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Women's perception of the benefits of mammography screening: population-based survey in four countries

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Background Screening programmes are often actively promoted to achieve high coverage, which may result in unrealistic expectations. We examined women's understanding of the likely benefits of mammography screening.

Methods Telephone survey of random samples of the female population aged ⩾15 years in the US, UK, Italy, and Switzerland using three closed questions on the expected benefits of mammography screening.

Results A total of 5964 women were contacted and 4140 women (69%) participated. Misconceptions were widespread: a majority of women believed that screening prevents or reduces the risk of contracting breast cancer (68%), that screening at least halves breast cancer mortality (62%), and that 10 years of regular screening will prevent 10 or more breast cancer deaths per 1000 women (75%). In multivariate analysis higher number of correct answers was positively associated with higher educational status (odds ratio [OR] = 1.44, 95% CI: 1.25, 1.66) and negatively with having had a mammography in the last 2 years (OR = 0.86, 95% CI: 0.73, 1.01). Compared with US women (reference group) and Swiss women (OR = 0.98, 95% CI: 0.82, 1.18) respondents in Italy (OR = 0.61, 95% CI: 0.50, 0.74) and the UK (OR = 0.73, 95% CI: 0.60, 0.88) gave fewer correct answers.

Conclusion In the US and three European countries a high proportion of women overestimated the benefits that can be expected from screening mammography. This finding raises doubts on informed consent procedures within breast cancer screening programmes.

Users of health services should receive accurate information on the effectiveness, risks, and limitations of medical interventions in order to be able to actively participate in decision making.[1] Ensuring that the target group of a screening programme receives accurate information about benefits and harms of screening presents particular challenges. Most people targeted for screening are free from disease and not in regular contact with health services. Participation in screening programmes must therefore be actively promoted to achieve high coverage. Indeed, in one study the perceived benefits of mammography screening were found to be predictive of participation in Caucasian (but not in African American) women, and another study, also based on the Health Beliefs Model, reported that perceived benefits accounted for a substantial proportion of the variance between women who wanted a mammogram and women who did not.[2,3] Of note, some have argued that women who are not

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complying with screening recommendations 'would benefit from additional emphasis on mammography benefits'.[4]

The promotion of population-based screening may result in unrealistic expectations, and truly informed consent may therefore be difficult to achieve. For example, women may erroneously believe that screening prevents breast cancer rather than detecting cancer at an earlier stage. A recent survey in Geneva showed that only 20% of women assessed screening efficacy realistically.[5] We examined women's perceptions on the likely benefits of mammography screening in four industrialized nations, the US, the UK, Italy, and Switzerland, countries which differ with respect to national screening policies and the implementation of screening programmes.

Methods

A survey of women's understanding of the likely benefits of mammography screening was performed in the US, UK, Italy, and Switzerland during October and November 1999. The UK implemented a national breast cancer screening programme in 1988 with an annual uptake rate of about 70% among the target group of women aged 50–64 years.[6] In Italy there are 52 regional programmes involving women aged 50–69 years.[7] The US and Switzerland do not have national population-based programmes, however, opportunistic screening or case finding is widespread in both countries.

Trained interviewers from an independent survey company conducted computer-assisted telephone interviews. A random digit dialling method was used to produce telephone numbers and contact households.[8] A sample size of 1000 interviews per country was considered adequate to detect meaningful differences in knowledge levels between countries and groups of women defined by socio-demographic characteristics. No formal sample size calculation was performed. All phone calls were made between 5:30 pm and 8:30 pm local time. This time window was chosen to make sure that women working outside the house would also be included. When a woman was contacted she was asked whether she would be willing to participate in a survey on breast cancer screening. She was advised that the interview would last about 5 minutes. Response rates were calculated as the proportion of contacted women who answered all three questions. Reasons for non-participation were not recorded.

