

Anxiety in a cohort of Swiss women participating in a mammographic screening programme

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Abstract

Objectives—To follow up anxiety in a cohort of women screened for breast cancer.

Methods—Within the framework of a pilot screening programme for breast cancer in the Canton of Vaud (Switzerland), a cohort of 924 participants aged 50–70 years were invited to answer questions on anxiety related to mammography screening. Anxiety was measured using a specific tool, the psychological consequences questionnaire (PCQ), and a new single item, direct question, breast cancer anxiety indicator (BCA). Participants were asked to fill in the questionnaire at four different phases: at screening, before the result, and 2 and 8 weeks after the result. The final response rate was 93.7%. Predictors of anxiety at each phase were assessed using multiple regression.

Results—Among those screening negative (94.7%), anxiety at screening was very low and remained so during the screening process. Among those screening false positive, anxiety was significantly higher 8 weeks after having received a negative diagnosis. Predictors of anxiety before screening were lower education and higher age, with a strong exogenous anxiety component. For subsequent phases, the initial anxiety score and education were the main determinants. Furthermore, a false positive result at screening was the most important predictor of anxiety 2 months after negative diagnosis. Anxiety measured with the BCA was strongly correlated with the PCQ.

Conclusion—Anxiety was very low at screening and remained so during the process for negative women. Initial anxiety level was a strong predictor of anxiety during the entire process, up to 8 weeks after a negative result, and could be easily assessed using the BCA. The sustained higher anxiety level among those screening false positive is an undesirable side effect of the programme.

(J Med Screen 2001;8:213–219)

Keywords: anxiety; screening; breast cancer; test

Psychosocial aspects have to be taken into account in the management and the evaluation of secondary prevention. They make a substantial part of intangible costs and advantages of any screening.^{1–4} Therefore, these aspects have been under study in different circumstances, such as prenatal diagnosis,^{5–9} cholesterol screening,^{10–11} or cancer screening.^{12–17} Breast

cancer screening has also been studied in this perspective, and this interest has been reinforced by the current large scale implementation of screening programmes.^{18–27}

For women who have a cancer diagnosed during a screening programme, anxiety is part of the disease and should be addressed accordingly.^{28–29} But anxiety among those who screen negative or false positive is an undesirable side effect of the screening: it increases the intangible costs of the programme and might deter women from participation and long term adherence. Although these aspects are often mentioned in the literature,^{26–30–34} explicit measurement of anxiety is still scant. Various generic tools have been used to measure anxiety related to breast cancer screening.^{21–35–37} Recently, a specific tool, the psychological consequences questionnaire (PCQ) was created.³⁸ This tool has been used in Australia³⁹ and, with some adaptation, in the United Kingdom⁴⁰ and in Sweden.⁴¹

As part of a pilot breast cancer screening programme implemented in the Canton of Vaud in Switzerland between 1994 and 1998,⁴² this study was designed to measure the level of anxiety among people screened, in an 8 week follow up with a standardised instrument and a simpler, alternative tool.

Population and methods

The main characteristics of the population and methods of the study are briefly summarised here; they have been described fully elsewhere.⁴³ In a pilot screening programme for breast cancer in the Canton Vaud (Switzerland),⁴² all 11 500 women aged between 50 and 70 years in two regions received a personal invitation to participate in a free of charge mammography examination at a 2 year interval. A brief leaflet describing the programme—including the mammographic procedure, meaning of negative or positive mammography, information about the frequency of cancers detected in mammographic screening, and useful addresses for additional information and support—was sent with the invitation letter. A limited information campaign was set up to explain the programme, including public conferences and posters in various public places. The examination was performed in two public hospitals by radiology technicians specially trained for the programme and instructed to inform women about the procedure. Those screened received the mammography result by mail at home, about 5 days after the examination. Those screened positive were informed in that letter that additional investigations were necessary and they were invited to consult their physician, who

