Perceived sensitivity of mammographic screening: women's views on test accuracy and financial compensation for missed cancers

Alexandra Barratt, Jill Cockburn, Colin Furnival, Amanda McBride, Louise Mallon

Abstract

Objectives—To estimate women's expectations of the accuracy of screening mammography and to explore attitudes towards compensation for missed cancers.

Design—Cross sectional survey (by telephone).

Setting—Australia; population-based survey conducted in April 1996.

Participants—Random sample of women aged 30–69 years. A total of 2935 women completed the Breast Health Survey (adjusted response rate 65%). A random sample of 115 completed this sub-survey on perceived sensitivity of mammographic screening and compensation for missed cancers.

Results—About one third of women (32.2%, 95%CI 23.7, 40.7) had an unrealistically high expectation of the sensitivity of screening mammography, reporting it to be 95% or higher. Approximately 40% of the women (43.5%, 95%CI 34.4, 52.6) thought that screening mammography should pick up all cancers (should have a sensitivity of 100%). Just under half the women (45.2%, 95%CI 36.1, 54.3) said financial compensation should be awarded for a cancer missed by screening mammography even if the cancer was missed as a consequence of the small failure rate of the test. Younger women living in metropolitan areas and women who had realistic expectations of the accuracy of the tests were more likely to favour financial compensation.

Conclusion—Unrealistically high expectations of the sensitivity of screening mammography were common in this group of women. Many women favoured financial compensation for missed cancers even if the cancer was missed solely because of the failure rate of the test. Public education is required to inform women of the limited sensitivity of breast cancer tests but this may not reduce claims for financial compensation when cancers are missed.

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the range 75% to 95%.^{1,2} There is evidence that women are not well informed about the accuracy of screening mammography and may not be aware of the false negative rate (1– sensitivity). A recent survey of 58 pamphlets about mammographic screening in Australia found that information about the accuracy of screening mammography was provided only occasionally, with a quarter of pamphlets giving information about sensitivity and none giving information about specificity.³ Earlier work showed that 35% of women thought that screening mammography would detect breast cancer in 95–100% of cases.⁴ Some authors have speculated that this ignorance contributes to a sense of anger and betrayal if a cancer is missed, which may make women more likely to sue for negligence and financial compensation.⁵

Women have already successfully sued for false negative results in the context of diagnostic tests (that is, tests applied to symptomatic women) in Australia. For example, in 1994 an Australian woman successfully sued a pathology laboratory for the delay in diagnosing her cancer of the cervix after a negative Pap smear, taken to investigate irregular vaginal bleeding.⁶ To the best of our knowledge no one has successfully sued for negligence over a false negative result of a screening test in Australia although it is impossible to determine what cases may have been settled out of court. Therefore it remains unclear whether a similar outcome may be achieved in the screening context. It has been argued that successful claims against a screening programme could render the breast and cervical screening programmes in Australia unsustainable because of increasing costs and increasing overdiagnosis and overtreatment of minor abnormalities.^{7,8} Similar concerns have been expressed in the UK^{9,10} and the USA.¹¹ It has been suggested that public education emphasising that screening tests are not, even at the highest levels of practice, 100% accurate may be helpful.^{5,8,9,11}

Methods

We used the 1996 National Breast Health Survey (undertaken by the National Health and Medical Research Council's National Breast Cancer Centre) to undertake some exploratory work on women's expectations about the accuracy of screening mammography and their attitudes towards legal action and financial compensation for missed cancers. A detailed description of the survey has been published.¹²

Department of Public Health and Community Medicine, University of Sydney, NSW, Australia
A Barratt

Discipline of Behavioural Science in Relation to Medicine, University of Newcastle, NSW, Australia
J Cockburn

Royal Brisbane Hospital, QLD, Australia
C Furnival

NHMRC National Breast Cancer Centre of Australia, NSW, Australia
A McBride

United Medical Protection, NSW, Australia
L Mallon

Correspondence to:
Dr A Barratt, Department of Public Health and Community Medicine, Building A27, University of Sydney, NSW, 2006 Australia.