Three closed questions were asked relating to whether screening prevents breast cancer, what reduction in breast cancer mortality can be achieved among women aged ⩾50 years, and how many deaths can be prevented among 1000 women screened for 10 years (Table 1). These questions were developed in Italian and piloted in 82 women in Bellinzona, Switzerland. The final version was translated to English, French, and German. The correct answer to the first question was 'mammography screening does not have any influence on the risk of contracting breast cancer'. Based on a meta-analysis of randomized controlled trials which showed a reduction in breast cancer mortality of 26% (95% CI: 17%, 34%), the most appropriate answer to the second question was that 'screening reduces breast cancer mortality in women aged ⩾50 years by about a quarter'.[9] Finally, based on this risk reduction and the breast cancer mortality rates published by WHO for women aged ⩾50 years,[10] it can be assumed that between 5.1 deaths (Italy) and 6.7 deaths (UK) could be prevented among 1000 women aged ⩾50 screened every 2 years for 10 years. The correct answer to the third question therefore was that 'about five deaths can be prevented'. This is higher than the widely quoted figure,[11] from randomized trials, of 1 death prevented per 1000 women screened for 10 years, because we included in our calculation all women aged ⩾50 years. The elderly, who have high breast cancer mortality rates, were generally excluded from trials.

We computed a knowledge score with a range of 0 to 3 by adding the number of correct answers. We used multivariate ordered logistic regression to estimate the relationship between the ordinal score variable and five independent variables: age group (15–29, 30–39, 40–49, 50–59, ⩾60 years), level of education (lower versus higher), occupation (full-time, part-time, none), history of mammography in the past 2 years, and country. Higher education was defined as completed secondary school and above. We used ordered logistic regression (also known as proportional odds regression),[12] to model the cumulative response probabilities of giving k correct answers (cump_K). The model coefficients can be interpreted as odds ratios (OR) comparing the odds of cump_K for different levels of the predictor variable. An OR greater (smaller) than 1 shifts the distribution of correct answers upwards (downwards) whereas an OR of 1 indicates that the variable does not affect the distribution of correct answers. We computed tests of interaction to examine whether the effect of socio-demographic variables (age, educational level, occupation, history of mammography) on knowledge scores differed across countries by including interaction terms in the model. Standard logistic regression analyses were performed to investigate determinants of correct answers to the three individual questions. All analyses were performed using the Stata software package (version 8, Stata Corporation, College Station, USA).[13]

Results

A total of 5964 women were contacted and 4140 women (69%) participated. Response rates were 69% for the US (1003 of 1443 contacted women), 70% in the UK (1108 out of 1578 women), 70% for Italy (1001 of 1431 women), and 68% for Switzerland (1028 of 1512 women). A total of 1599 (39%) women in the four samples were aged ⩾50, 2613 (63%) had completed secondary school, 1879 (45%) were in full or part-time jobs, and 1455 (35%) had undergone mammography in the past 2 years.

Only a minority of women (26%) correctly indicated that screening does not have any influence on the risk of contracting breast cancer (Table 1). Even smaller proportions of women expected a reduction in mortality close to the estimate from randomized controlled trials (19%). Women resident in the US were more likely to answer the first question correctly than women from the other countries. Conversely, respondents in the US less often gave the appropriate answer to the second question. Few women (4% overall) answered the last question on the absolute number of deaths prevented correctly, with the surveys in continental Europe yielding a slightly higher proportion of correct answers. For all three questions the differences between countries continued to be evident in multivariate logistic regression analyses adjusted for age, educational level, occupation, and history of mammography (tables available from authors).

Table 1 Women's perception of the benefits of mammography screening in four countries