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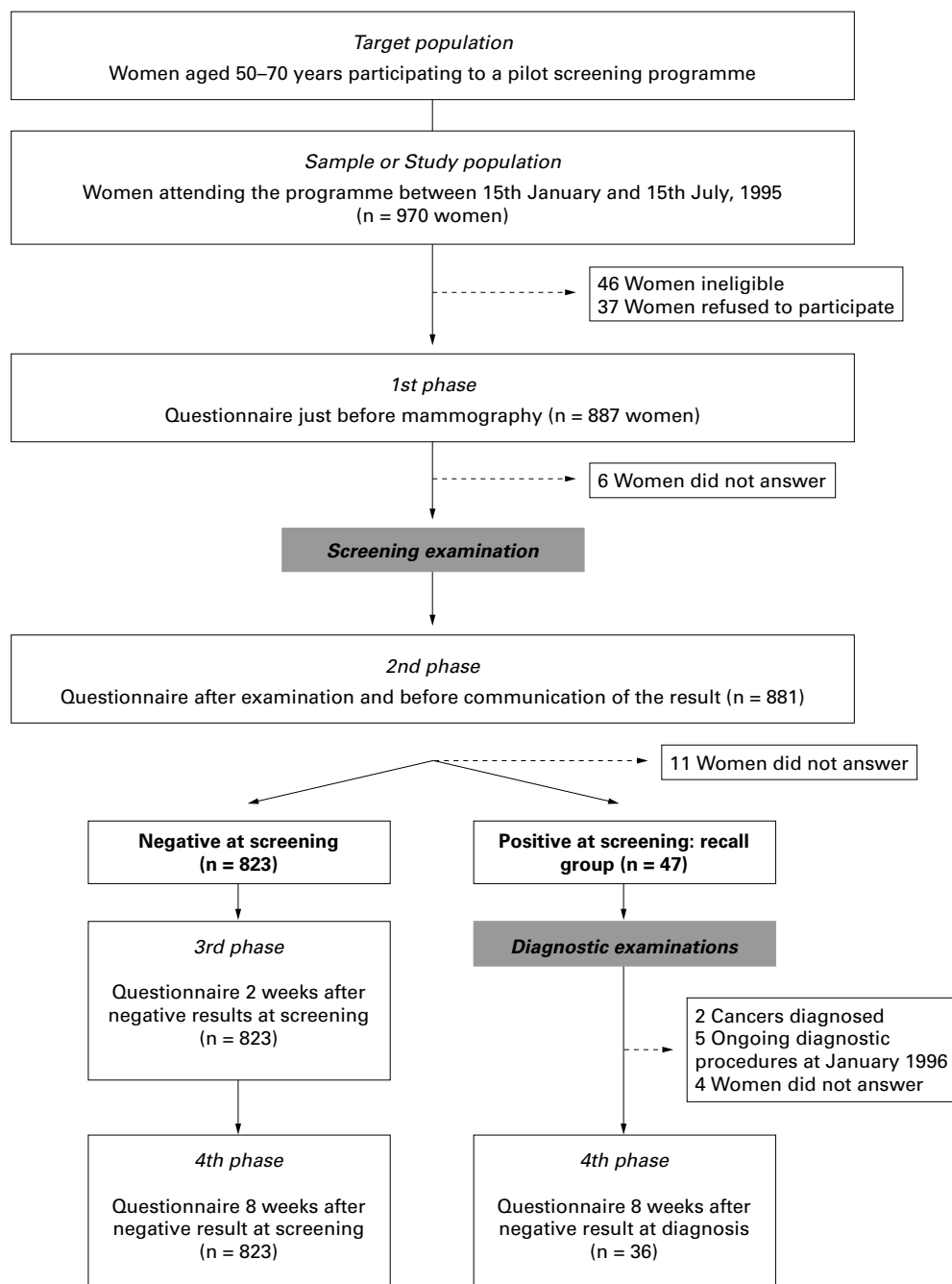


Figure 1 Flow chart of the anxiety study in the pilot breast cancer screening (Canton of Vaud, Switzerland, 1994–8).

had received a copy of the result. They were also reminded of the high probability of a final negative cancer diagnosis.

The study design is summarised in figure 1. The study population considered in this paper were the 970 women who attended the screening units between 15 January and 15 July 1995, at the first round of screening about 1 year after the start of the programme. The data for the entire screened population and used for comparison with the study population, covered the period between 1994 to the end of 1996.