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Screening mammography is provided for women aged about 50 to 70 years in many countries including the United Kingdom, USA and Australia. Estimates of the sensitivity of screening mammography vary from study to study and according to age but generally lie in

Table 1 Sociodemographic profile of participants compared with whole survey group and Australian national data

Characteristic	ABS (Australian national data) %	Breast Health Survey (n=2935) %	Subset reported here (n=115)	
			%	Number
<i>Age (y)</i>				
30–39	33.2	30.7	31.3	36
40–49	30.1	31.7	32.2	37
50–59	20.6	22.1	23.5	27
60–69	16.1	15.3	13.0	15
<i>Marital status</i>				
Never married	5.8	5.8	6.1	7
Married/de facto	78.5	79.7	72.2	83
Separated/divorced/widowed	15.8	14.5	21.7	25
<i>Post-school education</i>				
None	54.0	47.1	40.9	47
Trade certificate	3.1	4.2	6.1	7
Degree or higher	14.6	17.7	11.3	13
Other	28.3	31.0	41.7	48
<i>Household income</i>				
\$0–19 999	N/A		20.0	23
\$20 000–29 999			17.4	20
\$30 000 and over			38.4	44
Can't say/refused			24.3	28
<i>Country of birth</i>				
Australia	69.2	76.0	71.3	82
Other	30.8	24.0	28.7	33
<i>Language spoken at home</i>				
English	N/A	96.6	98.3	113
Chinese language		0.3	0.9	1
European language		2.1	0.9	1
Other		1.0	0	
<i>Employment</i>				
Full time	26.2	27.9	28.7	33
Part-time	27.9	29.1	28.7	33
Looking for work	3.3	3.9	4.3	5
Not looking for work	42.6	39.1	38.3	44
Have ever had a mammogram	50.0	55.0	57.4	66

Briefly, the Breast Health Survey was conducted nationally by telephone by a market research company on behalf of the National Breast Cancer Centre (NBCC) in April 1996 to estimate current knowledge and behaviour in relation to breast cancer and early detection practices. A simple random sample of 3000 women aged 30–69 years was used with stratification by State and by area of residence (urban and rural).

A random sample (n=115) of all respondents to the Breast Health Survey were asked an extra set of questions about medicolegal aspects of diagnosis, the results of which are reported in this paper. The medicolegal questions were developed specifically for this work; they were based on previous work by Cockburn *et al.*⁶ and were qualitatively pilot tested with 20 volunteers, revised and pilot tested again with a further 100 volunteers before the main survey. Only 115 women were asked these additional questions as we estimated that 95% confidence limits of approximately +/- 10% would be adequately precise and because it was not considered feasible to ask all women to spend the extra 20 minutes that was required to answer these questions.

VALIDATION OF THE SURVEY

To assess potential selection bias we obtained data from February 1996 Australian Bureau of Statistics (ABS) Population Survey Monitor, which is conducted quarterly by household interview for the Commonwealth Government to supplement census data. In addition we placed one of our questions, "Have you ever had a mammogram?", into the ABS survey. The question was asked only of women 30–69

years in the ABS survey to provide a result comparable with our study.

STATISTICAL METHODS

SPSS statistical package was used for all analyses. We calculated 95% confidence intervals for important proportions. Where it was necessary to compare means, a *t* test for independent samples was used and differences in proportions were compared using the χ^2 statistic. Logistic regression using backwards stepwise elimination of variables was used to model the predictors of favouring financial compensation. We calculated 95% confidence intervals around the coefficient estimates and exponentiated to give the confidence intervals around the estimated odds ratios.

Results

RESPONDENT CHARACTERISTICS AND RESPONSE RATE

The raw response rate (completed interviews over contacted eligible women) was 70.2%; the adjusted response rate (adjusting for eligible women among those who could not be contacted) was 64.4%. The results reported here are based on responses from 115 women who were chosen at random from the total sample of 2935 women to complete extra questions on medicolegal issues. These women were similar to the total group in sociodemographic characteristics (table 1); for example the mean age of the subset of 115 women was 46.38 years compared with 46.35 years for the whole group ($t=0.036$, $p=0.972$) and there were no differences in the proportions of women living in urban and rural/remote areas ($\chi^2 = 1.077$, $p=0.30$). The women in both the total survey group and the subset reported here were similar to Australian national data as measured by the Australian Bureau of Statistics (table 1).¹³ Approximately half the women (57.4%) had ever had a mammogram, which is close to the national average of 50% (table 1).

PERCEIVED SENSITIVITY OF SCREENING MAMMOGRAPHY

Women were asked: "Imagine a situation where 100 women really have early breast cancer but the cancer is as yet undetected. Along with many other women they all have a screening mammogram (to detect breast cancer before any symptoms, like a lump, are present). On average, how many of the 100 women do you think the mammogram would pick up?" The meaning of each woman's response was checked by asking "So that means that it would pick up ...% of the cancers and miss ...% is that right?" in an iterative fashion until the respondent and the interviewer agreed upon the percentage picked up.

In subsequent questions, women were asked "... realistically how many of these 100 women do you think the test should pick up?" and "Of the 100 women who actually have breast cancer, what would you say would be the absolute minimum number that the screening mammogram should detect to be called a worthwhile test?"