Question	US N = 1003 No. (%)	UK N = 1108 No. (%)	Italy N = 1001 No. (%)	Switzerland N = 1028 No. (%)	All women N = 4140 No. (%)
1. Mammography is an X-ray examination of the breasts. Which of the following statements concerning mammography reflects your opinion? Regular mammography every 2 years in women who are well:					
• prevents the risk of contracting breast cancer	262 (26)	191 (17)	325 (33)	101 (10)	879 (21)
• reduces the risk of contracting breast cancer	315 (31)	571 (52)	476 (48)	569 (55)	1931 (47)
• **does not have any influence on the risk of contracting breast cancer**[a]	**369 (37)**	**243 (22)**	**165 (16)**	**279 (27)**	**1056 (26)**
• don't know	57 (6)	103 (9)	35 (3)	79 (8)	274 (7)
2. In your opinion, to what extent can mammography reduce breast cancer deaths among women aged ⩾50 screened every 2 years for 10 years?					
• regular mammography hardly reduces breast cancer deaths	36 (4)	48 (4)	35 (4)	72 (7)	191 (5)
• **reduces mortality due to breast cancer by about a quarter**[a]	**123 (12)**	**241 (22)**	**173 (17)**	**251 (24)**	**788 (19)**
• by about half	336 (33)	354 (32)	324 (32)	358 (35)	1372 (33)
• by about three-quarters	288 (29)	187 (17)	201 (20)	154 (15)	830 (20)
• prevents practically all deaths due to breast cancer	93 (9)	53 (5)	160 (16)	48 (5)	354 (9)
• don't know	127 (13)	225 (20)	108 (11)	145 (14)	605 (15)
3. In your opinion, how many deaths due to breast cancer can be prevented among 1000 women aged ⩾50 who have regular mammography every 2 years for 10 years?					
• no deaths prevented	9 (1)	14 (1)	16 (2)	36 (4)	75 (2)
• **about 5 deaths prevented**[a]	**27 (3)**	**28 (3)**	**40 (4)**	**52 (5)**	**147 (4)**
• about 10 deaths prevented	48 (5)	60 (6)	52 (5)	83 (8)	243 (6)
• about 20 deaths prevented	83 (8)	115 (10)	91 (9)	93 (9)	382 (9)
• about 40 deaths prevented	117 (12)	153 (14)	210 (21)	148 (14)	628 (15)
• about 80 deaths prevented	151 (15)	111 (10)	176 (18)	115 (11)	553 (14)
• more than 100 deaths prevented	455 (45)	302 (27)	257 (26)	269 (26)	1283 (31)
• don't know	113 (11)	325 (29)	159 (16)	232 (23)	829 (20)

[a] Correct or most appropriate answer.

Table 2 gives the distribution of knowledge scores in each country for all women and separately for women aged 40–49 years, 50–59 years, and ⩾60 years. Overall, the majority of women did not give any correct answer (59%). There was a tendency for older women to be less knowledgeable than young and middle-aged women. The results from univariate and multivariate ordinal logistic regression analyses are shown in Table 3. In univariate analysis women aged ⩾50 years had lower knowledge scores than younger women, but this difference was attenuated in multivariate analysis. Similarly, women who did not work and women with a history of mammography had lower scores in univariate analysis, with associations attenuated in multivariate analysis. In univariate and multivariate analyses, women with higher educational levels had higher scores than women with less education and, compared with women in the US, respondents in Italy and the UK had lower knowledge scores. Knowledge in Switzerland was comparable to the US. There was some evidence that the effect of a history of mammography ($P = 0.024$ by test of interaction), and the effect of educational level ($P = 0.015$) differed across countries. In analyses stratified by country, the effect of a previous mammography on knowledge scores was stronger in Italy (OR = 0.71, 95% CI: 0.50, 1.00) but weaker in Switzerland (OR = 0.78, 95% CI: 0.58, 1.06) and the US (OR = 0.87, 95% CI: 0.63, 1.21), and in the opposite direction in the UK (OR = 1.17, 95% CI: 0.83, 1.67). The effect of higher levels of education was strong in the US (OR = 1.87, 95% CI: 1.43, 2.47) and the UK (OR = 1.70, 95% CI: 1.26, 2.30) but weaker in Switzerland (OR = 1.33, 95% CI: 0.98, 1.80) and absent in Italy (OR = 0.99, 95% CI: 0.73, 1.33).