The specific tool used in this study was the psychological consequence questionnaire (PCQ),³⁸ reproduced in the appendix. The PCQ comprises 22 questions. This study uses only the 12 questions on negative conse-

quences of the three subscales: emotional (five items), physical (four), and relational (three). Answers are given on a quantitative score (0 to 3) for each item. An arithmetic mean score for each subscale is computed for each respondent. The PCQ was translated into French by the authors and checked with back translation. The comprehension and sensibility of the translation have been tested and found satisfactory (data not shown here).

In addition to the PCQ, a single direct question on the global perception of anxiety specifically related to breast cancer (breast cancer anxiety indicator (BCA)), covering the same time frame as the PCQ, was devised in French by the authors and added to the questionnaire (see appendix): “To summarise, how do you

Table 1 Distribution (% (95% CIs)) of demographic and health care characteristics of women surveyed and of all other women screened

	Women surveyed (n=887)	95% CI	Other women screened in the programme outside the period studied (n=3931)
Age (y):			
50–4	36.1	(32.9 to 39.3)	33.7
55–9	22.1	(19.4 to 24.8)	22.3
60–4	19.7	(17.1 to 22.3)	21.4
65–9	22.1	(19.4 to 24.8)	22.7
Swiss nationality	93.3	(91.7 to 94.9)	87.4
Education (<10 y of schooling)	40.4	(37.2 to 43.6)	38.1
Marital status :			
Single	3.8	(2.5 to 5.1)	5.9
Married	76.6	(73.8 to 79.4)	69.3
Separated/divorced	8.6	(6.8 to 10.4)	11.4
Widow	11.0	(8.9 to 13.1)	13.5
Children (n):			
0	12.3	(10.1 to 14.5)	13.2
≥1	87.7	(85.5 to 89.9)	86.8
Ever had mammography	73.3	(70.4 to 76.2)	66.7
Had mammography within 2 y	27.9	(25.0 to 30.8)	27.9
Ever had Pap smear	85.9	(83.6 to 88.2)	98.2
Had Pap smear within 2 y	67.3	(64.2 to 70.4)	60.9
Any familial antecedent of breast cancer	15.8	(13.4 to 18.2)	14.4
Any antecedent of breast disease	13.9	(11.6 to 16.2)	12.9
Any breast anomaly on visual exam	9.9	(7.9 to 11.9)	15.8
Screening centres :			
A	28.1	(25.1 to 31.1)	30.9
B	71.9	(68.9 to 74.9)	69.1
Negative screens	94.7	(93.2 to 96.2)	94.8

95% CI computed by normal approximation.

rate your anxiety in relation to breast cancer during the last week ?” Answers are given on a quantitative scale from 0 (not at all anxious) to 5 (very anxious).

Anxiety was measured at four phases during the screening process (fig 1): just before examination, before the result, 2 weeks and 8 weeks after a negative result at screening; for the recall group, phase 3 was omitted and anxiety was measured 8 weeks after a negative result at diagnosis.

At the first phase the questionnaire was presented by a study nurse at the screening centre and filled in there. Women were given the questionnaire for phase 2 with a reply paid envelope and asked to fill it in at home before the result. To assure that this questionnaire was filled in before receiving the screening result, a reminder was mailed to those to be screened the day of the examination. Questionnaires for phases 3 and 4 were mailed and reminders were sent to the non-respondents.

The evolution of anxiety levels according to the BCA and the scores of the three dimensions of the PCQ was assessed using graphs. The relations between the three dimensions of the PCQ and the BCA were assessed using correlation analysis (Pearson's correlation coefficients).

To assess the determinants of anxiety at each phase, multiple regression analyses were performed with the anxiety level, measured by the BCA, as the dependent variable at each phase. The independent variables in each regression were age (in four 5 year classes considered as a numeric variable), education (years of schooling dichotomised at 10), marital status (dichotomised in married versus other), having one or more child (yes versus no), nationality (Swiss versus other), any familial antecedent of breast cancer, any antecedent of breast disease, any breast anomaly on visual examination, and

centre of screening (centre A versus centre B); lifetime indicators of experience of mammography and Pap smear test were also retained. In addition, the anxiety level (BCA score) at screening was added as a predictor variable for phases 2 to 4 and the screening result was added for phase 4 (recalled women were omitted for phase 3).

