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Monitoring women's experiences during three rounds of breast cancer screening: results from a longitudinal study

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Objectives: (a) To monitor experiences of women during three successive rounds of breast screening; (b) to examine the impact of previous experiences (obtained either immediately after the latest mammogram or shortly before the subsequent one) on reattendance; and (c) to examine which factors are associated with the experience of pain and distress during screening.

Setting: The Dutch Breast Cancer Screening Programme

Methods: 2657 women completed a baseline measurement (response rate 67%) about 8 weeks after they had been invited for an initial mammogram (T_1). Actual participation data of these women in the second and third rounds of screening were collected. Follow up questionnaires were sent to subgroups of the sample at different times: shortly before the second screening (T_2 ; response rate 86%), shortly after the second screening (T_3 ; response rate 85%), shortly before the third screening (T_4 ; response rate 80%), and shortly after the third screening (T_5 ; response rate 78%).

Results: Most women were satisfied with the first screening round and remained positive about subsequent screens. Although pain and anxiety were not uncommon, only a few (10%–15%) experienced moderate or severe levels of distress or pain. Experiences were relatively stable: women who experienced pain in the first screen were more likely to experience pain in subsequent screens (r values from 0.39 to 0.50). Fear of breast cancer was associated with increased distress related to mammography and, to a lesser extent, with increased pain during the mammography. Evidence was found for a relief effect: women were more positive about their previous screen when asked shortly after this screen, than when asked just before the subsequent one. Previous experiences (obtained either proximally or distally) were only slightly predictive for future attendance.

Conclusion: Experiences during mammography are fairly stable. Negative experiences were generally not a reason to drop out of the programme.

Studies in different countries with differently organised breast screening programmes have shown that women who participate in breast cancer screening are in general positive about the course of the breast examination.^{1–10} However, negative experiences are not uncommon. Anxiety or stress provoked by the breast examination or by the possible result, have often been related to mammography.^{4, 9, 11–13} Pain or discomfort due to the compression of the breasts are even more common negative aspects of screening.^{2–4, 6–9, 14–17} Negative experiences at screening might form a reason for women to drop out of the screening programme and should therefore be carefully monitored. Ongoing evaluation of experiences of the participants with the breast cancer screening programme is also important in assessing and minimising possible adverse side effects of screening. The aims of the present study were threefold: (a) to monitor experiences of women during three successive screening rounds; (b) to examine in a prospective design the impact of previous experiences (obtained either immediately after the latest mammogram or shortly before the subsequent one) on reattendance; and (c) to examine which factors contribute to the experience of pain and distress during screening.

Influence of negative experiences on repeat attendance

Many previous studies have related mammographic experiences of women to their future screening plans.^{3, 4, 6–8, 14} However, these studies provide no conclusive evidence for a strong relation between negative screening experiences and intentions to reparticipate. Studies that have examined the impact of (negative) screening experiences on actual reattendance are usually retrospective. The results from these studies generally suggest a strong impact of previous experiences on

subsequent attendance.^{18–22} For example, in a study by Elwood *et al.*,¹⁸ 58% of the non-participants in second screening said that the previous mammographic experience had had a major influence on their decision not to reattend. Most of them (75%) said that it was because the previous mammogram had been painful. However, in a prospective British study by Rutter,²³ it was found that first round experiences, collected shortly after the initial screening round, were of only minor importance in predicting future attendance.

There may be various explanations for the discrepancy between the results from retrospective and prospective studies. In the retrospective studies, women might have considered their experiences in multiple screening rounds, and not just their experiences with one specific mammogram. In retrospective studies the danger also exists of rationalisation: women might have brought their views about earlier screens into line with their later behaviour. However, it is also possible that a woman's perceptions about her previous screen change over time. In the prospective study by Rutter, experiences were assessed shortly after the (initial) breast examination, and might reflect a relief effect: when completing the questionnaires, the next screening round was still far ahead and most women had just recently learned that no indications for breast cancer were found. Evidence for a relief effect after mammography has been provided by two previous

Abbreviations: MANOVA, multivariate analysis of variance; T_1 , 6 weeks after the first screening; T_2 , 6 weeks before the second screening; T_3 , 6 weeks after the second screening; T_4 , 6 weeks before the third screening; T_5 , 6 weeks after the third screening;

studies.²⁻²⁴ In both these studies, women were questioned twice about their experiences of mammography: immediately after screening and a few weeks later. The results from the study by Bakker *et al*² showed that women recollected more anxiety in the second measurement. In the study by Bruijninx *et al*,²⁴ it was found that the percentage of women who recollected that the mammography as painful increased as time passed by. Aro *et al*¹⁴ have argued that fluctuation of reported mammography pain should be studied over time, because there is evidence from dental patients that memory is reconstructed over time to become consistent with expectations and anxiety.²⁵ One of the aims of the present study was to examine whether the perceptions of the previous screen changed in the period between two subsequent screenings. We were also interested in whether the recollections of the previous screen assessed shortly before a subsequent screen, were more predictive of subsequent attendance than the experiences assessed shortly after the particular previous screen.