Discussion

To our knowledge this is the first international survey of women's perceptions of the benefits of breast cancer screening which uses common methods in random samples of the general population. We found that in the US and three European countries women clearly overestimated the benefits that can be realistically expected from mammography screening. This was somewhat more pronounced in the UK and Italy, the two countries with a National Health Service and established national or regional population-based screening programmes, than in the US or Switzerland, countries with a strong private health care sector where women are screened on an opportunistic basis. Centrally organized screening programmes are governed by coverage targets, which determine, for example, payment to general practitioners. It seems possible that this may act as a deterrent to giving complete and balanced information.[14,15]

Unsurprisingly, better educated women tended to provide more correct answers than women with lower educational attainment. We were interested in the effect of invitations to undergo mammography screening and therefore included women aged ⩾50 years as well as younger women. There was some evidence that women in the age groups targeted by screening programmes were less well informed than younger

Table 2 Distribution of correct or most appropriate answers according to country in all women and women of different age groups

No. of correct or most appropriate answers	US No. (%)	UK No. (%)	Italy No. (%)	Switzerland No. (%)	All women No. (%)
All ages					
0	552 (55)	676 (61)	683 (68)	552 (54)	2463 (59)
1	389 (39)	357 (32)	266 (27)	379 (37)	1391 (34)
2	56 (6)	70 (6)	44 (4)	88 (9)	258 (6)
3	6 (1)	5 (1)	8 (1)	9 (1)	28 (1)
Women aged 40–49 years					
0	99 (48)	100 (57)	120 (69)	111 (55)	430 (57)
1	93 (45)	63 (36)	43 (25)	69 (34)	268 (36)
2	14 (7)	10 (6)	8 (5)	17 (9)	49 (6)
3	2 (1)	1 (0.6)	2 (1)	3 (2)	8 (1)
Women aged 50–59 years					
0	118 (59)	88 (62)	117 (74)	106 (63)	429 (64)
1	70 (35)	46 (32)	33 (21)	45 (27)	194 (29)
2	12 (6)	8 (6)	7 (4)	16 (9)	43 (6)
3	1 (0.5)	1 (0.7)	1 (0.6)	2 (1)	5 (1)
Women aged ⩾60 years					
0	160 (61)	165 (64)	161 (74)	104 (55)	590 (64)
1	90 (34)	76 (30)	49 (22)	70 (37)	285 (31)
2	12 (5)	15 (6)	7 (3)	14 (7)	48 (5)
3	2 (0.8)	1 (0.4)	1 (0.5)	1 (0.5)	5 (0.5)

Age missing in one woman.

Percentages do not always add up to 100% due to rounding error.

Table 3 Probability of a larger number of correct or appropriate answers. Results from univariate and multivariate ordinal logit regression analyses

	No. of women[a]	Odds ratio (95% CI)	
		Crude	Adjusted[b]
Age (year groups)			
15–29	963	1.00 (ref.)	1.00 (ref.)
30–39	822	1.00 (0.83, 1.20)	0.97 (0.80, 1.17)
40–49	755	1.00 (0.83, 1.21)	1.02 (0.84, 1.25)
50–59	671	0.76 (0.63, 0.93)	0.83 (0.66, 1.04)
⩾60	928	0.76 (0.63, 0.91)	0.88 (0.71, 1.08)
Education			
Lower	1497	1.00 (ref.)	1.00 (ref.)
Higher	2613	1.63 (1.43, 1.85)	1.44 (1.25, 1.66)
Occupation			
Full time	1106	1.00 (ref.)	1.00 (ref.)
Part time	773	1.01 (0.85, 1.22)	1.03 (0.85, 1.23)
Does not work	2195	0.82 (0.71, 0.94)	0.98 (0.84, 1.15)
History of mammography[c]			
No	2664	1.00 (ref.)	1.00 (ref.)
Yes	1455	0.85 (0.75, 0.96)	0.86 (0.74, 1.01)
Country			
US	1108	1.00 (ref.)	1.00 (ref.)
UK	1003	0.81 (0.69, 0.96)	0.73 (0.60, 0.87)
Italy	1001	0.59 (0.50, 0.71)	0.61 (0.50, 0.74)
Switzerland	1028	1.11 (0.94, 1.31)	0.98 (0.82, 1.18)

[a] Due to missing data numbers do not always add up to the total of 4140.

[b] Adjusted for all variables in the table with a total of 4060 women in the analysis.