Results

STUDY POPULATION

Among the 970 women screened in the period studied, 46 (4.7%) were ineligible due to illiteracy, inadequate knowledge of the French language, or severe learning difficulties. Among the 924 eligible women, 37 (4.0%) refused to participate to the study—that is, to fill in a written questionnaire—887 women agreed to participate to the study, yielding a 96.0% initial response rate and a 93.7% final response rate.

Women refusing to participate to the study were not significantly different from those studied in sociodemographic characteristics, screening behaviour/early detection practices, antecedents of breast disease or family antecedent of breast cancer, breast anomaly, and result of the examination (data not shown). The only significant difference between women refusing to participate to the study and the sample was the mean lapse of time between invitation and examination: it was longer by the first group (213 days versus 149 days).

Table 1 compares the study population (n=887) with the women screened in the programme (n=3931). Overall, the first were mostly similar to the second. However, women surveyed in the study were more likely to ever have had a Pap smear and to have a breast anomaly on physical examination than those screened in the programme outside the period of the study.

EVOLUTION OF ANXIETY AS MEASURED BY THE PCQ AND THE BCA

Figure 2 shows the evolution of the anxiety levels among negative and false positive women as measured on the BCA and the three subscales of the PCQ. Anxiety experienced before screening was very low with little variance and remained so throughout the process in negative patients.

Anxiety scores for the recall group are the same as those of the negatives for the first and the second phase. However, this group experienced a significantly higher anxiety level at phase 4, 8 weeks after having been informed that the diagnosis result excluded a cancer.

CORRELATION BETWEEN THE PCQ AND THE BCA

The BCA was significantly correlated with the PCQ, and best correlated with its emotional dimension (table 2). This correlation was better for the latest phases. Graphically as well, the evolution of the BCA corresponded broadly with the emotional dimension of the PCQ (fig 2). Subsequent analyses relied on the BCA as the anxiety measure.

Table 2 Correlation coefficients (Spearman) between the three dimensions of the PCQ and the BCA

	BCA score			
	Phase 1 at screening n=887	Phase 2 before result n=881	Phase 3 2 weeks after result† n=823	Phase 4 8 weeks after result n=859
PCQ emotional dimension	0.56**	0.67**	0.67**	0.70**
PCQ relational dimension	0.32**	0.47**	0.48**	0.51**
PCQ physical dimension	0.26**	0.42**	0.47**	0.54**

**p≤0.01.

†Negative screens only.

BCA=breast cancer anxiety; PCQ=psychological consequences questionnaire..

EVOLUTION OF ANXIETY FOR WOMEN WITH ZERO AND ABOVE ZERO ANXIETY SCORE BEFORE SCREENING

Figure 3 shows the evolution of the anxiety levels measured with the BCA among women screened negative according to their anxiety at screening dichotomised as zero versus above zero. Two points stand out. Firstly, the 74.4% of women with a zero level of anxiety before screening showed a very small increase in anxiety before the result and subsequent stabilisation at this level; by contrast, the 25.6% who experienced distress at screening showed a marked significant decrease at the following phases. Secondly, despite this convergence, the anxiety level of the second group remained significantly higher. Thus, it seems that initial anxiety level significantly discriminates between these two groups. The same evolution was found in the emotional dimension of the PCQ (data not shown). Small sample size and wide confidence intervals precluded any defi-

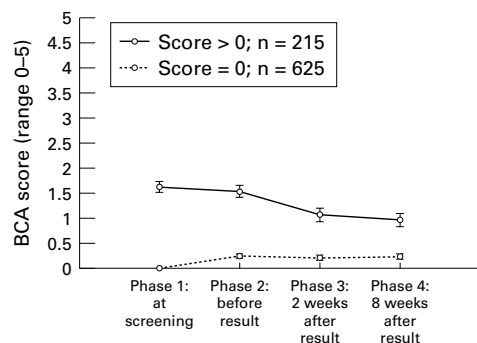


Figure 3 Evolution of anxiety among the screen negative group with BCA score of 0 (n=625) and BCA score above 0 (n=215) at screening, with 95% confidence intervals.

nite conclusion for the other two dimensions of the PCQ (data not shown).