Possible causes of pain and distress during mammography

Although pain, due to compression of the breasts, is a common side effect of screening mammography, various studies have shown that the amount of pain experienced during mammography varies widely: some women report no pain at all, whereas others report severe pain.²⁶⁻²⁷ Studies that have tried to understand these differences have mainly focused on socio-demographic variables (age, education, marital status) or variables of medical history (menstrual cycle, menopausal history, use of hormones, breast size, breast density, family history of breast cancer).^{14-17, 26-32} These variables, however, do not seem to be consistently associated with the amount of pain experienced during a mammogram. One variable that has been repeatedly found to be associated with pain, is women's anticipation of pain.^{14, 17, 24, 27, 31} Likewise, nervousness or anxiety about having the mammogram has been found to be associated with painful mammograms.^{24, 28, 30}

Although anticipation of pain is thus an important predictor of actual pain, it is not quite clear from where a woman's anticipation of pain, or her nervousness about having the mammogram, stem. On the one hand, it is likely that previous painful mammograms will increase a woman's anticipation of pain for subsequent screens. In the present study we wanted to gain further insight into the relation between amount of pain in the first mammogram and amount of pain in subsequent mammograms. On the other hand, several studies have showed that circumstantial factors, especially the role of the screening staff, are also associated with the amount of perceived pain.^{14, 24, 28, 33} For example, the attitude of the screening personnel to pain (obtained from those personnel) has been found to be significantly related to the pain reported by the woman.²⁴ The procedure, whether or not the woman is instructed to say "stop" if the pain is too much, has also been found to be related to experienced pain.^{24, 33} It was expected

that anticipation of pain and nervousness about having a subsequent mammogram would be influenced not only by the actual perceived pain in previous mammograms, but also by a woman's belief of the reason for previous pain. Based on Weiner's attribution theory,³⁴ it was expected that women who attributed their pain to stable factors (such as breast size), would expect more pain for subsequent screens than women who attributed their pain to unstable or circumstantial factors (such as treatment by the staff).

In summary, the present study was conducted to examine variations in the responses to first, second, and third screens. We were also interested in fluctuations in the recollection of the latest screen as time passed. The impact of previous experiences (obtained either immediately after the latest mammogram or shortly before the subsequent one) on reattendance was examined in a prospective design. Finally, we examined which factors (factors related to the woman, previous experiences, and circumstantial factors) were associated with the experience of pain or distress during the breast examinations.

SUBJECTS AND METHODS

This study was performed within the Dutch Breast Cancer Screening Programme, which has been gradually introduced nationwide from 1990–7. In the Dutch screening programme all women aged 50–69 years are personally invited biennially for a free mammogram. The invitations include a fixed appointment which can be changed upon request. The data presented in this paper were collected in 1992–8, in various parts of The Netherlands, including two urban regions (Tilburg and The Hague/Voorburg) and two rural regions (IJssel-Vecht and Haaksbergen). In all these regions, the screening was being introduced at the start of our study. Baseline questionnaires were sent to 4711 women in the different regions, about 8 weeks after they had taken part in the first screening round. Of the 3148 (67%) women who returned a baseline questionnaire 491 were not eligible for follow up for various reasons (too old for subsequent screening, under treatment or supervision for breast cancer, did not give permission to collect participation data, administrative difficulties) leaving a total of 2657 for the present study.

From these women, actual participation data in second and third rounds were collected from the screening authorities.