Table 2 Women's estimates of the sensitivity of screening mammography (correct answer for current sensitivity shown in *italics*)

	Women reporting each category of sensitivity for:					
	Cancers that are currently detected by screening		Cancers that should be detected by screening		The minimum number of cancers that should be detected for screening to be worthwhile	
Sensitivity (%)	%	(n)	%	(n)	%	(n)
0–59	13.9	(16)	9.6	(11)	20.9	(24)
60–79	13.0	(15)	4.3	(5)	7.0	(8)
80–89	14.8	(17)	5.2	(6)	9.6	(11)
90–94	20.0	(23)	14.8	(17)	16.5	(19)
95–99	28.7	(33)	19.1	(22)	21.7	(25)
100	3.5	(4)	43.5	(50)	13.9	(16)
Can't say	6.1	(7)	3.5	(4)	10.4	(12)
Total	100	115	100	115	100	(115)

Table 2 gives the responses to these questions.

There was substantial variation in women's estimates of the sensitivity of screening mammography; only 35% (34.8%, 95%CI 26.1, 43.5) reported it to be in the range of 80–94%, which is correct allowing for the known variation in sensitivity by age. However, about one third (32.2%, 95% CI 23.7, 40.7) had unrealistically high expectations of the sensitivity, reporting it to be over 95%.

Almost half the women (43.5%, 95%CI 34.4, 52.7) thought that screening mammography "realistically should" pick up all cancers (that is, should be 100%), and three quarters of the women (77.4%, 95%CI 69.8, 85.0) reported that the sensitivity should be over 90%.

Nevertheless, women were prepared to accept much lower sensitivities before deciding that screening would not be worthwhile. Only 14% of women (13.9, 95%CI 7.6, 20.2) said 100% of cancers should be detected for screening to be worthwhile. About half the women (52.1%, 43.0, 61.2) reported screening would be worthwhile if sensitivity was 90% or better.

PROPORTION OF WOMEN FAVOURING COMPENSATION FOR A BREAST CANCER MISSED BY SCREENING

Women were asked "A woman who has undetected early breast cancer is invited to have a screening mammogram. Due to the small error rate of the test the cancer is not picked up at this stage. The cancer is detected only at a later stage by a separate test. Do you think this woman should receive compensation?" Subsequently women were asked a similar question but in a situation where the cancer was not detected because someone involved in performing the test made a negligent error, for instance did not pass on an abnormal result.

Table 3 Predictors of being in favour of financial compensation for false negative screening result

	B	OR (Exp B)	(95% CI)	Significance (p)
Constant	0.673			
Age	−0.052	0.950	0.91, 0.99	0.026
Area of residence (metropolitan)	1.816	6.147	1.72, 21.93	0.005
Risk perception (low to average)	1.071	2.919	1.12, 7.58	0.028
Expectation of accuracy of screening mammography (unrealistically high)	−0.994	0.370	0.14, 0.97	0.042

Forty five per cent of women (45.2%, 95%CI 36.10, 54.3) were in favour of financial compensation being awarded if the breast cancer was missed because of the failure rate of the screening test. However, if the cancer was missed because of a negligent error made by someone in the screening process, 93% (95%CI 88.3, 97.7) of women thought compensation should be awarded.

PREDICTORS OF FAVOURING COMPENSATION FOR A BREAST CANCER MISSED BY SCREENING (BECAUSE OF THE FAILURE RATE OF THE TEST)

In the main survey women were asked questions about breast cancer incidence and about their perceived likelihood of getting breast cancer.¹⁵ From the responses to these questions variables were constructed to represent women's knowledge about breast cancer (based on whether she could accurately report the breast cancer incidence in Australia) and her perceived risk as either low to average (<12%) or high (>12%). In addition a variable based on whether women were realistic or unrealistic in their beliefs about the sensitivity of screening mammography was constructed from the data presented in table 2. Women who thought that the sensitivity of screening mammography is 95% or greater were classified as unrealistic.

The major sociodemographic factors (age, education, and area of residence) plus the developed variables outlined above, were tested in the logistic regression model because it was thought a priori that these variables might influence women's views and univariate analysis supported this. A personal history of mammography was not associated with favouring compensation in univariate analysis (women were just as likely to favour compensation whether they had had a mammogram or not, ($\chi^2 = 0.21$, $p=0.88$) so this variable was not entered into the model.

Significant predictors of favouring financial compensation even if the delay was attributable to the error rate of the test were younger age, residence in an urban rather than a rural area, a realistic perception of the accuracy of screening mammography and a perception that one's own risk of breast cancer is about population average or less (table 3).

MOTIVATION FOR LEGAL ACTION

Women were asked "If a woman did take legal action to obtain compensation because her breast cancer was not diagnosed for whatever reason, what do you think her main motivation would be for taking legal action?"