DETERMINANTS OF ANXIETY AT EACH PHASE

In the first phase, two predictors of the BCA score in the multiple regression had coefficients which were statistically significant but of low magnitude (table 3): education (anxiety was lower for those with more years of schooling) and age (anxiety decreased with age). However, the poor fit of the model meant that the initial anxiety level may be mostly an exogenous event.

At the second phase, the fit of the model was much higher. Significant predictors of anxiety at this phase were ever had a Pap smear, ever had a breast disease, and the anxiety level at

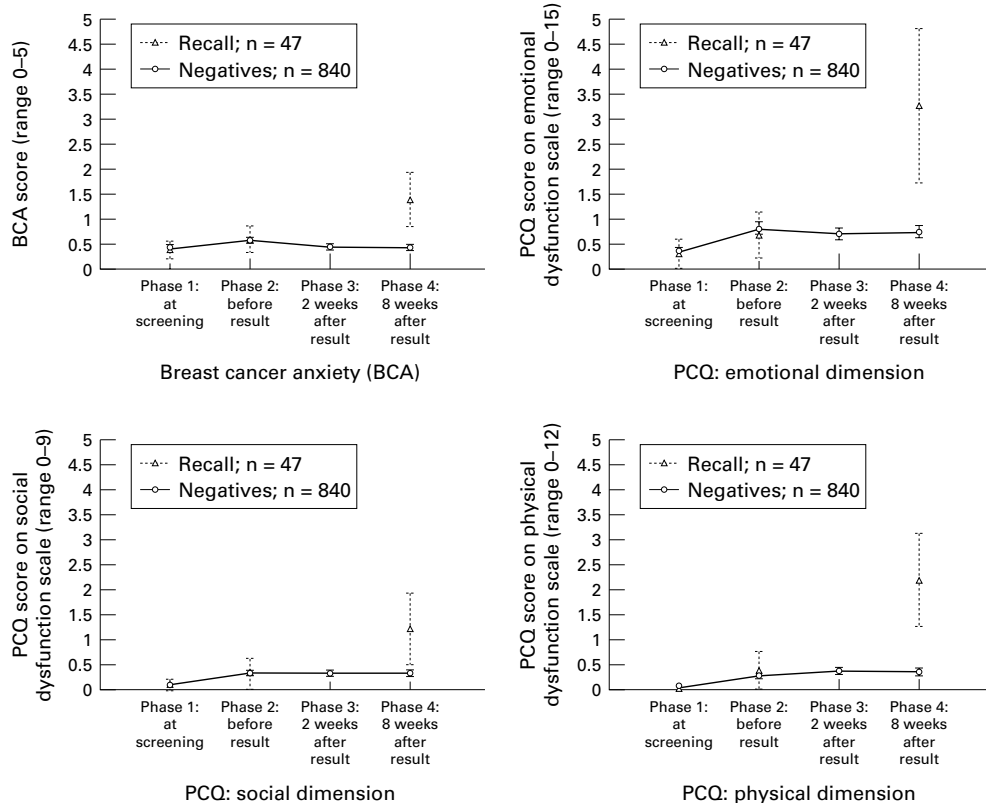


Figure 2 Evolution of anxiety measured by the BCA and the PCQ (mean score with 95% confidence limits) according to the phases of the screening process. Levels and evolution of anxiety for the negative women are shown with circles (mean score with 95% confidence limits) joined by solid lines; the recall group is shown with triangles and their confidence limits as dotted lines. No data is shown for this group at phase 3 as they were not followed by the study during diagnostic exams.