Of the 2657 women involved in the study, 323 had objected (in their baseline questionnaires) to receiving further questionnaires, leaving 2334 women eligible for follow up questionnaires. So as not to overload women with questionnaires and not to interfere with attendance too much, the study was designed in a way that each woman would receive no more than two follow up questionnaires. Therefore, the 2334 women were randomly assigned to four subgroups. One group (group 4) would receive no additional questionnaires. This enabled us to investigate whether the receipt of a questionnaire influenced reparticipation. The other three subgroups received questionnaires at four different times (table 1). Follow up questionnaires

Table 1 Plan and response rates for follow up measurements for women involved in the study

	n	T ₂	T ₃	T ₄	T ₅
Group 1	585	x	–	x	–
Group 2	591	–	x	x	–
Group 3	579	–	x	–	x
Group 4	579	–	–	–	–†
Total	2334				
Sent		n=585	n=1170	n=1063*	n=645†
Response		n=496 (86%)	n=984 (85%)	n=846 (80%)	n=486 (78%)

*Due to drop out the number of questionnaires sent at T₂ (1063) was less than the sum of the women from group 1+2 (1176); †due to drop out only 515 women from group 3 were eligible for the T₅ questionnaire. To ensure that enough questionnaires were filled out, additional T₅ questionnaires were sent to a random selection of 130 women from group 4.

were sent to these subgroups 6 weeks before the second screening round (T_2), 6 weeks after the second screening round (T_3), 6 weeks before the third screening round (T_4), and 6 weeks after the third screening round (T_5).

Response and drop out

T_2 questionnaires were sent to 585 women from group 1 (five were not contactable) of which 496 were returned (net response rate $496/580=86\%$). T_3 questionnaires were sent to all 1170 women from groups 2 and 3 (13 were not contactable) of which 984 were returned (85%). T_4 questionnaires were sent to 1063 eligible women from groups 1 and 2 (113 women dropped out from the original sample). Of the 1063 sent questionnaires 12 were undeliverable and 846 were returned (80%). T_5 questionnaires were sent to 515 women from group 3 (64 women dropped out from the original sample). The main reasons for dropping out were that women had become too old for subsequent screening or had moved out of the region. Because the number of women eligible for a T_5 measurement was small, 130 randomly selected women from group 4 were added to the sample. Of the total of 645 sent T_5 questionnaires (24 were not contactable) 486 were returned (78%).

The questionnaires

All questionnaires were self administered. The questionnaires for baseline and follow up measurements were to a large extent identical, but differed in some aspects. The questions included and the differences between the questionnaires are discussed later.

Variables related to the woman (background)

Some sociodemographic characteristics including age, education, and country of birth were only recorded at the baseline measurement. Marital status was assessed in all five measurements. Likewise, regular (monthly) performance of breast self examination (yes or no), experience with breast cancer in someone close (yes or no), family history of breast cancer (does or does not have her mother or sister treated for breast cancer), and fear of breast cancer were assessed in all five measurements. Fear of breast cancer was measured with an adapted version of the fear of cancer questionnaire.^{35, 36} In the adapted eight item version of the scale ($\alpha=0.92$), women were asked to indicate the extent to which negative emotions would be aroused by four hypothetical situations (reading an article about breast cancer, viewing a TV programme about breast cancer, hearing that an acquaintance has got breast cancer, or receiving an invitation for a breast examination). For each situation, women were asked to indicate on a four point scale, ranging from not at all (1) to very much (4), the extent to which the given situation caused nervousness or anxiety.

Experiences during the latest mammography

Organisational aspects that were measured were travel times, waiting times, and appreciation of privacy within the unit. Perceived treatment by staff was measured with a five item scale ($\alpha=0.79$). Women were asked to mark at four point scales, ranging from not at all (1) to very much (4), the extent to which they found the radiology assistants kind, comforting, interested, and impersonal, and whether the assistants took enough time. Levels of distress related to mammography were measured with five items. Women were asked to indicate the extent to which they had felt tense or anxious during the breast examination and in the period between the examination and the receiving of the screening result. Answering options ranged from not at all (1) to very much (4). As well as these four questions, women were asked to mark the extent to which they had worried about the test results. Answering options ranged from not at all (1) to very much (4). Because the five anxiety items were all highly intercorrelated, they were summarised into a scale ($\alpha=0.91$). To measure pain,

women were asked to indicate the amount of experienced pain on a four point answering scale, ranging from not painful at all (1) to very painful (4). On a more general level, women were asked to mark on a four point scale ranging from 1 to 4, their general satisfaction with the breast examination.

The experiences during the latest mammogram were measured as described, in the baseline measurement as well as in all four follow up measurements. However, in the measurements shortly before an invitation for subsequent screening (T_2 and T_4), women were given the extra answering option "I don't remember anymore" for all of the above questions. Because only a few women used this category, the don't remember answers were afterwards coded as missing values. General satisfaction was only measured in the measurements shortly after a screening round (at T_1 , T_3 , and T_5).

In all four follow up measurements, women were asked to attribute the presence or absence of pain during their previous mammogram. Women who had experienced pain were asked to select the most important reason for their pain out of eight (four stable and four unstable) variables (see table 7). Likewise, women who had not experienced pain (or experienced only a little pain) were asked to pick out the most important reason for the absence of pain. Similar variables were offered (see table 8).

