and others in a similar study.⁶

To assess the possibility of influence by any sociodemographic background characteristics on coping ability we analysed the data for the recalled women using a multivariate model (table 3). The analysis also included the mean score for the first measurement of the PCQ and its association with the outcome measure and, hypothetically, the scores for individual items on the first questionnaire.

As expected, the mean score for the first measurement of the PCQ was the strongest factor for the distress level at six months ($p < 0.001$). Higher levels of distress were evident among women with less school education and those living in high density urban areas ($p < 0.001$ and $p < 0.01$ respectively). Widows had lower levels of distress at six months than other women ($p < 0.05$). Women with two or more children had lower levels of distress than those with one child or no children at all ($p < 0.05$). The women’s age and employment level were not associated with psychological distress.

Table 2 Level of distress expressed as total Psychological Consequences Questionnaire (PCQ) score

Distress after 6 months	Distress immediately after recall examination		
	None or mild No (%)	Moderate or severe No (%)	Total No (%)
None or mild	A 126 (54)	B 71 (30)	197 (84)
Moderate or severe	D 3 (1)	C 35 (15)	38 (16)
Total	129 (55)	106 (45)	235 (100)

“None or mild” represents a total score of 0–8 (arithmetic mean 0–<0.75) on the PCQ and “moderate or severe” represents a total score of 9–36 (arithmetic mean 0.75–3.0).

Discussion

Most women who are recalled appear to cope well and they report only slight or no distress. The remaining women have moderate or severe distress initially, but most of them cope well over a period of time. At six months, however, 15% of the recalled women still had increased levels of distress. Our data suggest that women with a low educational level, those living in high density urban areas, and those with only one child or no children at all are especially at risk of developing longlasting psychological reactions. Widows seem to have lower distress levels at six months than other women, indicating a better coping ability.

The PCQ has been shown to be a valid and reliable measurement in Australian studies.¹¹ It is also used in the United Kingdom¹²⁻¹⁴ for following up psychological consequences after breast screening. It was translated into Swedish and checked by back-translation into English by independent people. It was validated in the Swedish version against the Symptom Check List (SCL-90), a well established measurement which has been used for many years in Sweden, in a pilot test of 220 women before the start of the study.

The fact that the median age of the recalled group was two years lower than that of the screen negative group is probably a reflection of the higher recall frequency among younger women due to dense breast tissue.

The possibility of psychological side effects from breast cancer screening has been a matter of great concern since the very beginning of mammography screening programmes.¹⁵⁻¹⁶ Previous research has shown that for women with a normal screening mammogram there is little or no distress, and that any distress is of short duration.^{2-5,9,17} Our results lend further support to these findings. However, it is still possible that qualitative methods, such as in-depth interviews, might yield other findings.

For the recalled women the median level of distress was significantly higher at six months than it was among those with normal screening mammograms. This finding is in accordance with the results of a recent study by Brett *et al.*,¹⁸ in which it was found that all groups of women who went on for further investigation showed significantly greater adverse psychological consequences at five months than women who had a normal screening mammogram. It is in contrast, however, with a similar Australian study,⁵ where no such difference was found. The follow up questionnaire in the Australian study was conducted after a somewhat longer period, eight months instead of six, but it is unlikely that this small difference in the time of follow up could explain the difference in the level of distress. The mean level of distress was less than 1 in both groups at both T1 and T2. The reason for the low average score is that the majority of the participating women in both the screen negative group and the recalled group reported no or only little distress on most items. Similar levels were found in the Australian study.

Women living up-country in small villages appear to cope more effectively than those living in urban and semiurban areas. We believe that this may be due to better social networks and less anonymity in the rural setting. The way appointments for screening are made—that is, inviting women from neighbouring villages or blocks within a period of one to two weeks, seems to make breast screening a general topic of the day for the women in that particular neighbourhood. This may further strengthen the support the participating women can give to one another.

Our results indicate an increased risk of longlasting, increased distress levels among women with a low level of education. The finding that educational level is related to women's distress scores in this situation is supported by other studies.¹⁹⁻²⁰ Probable explanations are that women with lower levels of education do not have the same access to relevant information as well educated women, that they do not always fully understand the information that they are given, that they are, in fact, given less information by health professionals, and that these women may have fewer material and social resources to buffer the adverse effects of false positive results.

Widows have lower levels of distress than all other categories of women. This has not been reported before. One possible explanation might be that the loss of the husband and the bereavement has given them an experience that helps them to cope better with the threat that the initial positive result entails. Women with two or more children also have lower levels of distress at six months, a finding that might be explained by the greater life experience of a mother with several children compared with those with one child or no children at all.

A number of suggestions for practical solutions for alleviating the adverse psychological effects after recall and assessment were recently published,²⁰⁻²¹ underlining among other things the importance of carefully phrased written information, allowing women to disclose their fears, and confirming the test results in a letter after assessment. One way of organising assistance for the women with an increased risk of less effective coping would probably be through support and follow up, either by a member of staff at the recall unit or through counselling services attached to the unit.

Funding: This study was funded by the Research Foundation of the Department of Oncology, Umeå University and Mid-Sweden Research Centre, County Council of Västerbotten.

Conflict of interest: None.

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