Table 3 Determinants of anxiety at different stages of the study (multiple regressions)

	Phase 1: at screening n=886		Phase 2: before result n=877		Phase 3: 2 weeks after result* n=823		Phase 4: 8 weeks after result n=852	
	B	p Value	B	p Value	B	p Value	B	p Value
Constant	0.371	0.032		NS	0.370	0.010	0.328	0.049
Age	-0.063	0.010		NS		NS		NS
Education (<9 y of schooling)	-0.147	0.012		NS	-0.159	0.001	-0.165	0.004
Marital status (married)		NS		NS		NS		NS
Nationality (Swiss)		NS		NS		NS		NS
Having children (one or more)		NS		NS		NS		NS
Mammography (ever had, lifetime)		NS		NS		NS		NS
Pap smear (ever had, lifetime)		NS	0.119	0.050		NS		NS
Familial antecedent of breast cancer (any)		NS		NS		NS		NS
Antecedent of breast disease (any, lifetime)		NS	0.176	0.007		NS		NS
Breast anomaly (any, lifetime)		NS		NS		NS		NS
Screening centre attended (centre A)		NS		NS		NS		NS
BCA score at screening	—	—	0.758	<0.001	0.541	<0.001	0.460	<0.001
Screening result (false positive)	—	—	—	—	—	—	0.918	<0.001
Adjusted R ²		0.012		0.507		0.333		0.244

BCA=breast cancer anxiety.

*Phase 3=negative screens only.

Dependent variable at each phase: BCA score at that phase.

Regression coefficients not significant at 0.05 level are omitted from the table.

For dichotomised variables, the contrast with the reference category only is mentioned in parentheses. Age was coded as a numeric variable with four 5 year classes.

screening; the third may be the exogenous anxiety noticed at phase 1.

At phase 3, recalled women were omitted. The fit was acceptable; the predictors were education and anxiety level at screening.

At phase 4, the fit was somewhat lower; the predictors of anxiety were education, anxiety level at screening, and false positive result at screening.

Discussion

The purpose of this study was to evaluate the psychosocial impact of a breast screening programme in a cohort of Swiss women.

Limitations of this study must be acknowledged. Only the first round of an ongoing, systematic screening is considered here, and the level of anxiety among those screened may change over time, along with a change in the perception of the programme by the participants or improvement of the professional skill of the screening team. Secondly, the specific period and location of this study may not be representative of the whole programme, although data from table 1 do not suggest that major biases are present. Differences with the study population are likely to be due to specificities of the geographical areas targeted for screening during the study period.

This study confirms known features of breast screening programmes as well as insights into as yet unreported new findings.

A first result was the low mean level of anxiety at the examination, even lower than in the Australian study³⁹ which is directly comparable because the same instrument was used. This low mean anxiety was maintained throughout the process, as has been found in Australia³⁹ and in the United Kingdom.²⁷ However, in our study a quarter of the negative screened women experienced some anxiety at screening; this moderate level of anxiety, although decreasing, still persisted 8 weeks after the result.

A second result was the sustained higher anxiety level despite a negative diagnosis among women positive at screening. Although there was no measurement at phase 3 for these women, their anxiety is likely to have been at its

highest then. Similar findings have been reported by other studies,^{21 23 24 27} although direct comparisons are limited due to the wide disparity of the tools used. Beyond the 8 week period covered by our study, some authors have reported substantial levels of anxiety (or other specific problems) at 3 months (41% among false positive versus 17% among negative),⁴⁴ 6 months (15% among false positive),⁴¹ or after 18 months (29% among false positive).^{19 24 39} Even suicide has been reported as a likely consequence of a false positive result.⁴⁵

This sustained anxiety among screened positive women is a substantial intangible cost induced by screening. Even if the final impact is limited because of the low proportion of positive screened (about 5% in this study) at each round, the cumulated number of women experiencing a false positive result is substantial after several screening rounds.⁴⁶ This is a further reason for targeting the lowest possible rates of false positive women at screening.⁴⁷ In addition, the provision of personal counselling for women screened positive should be considered as a standard part of any programme.

Thirdly, some predictors of anxiety among the people screened negative are identified. At screening, higher age and low education are important ones. The second is a classic finding in preventive activities according to various studies.^{41 48} This is probably related to a lesser access to relevant information, a poorer understanding of available information, and to a social construction of anxiety. Indeed, a separate study of a group with low educational level found that the non-participants in this Swiss programme cumulated social deprivation and depressive mood.⁴⁹ However, a large part of the anxiety at screening may be due to a pre-existing or reactivated state not properly accounted for by the available information for this study.