Anticipation of pain and anxiety shortly before a subsequent screening

In the measurements shortly before a subsequent screening round (T_2 , T_4), a few questions about women's feelings about the coming mammogram were included. Women were asked to mark on an 11 point scale, ranging from not painful at all (0) to the worst possible pain (10), the extent to which they expected the forthcoming breast examination to be painful. Anxiety about the forthcoming screening was also measured by asking women to indicate the extent to which they felt nervous and anxious about the approaching breast examination and the extent to which they worried about the results. Answering options ranged from not at all (1) to very much (4). The answers for the last three questions could be averaged into an "anxiety before examination" scale ($\alpha=0.89$).

Statistical analyses

Pearson's correlation coefficients were computed to examine the relations between specific experiences and the relation between pain and distress on the one hand, and variables related to the woman on the other. Tests for differences within subjects (multivariate analysis of variance (MANOVA) and paired t tests) were used to compare experiences with first, second, and third screening rounds. Similar analyses were used to examine differences in the perception of the latest mammogram as time passed: T_2 data were compared with T_1 data, and T_4 data with T_3 data. To test the influence of experiences on actual reparticipation, differences between attenders and non-attenders in subsequent screens were examined with MANOVA and t tests.

RESULTS

Baseline measurement

Description of the study group.

The mean age of the women involved in the study was 58.3 years at baseline measurement. Most women were married (78%), not employed (85%), and had lower education levels (68%). Most women (67%) knew someone close who had been treated for breast cancer, 11% had her mother or sister treated for breast cancer. One third (33%) indicated that they performed breast self examination on a regular basis (once every month). The mean score for the fear of breast cancer scale was 1.8, indicating that women in general were not too anxious about breast cancer.

Table 2 Experiences with the first breast examination in the Dutch Breast Cancer Screening Programme*

		n	%
Generally satisfied	Very unsatisfied (1) Quite unsatisfied (2) Quite satisfied (3) Very satisfied (4)	71 20 298 2025	3 1 12 84
Travelling time	<15 minutes (1) 15–30 minutes (2) 30–60 minutes (3) >60 minutes (4)	1697 586 109 15	71 24 5 1
Waiting time	No waiting time (1) <15 minutes (2) 15–30 minutes (3) >30 minutes (4)	480 1699 212 19	20 71 9 1
Enough privacy	Too little (1) Little (2) Enough (3)	13 28 2373	1 1 98
Treatment by staff	5 item scale, (min 1–max 4)		mean=3.5
Distress	7 item scale (min 1–max 4)		mean=1.6
Pain	Not painful (1) A little painful (2) Rather painful (3) Very painful (4)	1030 1026 281 85	43 42 12 4
Duration of pain†	No pain/disappeared immediately (1) Lasted several minutes (2) Lasted several hours (3) Lasted for longer than a day (4)	1490 250 128 82	76 13 7 4

*Total number of respondents may vary due to non-response for individual questions; †in one region this question was not included, leaving fewer subjects for analysis.

How did women experience their first mammogram?

Participation in the first round of the screening was high: 92.9% (2469/2657) of the women indicated that they had attended the first screening round. Table 2 summarises their responses to this first screen. Women tended to be very satisfied about the course of the first screen. Travel times and waiting times were acceptable and women generally felt very well treated by the radiology assistants in the unit. The average score for anxiety related to mammography was 1.6, indicating that in general neither the breast examination nor the waiting for the test result caused extreme anxiety. However, about 10% of the women had average scores of 2.5 or more, indicating moderate to extreme levels of anxiety. Nearly half of the participants (45%) reported that they had not worried at all about the test results; 11% had worried quite a lot or very much. It was found that 57% considered the mammography to be painful to some degree. However, only 16% reported moderate to severe pain. Although most women indicated that the pain disappeared immediately after the breast examination, 128 women (7%) reported that the pain lasted for a couple of hours; a few women (4%) even reported that the pain lasted for longer than a day.

Follow up measurements

How do women experience subsequent mammograms?

The mean scores on experiences with first, second, and third screening are presented in table 3.

A group of 850 women participated both in first and second screening and filled out questionnaires at T_1 and T_2 . Comparisons within subjects in this group showed that in general women were more satisfied with their second breast examination. In comparison with the first breast examination, the second breast examination had caused less anxiety, and women had to wait less time for their turn. On the other hand, women were somewhat less positive about the treatment by staff at the second breast examination. The experience of the

third screening did not differ from the second screening, but differed in a similar way from the first screening. From the significant moderate correlations between experiences in the first screening round and those in subsequent screening rounds, it can be concluded that (with the exception of waiting times and general satisfaction) the experiences during the different screening rounds were fairly stable. Thus, women who experienced distress or pain during the first screening round were more likely to experience distress or pain in subsequent screening rounds.