[c] Having had a mammography in the last 2 years.

women, and that women who recently underwent screening were less well informed than women who did not. The lower knowledge scores in older women was partly explained by lower levels of educational attainment in this group. Interestingly, an analysis of US women's magazines found that the information provided is persuasive and prescriptive in magazines aimed at lower educational levels but more balanced and informative in publications read by women with higher education.[16]

An Australian study of 58 pamphlets on mammography screening found that benefits were generally expressed as relative risk reductions and only a minority mentioned the possibility of false positive or false negative tests.[17] No leaflet gave absolute risk reductions or the number of women that need to be screened to avoid one death. Patients, purchasers, and doctors consider an intervention to be more desirable when effectiveness data is presented in relative rather than absolute terms.[18–20] In an earlier survey,[21] we found that the public's willingness to participate in a hypothetical screening programme is clearly influenced by the quality and extent of the information provided.

Our study has a number of limitations. It consisted of three questions on the likely benefits of screening only, and did not examine the awareness of adverse effects, including the consequences of exposure to radiation and of false positive or false negative test results. Indeed, it could be argued that by exclusively addressing the benefits of screening our survey may have contributed to unrealistic expectations. An Australian study found that women also have unrealistically high expectations of the sensitivity of screening mammography, with about 40% of women reporting that screening should detect all cancers (sensitivity of 100%).[22] More recently, a study of women in the US reported that women were aware and tolerant of false positive mammography results although few had heard about ductal carcinoma in situ.[23]

The questionnaire was developed in consultation with health professionals with expertise in this area. These experts agreed that all three questions were relevant, although we did not assess their judgements formally. We discussed an early draft of the questionnaire with six women of different educational levels and performed a pilot study in a larger group of women.

It is therefore reasonable to assume that our questionnaire has both face and content validity. The very small number of correct answers to our third question nevertheless raises the possibility that some women may have misunderstood the question and assumed that it related to women with breast cancer, rather than women attending breast cancer screening.

Questions had to be answered without warning in a short period of time during a telephone interview. The results from such a survey should not be over-interpreted: some women who do not answer correctly in this situation may still be able to appropriately appraise the pertinent facts and make informed choices when the decision is salient to them. By excluding households without phones and households with ex-directory (unlisted) numbers, surveys based on telephone interviewing may not obtain representative samples of the general population.[8] It is difficult to assess how this will have affected our results but people and households without telephones are a deprived group who would be expected to be less knowledgeable about breast cancer screening. It is possible that this may have introduced bias in comparisons between countries, if, for example, poorer households were excluded to a greater degree in the US than in the European surveys.

At the time this survey was conceived there was consensus that screening mammography reduces mortality from breast cancer among women in their 50s and 60s, although there was debate on the effectiveness of screening in younger women.[24] This changed recently with the publication of Gøtzsche and Olsen's meta-analysis of seven randomized trials of mammography screening, which concluded that screening was of uncertain benefit.[25,26] The authors considered five trials, which had shown a reduction in breast cancer mortality, to be of inadequate quality and excluded their results. A meta-analysis of the remaining two studies showed no protective effect of mammography. Furthermore, the meta-analysis showed an increase in mastectomies in screened women, and no reduction in all-cause mortality. The review by Gøtzsche and Olsen is, however, controversial and the WHO, the US Preventive Services Task Force, the Canadian Task Force on Preventive Health Care, and many other bodies continue to recommend mammography screening.[24,27,28] A detailed discussion of Gøtzsche and Olsen's review is beyond the scope of this article but, clearly, women considering screening need to know that there is debate, and what the issues are.

In conclusion, the female populations studied in four countries appear to be ill informed about the likely benefit of mammography screening and many women offered screening may not be able to exercise choice based on an accurate presentation of all pertinent facts. Using selected information about screening for encouraging high uptake is not appropriate, and there is an urgent need for correcting the misconceptions that are prevalent in the population.[15] Maureen Roberts, the clinical director of the Edinburgh Breast Screening Project who died of breast cancer argued over 10 years ago that 'the decision must be theirs, and a truthful account of the facts must be available to the public and the individual patient'.[29]

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KEY MESSAGES

- We examined women's understanding of the likely benefits of mammography screening in the US, UK, Italy, and Switzerland.
- A majority of women had unrealistic expectations regarding the likely benefit of mammography screening.
- Misconceptions were more prevalent in the two countries (UK, Italy) with established population-based screening programmes.
- The results raise doubts about informed consent procedures within breast cancer screening programmes.

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