At phase 2, the most important predictors were antecedent of breast disease (related to a possible feeling of being at risk) and anxiety level at screening. At subsequent phases after the result, predictors are low education and

anxiety at screening. A false positive result at screening was the most important predictor of long term anxiety at phase 4, weighting one full point of the BCA scale 8 weeks after negative diagnosis (recalled women were omitted for phase 3).

Similarly, Olsson *et al*,⁴¹ analysing false positive women, found that anxiety measured using the PCQ 1 week after having received the all clear was the best predictor of anxiety 6 months later.

Finally, this study has shown that anxiety can be adequately assessed using a simple instrument. Measuring anxiety is feasible with the PCQ. However, this study has shown that a much simpler one item instrument, the BCA, provides the same information. Single item instruments are less reliable than multi-item ones. However, this has to be weighted against the advantages provided by the simpler one item measure: better acceptability, easier to understand especially for foreign women or those with lower education, and lower cost of administration. Given the correlation between the BCA and the PCQ, it can be assumed that the anxiety level measured at screening by the BCA is an efficient long term predictor of future anxiety. From a practical perspective, this is an argument to detect distress and provide specific support for women showing a high anxiety level at the examination, who are more likely to suffer from the screening process itself. Measures aiming at decreasing the anxiety level are likely to provide additional benefits in maintaining the long term adhesion of the participants^{50 51}; indeed, anxiety experienced at the first round has been found to be a substantial determinant of subsequent participation.^{27 52-55}

To summarise, this study confirms the long term psychosocial cost paid by patients who screen positive. It also identifies predictors of anxiety easy to assess at the start of the process: education and initial level of anxiety (measured by the BCA) as predictors of long term anxiety and antecedent of breast disease as a predictor of anxiety before the result. Together, these findings provide simple and useful bases for managing part of the undesirable side effects of breast cancer screening.

The management of anxiety is still poorly addressed in most existing programmes, with little monitoring and evaluation regularly done or even planned. Therefore, a first step is to implement standardised measures of anxiety in the routine data collection from any screening programme. The PCQ is such an instrument, but the present study suggests that a more straightforward one item instrument gives similar information.

Anxiety at screening, experienced by a quarter of the participants, is a good predictor of long term anxiety and can easily be detected, thus providing an opportunity for counselling if needed. Recalled women, most of them false positive, bear the heaviest burden from screening. Two measures could alleviate their anxiety: a better preparation at screening to the possibility and meaning of a false positive

result and improvement in the modalities of result communication.

These routine data on anxiety should be regularly analysed, disseminated, and discussed, to improve the related processes.

Another step is to increase the research effort into the psychosocial aspects of screening.³ Many areas remain obscure, including the social construction of anxiety,⁵⁶ its relation to personal attitude, and the way health related information is able to modify it. This research line is of special relevance for developing and evaluating tailored messages given to potential participants,^{57 58} to women screened positive, or to those who are anxious before the examination.⁴⁸ Experiences in other fields of screening seem to be promising.^{59 60}

This study was supported by a grant from the Fondation Muschamp, Lausanne. We thank Jean-Pierre de Landsther, Director of the Breast Cancer Screening programme, and our colleagues from IUMSP Guy Van Melle and Patrick Morency for their insightful comments.

Appendix 1 Psychological consequences questionnaire (PCQ)*

Over the last week how often have you experienced the following things because of thoughts and feelings about breast cancer:

(0=not at all, 1=rarely, 2=some of the time, 3=quite a lot of the time)

(P) had trouble sleeping

(P) experienced a change in appetite

(E) been unhappy or depressed

(E) been scared and panicky

(E) felt nervous or strung up

(E) felt under strain

(S) found you have been keeping things from those who are close to you

(S) found yourself taking things out on other people

(S) found yourself noticeably withdrawing from those who are close to you

(P) had difficulty doing things around the house which you normally do

(P) had difficulty meeting work or other commitments

(E) felt worried about your future

*Only the 12 questions on negative consequences.

E=emotional dimension; P=physical dimension; S=social dimension.

Source: Cockburn J *et al*.³⁸

Appendix 2 Breast cancer anxiety indicator (BCA)

"To summarise, how do you rate your anxiety in relation to breast cancer during the last week?"

Not at all anxious←0-1-2-3-4-5→very anxious.

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