Did the perception of the previous mammogram change as time passes?

A group of 455 first round participants filled out follow up questionnaires at T_2 . By comparing their responses to first screen at T_1 with their recollections of it assessed at T_2 , insight could be gained into the elaboration of the first round experiences as time passed (table 4).

It was expected that women would be less positive about their previous screening as time had passed. The results met our expectations. At T_2 women were significantly less positive about their first mammogram than at T_1 . At T_2 women recollected longer travelling and waiting times and more distress than at T_1 . Also, women were somewhat less positive about the treatment by the staff, and recollected that the pain lasted longer. Similar findings were established between T_3 and T_4 .

To what extent did experiences influence actual reparticipation?

Actual repeat attendance of the women involved in the study was very high. Of all first round attenders who were invited for second screening, 94% reattended the second round and 94% reattended the third round. Of all second round attenders who were eligible for subsequent screening 95% reattended the third round. Many of those who did not reattend (17% of second round and 10% of third round non-reattenders) had

Table 3 Comparison of experiences of attenders of first, second, and third screening mammography in the Dutch Breast Cancer Screening Programme 1992–8

	Mean scores on specific experiences			Paired samples correlations*		
	In first round T_1 (n=2469)	In second round T_2 (n=908)	In third round T_3 (n=445)	T_1 v T_2 (n=850)	T_2 v T_3 (n=312)	T_1 v T_3 (n=421)
General satisfaction (1/4)	3.8	3.9†	3.9‡	0.16	0.20	0.12
Travel time (1/4)	1.4	1.4	1.4	0.53	0.57	0.26
Waiting time (1/4)	1.9	1.8†	1.8‡	0.16	0.24	0.12
Treatment by staff (1/4)	3.5	3.4†	3.3‡	0.48	0.49	0.37
Distress (1/4)	1.6	1.5†	1.5‡	0.63	0.72	0.61
Pain (1/4)	1.8	1.8	1.8	0.50	0.39	0.45
Duration of pain (1/4)	1.4	1.4	1.4	0.41	0.44	0.36

*All paired sample correlations were significant at $p < 0.01$; †significantly different ($p < 0.01$) from the score at T_1 , tested by paired t tests, $n=850$; ‡significantly different ($p < 0.01$) from the score at T_1 , tested by paired t tests, $n=421$.

Table 4 Comparison of the recollection of the experiences of latest screen, assessed immediately after screening (T_1 , T_3) and after 2 years (T_2 , T_4), in the Dutch Breast Cancer Screening Programme 1992–8

	Experiences (n=455) with first screen (mean scores) expressed at		Experiences (n=355) with second screen (mean scores) expressed at		Paired sample correlations†	
	T_1	T_2	T_3	T_4	T_1 v T_2	T_3 v T_4
Travel time (1/4)	1.37	1.44*	1.30	1.36*	0.49	0.52
Waiting time (1/4)	1.86	2.01***	1.76	2.00**	0.49	0.42
Treatment by staff (1/4)	3.56	3.46***	3.37	3.38	0.60	0.59
Distress (1/4)	1.59	1.68***	1.49	1.62***	0.69	0.68
Pain (1/4)	1.73	1.78	1.75	1.85**	0.69	0.72
Duration of pain (1/4)	1.36	1.44*	1.46	1.57**	0.74	0.55
	$F_{multiv}(6, 305)=5.90$ $p<0.001$		$F_{multiv}(6, 235)=15.76$ $p<0.001$			

* $p<0.05$; ** $p<0.01$; *** $p<0.001$; †all paired sample correlations were significant at $p<0.01$.

Table 5 Mean scores from the first round experiences of women who did and did not attend the second screening round

	First round experiences expressed after first screen (T_1)		First round experiences expressed before second screen (T_2)	
	Attenders (n=2221)	Non-attenders† (n=112)	Attenders (n=442)	Non-attenders‡ (n=17)
General satisfaction	3.8	3.7	–	–
Travel time	1.4	1.5 *	1.4	1.9 **
Waiting time	1.9	2.0	2.0	2.1
Treatment by staff	3.6	3.4 **	3.5	3.2
Distress	1.6	1.7	1.7	2.0
Pain	1.8	1.9 *	1.8	2.2
Duration of pain	1.4	1.5	1.4	1.6

* $p<0.05$; ** $p<0.01$; *** $p<0.001$; †women with legitimate reasons for not attending were not included; ‡because of the few non-attenders, differences between the groups were tested with non-parametric (Mann-Whitney) tests.

legitimate reasons for not attending: they had had a mammography recently, they had been treated for breast cancer recently, or had moved out of the region. To examine the influence of experiences on actual repeat participation, a comparison was made between first round experiences of reattenders and non-reattenders in the second round (table 5).