Their responses are given in table 4. Many of the responses were centred around issues of financial need both for the woman (for treatment) and for her family.

ALTERNATIVES TO TAKING LEGAL ACTION

Women were asked "Imagine a woman did take legal action to obtain compensation because her breast cancer was not diagnosed for whatever reason, what alternatives might be useful or acceptable to her instead of taking legal action?"

Table 4 Suggested reasons for starting legal action

Reason	Frequency	
	%	number
Provide financial stability/compensation for her family	22.6	26
To prevent it happening to someone else	12.2	14
She could die/lose a breast from it	11.3	13
Anger/bitterness	7.8	9
Make the people doing the test more responsible	6.1	7
Help pay medical bills/afford treatment	5.2	6
Publicity to expose negligence of person responsible	4.3	5
Psychological satisfaction	1.7	2
Revenge/vindictiveness	0.9	1
Other	10.4	12
Can't say	17.4	20
Total	100	115

Most women said there was no alternative to taking legal action (6%) or were unable to answer this question (63%). However, a few alternatives were offered that primarily related to some form of financial assistance or out of court payment to cover medical costs and family expenses (10%) or the provision of counselling services (5%).

Discussion

Although our sample was small, there is little evidence of selection bias as there were no important sociodemographic differences between the subset of women whose results are presented here, our total survey population ($n=2935$) and the Australian population as measured by the Australian Bureau of Statistics¹³ (table 1).

Women have been shown to overestimate both their chances of getting breast cancer and the effectiveness of screening in reducing breast cancer mortality.¹⁴ This study provides evidence that women also overestimate the accuracy of mammographic screening and is consistent with the earlier study by Cockburn *et al.*⁴ Furthermore, we found that almost half the women thought that screening mammography "realistically should" pick up all cancers (that is, should be 100%). The previous study was done in 1994, which suggests that public knowledge about screening mammography has not improved and expectations of accuracy are still high. This is not surprising given the enthusiastic way in which mammographic screening has been promoted, often with limited acknowledgement of the potential for both false negative and false positive results.^{3 15} Unfortunately we did not collect any information on the perceived specificity of mammographic screening. This should be investigated because it seems likely that many women may also be unaware of the likelihood of a false positive result and its potential consequences.

This study suggests that most women in Australia think that compensation should be awarded in cases where there is negligence on the part of one or more health professionals leading to a delayed diagnosis. Fewer, but still about half of surveyed women, thought financial compensation should be awarded for missed cancers even if the cancer was missed because of the error rate of the test and not because of negligence. Many women nominated financial needs as the primary motivation

for seeking compensation, which suggests that a system of no fault compensation for false negative reports, similar to systems of compensation for adverse effects after immunisation, might be helpful.

False negative results may occur for several reasons. Firstly, the cancer may have arisen after the mammogram, that is it may be an interval cancer that presents clinically before the next screen is due. Alternatively the cancer may have been present at the time of the mammogram but was missed either through negligent or non-negligent error. Resolving these distinctions may prove difficult in the courts as the issues are even more complex than they are around errors in diagnostic tests. In the case referred to earlier⁶ the judge determined that the interpretation of the smear made by the pathology company could not be explained as an acceptable different interpretation. Therefore the only explanation was that the interpretation was wrong and the error was made negligently. The decision as to whether a false negative report from a screening test is negligent rests with the judge hearing the case and presumably the decision will be made along the same lines. Currently therefore the outcome of such a case is unpredictable. This uncertainty has led to calls for statutory immunity from suit for providers of screening services who comply with certain standards of care as laid down by an appropriate accrediting agency.¹⁶

Information about both the false negative and false positive rate of screening tests should be provided so that people are better able to make an informed choice about participation in screening. In addition, it needs to be clear that a negative result does not completely exclude disease and tells nothing about whether disease will develop in the future.

Although it is intuitively appealing to think that if women have realistic information about the accuracy of mammographic screening they will be less inclined to seek financial compensation for missed cancers, this may not be the case. The results of this study suggest that as women's knowledge about the true accuracy of screening mammography increases we might expect that more women may seek financial compensation for missed cancers.

In conclusion, many women have unrealistically high expectations of the sensitivity of screening for breast cancer. About half of women favoured financial compensation for missed cancers even if the cancer was missed solely because of the failure rate of the test. Predictors of favouring compensation included young age and realistic expectations of the accuracy of tests. Consideration needs to be given to the legal status of non-negligent false results and alternative ways of compensating women whose cancers are missed. Public education is required to inform women of the accuracy of mammographic screening but this may not modify the widely held view that compensation should be sought when cancers are missed.

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