Table 5 shows that the women who did not return for second screening, expressed at T_1 significantly longer travel times, more pain, and less satisfaction about the treatment by the staff. It should, however, be noted that the effect sizes were small (<1% explained variance for any of the variables). In table 6, the mean scores for previous experiences (with first and second screen) are presented for attenders and non-reattenders in the third screening round. Again, previous

experiences (obtained either after the earlier screens or before the subsequent one) were only slightly predictive for reattendance.

Which factors can explain distress and pain during mammography?

To find possible determinants of distress and pain related to mammography, the correlations with background variables related to the woman and with circumstantial factors (treatment by staff, waiting time, appreciation of privacy) were examined. Distress was significantly correlated with general fear of breast cancer (correlations ranging from $r=0.66$ to $r=0.78$ in the various measurements). None of the other background variables was strongly associated with distress (Pearson's $r<0.10$). In none of the measurements was

Table 6 Mean scores from the first and second round experiences of women who did and did not attend the third screening round

	First round experiences expressed after first screen (T_1)		Second round experiences expressed after second screen (T_3)		Second round experiences expressed before third screen (T_4)	
	Attenders (n=1484)	Non-attenders† (n=91)	Attenders (n=668)	Non-attenders‡ (n=28)	Attenders (n=577)	Non-attenders‡ (n=20)
General satisfaction	3.8	3.6	3.9	3.7 *	–	–
Travel time	1.4	1.5	1.4	1.6	1.4	1.5
Waiting time	2.0	1.9	1.8	1.6 *	2.0	2.0
Treatment by staff	3.6	3.4	3.2	3.1	3.4	3.6
Distress	1.6	1.8 *	1.5	1.4	1.5	1.6
Pain	1.8	1.7	1.8	1.9	1.5	1.9 *
Duration of pain	1.4	1.4	1.4	1.6	1.3	1.5

* $p<0.05$; ** $p<0.01$; *** $p<0.001$; †women with legitimate reasons for not attending were not included; ‡because of the small number of non-attenders, differences between the groups were tested with non-parametric (Mann-Whitney) tests.

Table 7 Variables (%) affecting pain during previous mammography expressed at T₂–T₅

My last breast examination was painful because	T ₂ (n=191)	T ₃ (n=422)	T ₄ (n=446)	T ₅ (n=256)
Unstable variables:				
The machine was not in the right position	5	5	4	4
The assistant pressed harder than necessary	13	17	13	5
I happened to have sensitive breasts because of my cycle	2	1	–	–
I was too anxious	17	10	8	6
Stable variables:				
I have (too) small breasts	14	14	13	11
I have (too) large breasts	18	11	15	14
I have a low pain threshold	3	3	3	3
A mammography simply is a painful examination	30	41	44	58

Table 8 Variables (%) affecting lack of pain during previous mammography expressed at T₂–T₅

My last breast examination was not (or only a little) painful because	T ₂ (n=298)	T ₃ (n=518)	T ₄ (n=512)	T ₅ (n=232)
Unstable variables:				
The machine was in the right position	3	9	7	11
The assistant sensed well how hard she could press	28	27	28	28
I happened to have no sensitive breasts because of my cycle	1	–	–	–
I was at ease	13	17	15	18
Stable variables:				
I have small breasts	6	5	6	3
I have large breasts	4	4	3	4
I have a high pain threshold	9	10	9	12
A mammography simply is not a painful examination	35	28	33	25

distress related to mammography significantly associated with circumstantial factors.

Pain was significantly, although weakly, correlated with general fear of breast cancer (correlations ranging from $r=0.10$ to $r=0.25$). During the first three measurements, more highly educated women reported slightly more pain (correlations varying from $r=0.11$ to $r=0.13$). Only weak correlations between pain and circumstantial factors were established: pain was correlated with satisfaction about treatment by staff (significant correlations observed for T₁, T₂, T₃, and T₄ with correlation coefficients of respectively -0.15 , -0.20 , -0.12 , and -0.21), and with waiting time (significant correlations established at T₁, T₂, and T₄ with correlation coefficients of respectively 0.13 , 0.13 , and 0.15).

Women's reasons for pain

Table 7 shows that women who had experienced pain during the initial screening attributed this to various reasons, such as the size of the breasts, their nervousness during screening, and insensitive treatment by the assistant. The answer mentioned most in all measurements was "because a mammogram simply is a painful examination". The percentage of women who attributed pain to unstable factors diminished from 37% at T₂ (reflecting first round experiences) to 15% at T₃ (reflecting third round experiences). Women who experienced pain in subsequent screening rounds as well as the first seemed to have become convinced that a mammogram simply is a painful examination.

The absence of pain was more often attributed to unstable factors (table 8). In particular sensitive treatment by the laboratory assistant was mentioned often as the reason for lack of pain. Other reasons mentioned often were "A mammography simply is not a painful examination", and "I felt at ease".

Anxiety and anticipation of pain shortly before a subsequent screen

In the measurements shortly before a follow up screening (T₂ and T₄), women's anxiety about the coming breast examination was assessed. The mean score of anxiety before screening was 1.6 in both T₂ and T₄. About one third of the respondents indicated that they were a little nervous or anxious about the approaching screening; 9%–13% of the women indicated that they were quite or very nervous about it. In both T₂ and T₄, a few indicated that they worried a little (7%) or very much (4%) about the result of the coming breast examination.

It was expected that a previous painful mammogram would increase anxiety about the subsequent screen. To examine this, the partial correlation coefficient between anxiety before the second screening (expressed at T₂) and previous pain (expressed at T₁), was computed, while controlling for anxiety during the initial screening (expressed at T₁). Nervousness about the second screen (at T₂) was significantly influenced by pain experienced in the initial screen (partial $r=0.21$, $n=448$, $p<0.001$). Nervousness about the third screening was almost significantly influenced by pain in the second round (partial $r=0.10$, $n=350$, $p=0.071$).

The scores for anticipated pain ranged from 0 (no pain) to 10 (worst possible pain) and had a mean of 1.6 at both T₂ and T₄. Moderate pain (score 4–6) was expected by 18% of the women who filled out T₂ and by 23% of the women who filled out T₄. Severe pain (score >6) was expected by 8% at T₂ and by 6% at T₄. The amount of anticipated pain for the coming screening round was strongly influenced by previous pain (correlations ranged from $r=0.68$ till $r=0.82$). It was expected that women who attributed their pain in previous screening to stable factors, would anticipate more pain in subsequent screening rounds than women who attributed their pain to unstable factors. To test this hypothesis we compared the

expectations of pain in the two groups (stable or unstable), while controlling for previous pain. The results largely confirmed our hypothesis: women who attributed their pain in the first round to stable factors expected the second screening to be more painful than women who attributed their first round pain to unstable factors (means 4.1 v 2.9). This effect of attributing a reason for the pain was significant when previous pain expressed at T_2 was used as covariate ($p=0.039$), and also when previous pain expressed at T_1 was used as covariate ($p=0.001$). Expectations of pain for the third screening (established at T_4) showed similar results: women who attributed their pain at second screening to stable factors expected the third screening to be more painful than women who attributed their second round pain to unstable factors (means 3.5 v 2.9). This effect of attributing a reason for pain was significant when second round pain expressed at T_4 was included as a covariate ($p=0.011$), but not significant when second round pain expressed at T_3 was included as a covariate ($p=0.110$).

DISCUSSION

The results of our study showed that women were in general very positive about the course of the first round of the Dutch Breast Cancer Screening Programme. This includes high general levels of satisfaction, acceptable travel and waiting times, and satisfaction about treatment by staff and the privacy within the unit. These results are in accordance with previous studies that reported positive evaluations of breast cancer screening.¹⁻¹⁰ Although pain was common, only a few described the mammogram as rather (12%) or very (4%) painful. A significant few women indicated that the pain had lasted for more than several hours (7%), or even for more than a day (4%). For most women, the first breast examination had caused only little or no distress. For a few (<15%), however, the breast examination and the waiting for the result had caused moderate to severe distress.

The present study was the first to examine the experiences of women during three successive screening rounds. The results showed that women largely remained positive about the course of subsequent breast examinations. However, some (minor) changes occurred in the evaluation of the later mammograms. General satisfaction about the course of the mammograms increased and women reported less anxiety and shorter waiting times in later screens. On the other hand, in later rounds women were somewhat less satisfied about the treatment by the staff. Most changes seemed to occur in the second screening round and stabilised in the third. It can be concluded that the Dutch screening organisations have succeeded in establishing and maintaining high levels of client friendliness at screening.

Our data supported the existence of a relief effect, as reported by previous studies.^{2,24} Although women remained positive about their latest mammogram, they were somewhat less positive about it at the measurements shortly before a subsequent screen. In the measurements shortly before screening women recollected longer travel and waiting times, more anxiety, a worse treatment by the staff, more pain, and a longer duration of the pain.

An aim of this study was to examine whether negative experiences with screening were predictive for non-attendance in subsequent rounds. It is concluded that although some minor significant effects were found negative experiences were not strongly predictive of actual reattendance. This was also found previously.²³ Most women (>94%) reattended for screening, sometimes even despite negative experiences such as pain, distress, or long distance to the unit. The finding that previous experiences are not related to reattendance contrasts with previous retrospective studies, which have reported that non-attendance was related to negative experiences.¹⁸⁻²¹ In these studies women possibly have brought

their recollection of the experience of the screening in line with their non-attendance behaviour.

Our data showed that, except for general satisfaction and waiting times, experiences were relatively stable over several screens. In other words, most women tended to have similar experiences during the first, second, and third screening rounds. The amounts of both distress and pain in subsequent screens were significantly related to reported distress and pain in previous screens (r values varied from 0.61 to 0.63 for distress and from 0.39 to 0.50 for pain). Anxiety about having the mammogram was strongly associated with general fear of breast cancer. Anxiety about having the mammogram was not related to age, education, country of birth, employment, or marital status. Nor was it significantly associated with having a family history of breast cancer, or knowing someone close with breast cancer.

Previous pain was the best predictor of pain during mammography. Associations between pain and circumstantial factors (treatment by staff, waiting time) were generally weak. Although pain was thus a relatively stable factor, it was difficult to establish factors that make a woman prone to experiencing pain during a mammogram. Sociodemographic factors such as age, country of birth, and marital and employment status, were not related to pain. Previous studies have shown that family history was not associated with increased pain.^{14,15} The results from the present study are in line with these findings. The factor which was most consistently, although weakly related to pain (r values varied from 0.10 to 0.25), was general fear of breast cancer: women who were more afraid of breast cancer were more likely to experience pain.

Women themselves attributed their pain mostly to stable factors, such as the size of their breasts (too large or too small breasts) or the belief that a mammography simply is a painful examination. Especially in the earlier measurements, however, some women attributed their pain to unstable factors, such as unnecessary harsh treatment by the assistant, and being anxious. Several studies have shown that anticipation of pain is an important predictor of actual pain during mammography.^{14,17,31} In these studies it was not possible to examine the basis of the anticipation of pain. Our study showed that the anticipation of pain was to a large extent determined by experiencing pain during previous mammograms. However, this relation was modified by women's attributions: women who attributed their previous pain to unstable factors expected less pain in a future screening, than women who attributed previous pain to stable factors.

The relation between distress and pain during mammography seems to be complex. Pain leads to increased anxiety about having the next mammogram, whereas increased anxiety seems to cause increased pain.^{14,24} Efforts to make women feel at ease during screening might not only decrease anxiety but also pain. Peart³⁷ recommends a careful explanation of the importance of the compression before beginning and then slowly increasing the compression. For women during menstruation, a rescheduling of the mammography can be considered. Patient control over the mammography procedure has also been shown to decrease pain without compromising image quality³³ and might be a useful tool for the reduction of pain during the mammogram.

It should be mentioned that our study was subject to response bias. Participation in the initial screening round among baseline respondents was nearly 93%. This is considerably higher than the general participation rate in the Dutch Breast Cancer Screening Programme, which is about 79%.³⁸ Because this study was specifically aimed at examining the influence of previous mammographic experiences on participation in subsequent screening rounds, an overrepresentation of attenders at initial screening is not directly a threat for the validity of the present study. Yet there was also response bias in subsequent measurements: women who participated in

subsequent screenings were more like to fill out follow up questionnaires than women who did not participate in subsequent screening rounds (for example response in T₂ was 63% among non-attenders and 87% among attenders in the second screening; response in T₃ was 44% among non-attenders versus 88% among attenders in the second round screening). This may have led to overoptimistic findings, and the results from the follow up measurements must therefore be interpreted with caution.

In summary, women are very positive about the screening service and remain positive during the course of the programme. However, anxiety and pain or discomfort are not uncommon, and efforts to minimise these inconveniences should be continued. For some women, negative experiences during first screening such as long distance to the unit, a painful mammogram, and dissatisfaction about the treatment by staff, were reasons for not returning for subsequent screenings. However, the vast majority of women reparticipated in subsequent screening rounds despite these inconveniences.

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