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Exploring the reasons for non-participation of women in a breast cancer screening campaign

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Study objectives: to determine the reasons for non-participation in a programme of screening for breast cancer. Design: semi-structured telephone interview. Setting: a pilot programme of screening by mammography, targeted at all women aged between 50 and 70 years in two regions of Switzerland. Population: a sample of 33 non-participants were interviewed. Main results: few non-participants took advantage of the screening tests for female cancers. However, only one-quarter were determined never to have a mammography. The others did not participate because of organizational problems (one-quarter) or because they did not understand what a mammography involved (half). Conclusions: there is considerable scope for increasing the rate of participation. Efforts must be made to improve the information directed at the socially less favoured (the objectives of the screening and the organizational arrangements). Family doctors are frequently consulted and are best placed to communicate this information. They should be encouraged to play a much more active part in this respect.

Key words: breast cancer screening programme, non-participation

Screening of women aged over 50 years by mammography is widely recognized as being an effective means of reducing the mortality from breast cancer.[1] However, the impact of a screening programme may be limited by various factors,[2] notably poor technical quality of the examination, which reduces the predictive value of findings and a low rate of participation, which reduces the impact at the population level. Therefore, a crucial part of population screening for breast cancer is to monitor, analyse and improve the technique of screening and rates of participation.[3] This paper presents the results of a telephone survey carried out to determine the reasons for non-participation in a sample of non-participants in a pilot programme of breast cancer screening in Switzerland.

BACKGROUND, POPULATION AND METHODS

A programme of breast cancer screening by mammography was undertaken in three districts in the west of Switzerland in 1993 and will continue until 1997.[4] It targets every woman between 50 and 70 years old (n=11,500). The women are invited by personal letter to make an appointment for a mammography. An information leaflet about breast cancer and population screening by mammography is included with the letter. At the same time an awareness campaign is conducted, directed mainly at women and private medical practitioners. The result of the examination is communicated to each participant and her physician.

A probability sample of 70 women was drawn from 920 women identified as non-participants. Twenty-one women in the sample were ineligible (19 had already been screened outside the programme but they had not mentioned it and two had left the country). Of the 49 remaining women, nine could not be traced (there was no reply after several attempts to telephone or no reply to our letter in the case of those without a telephone), three were seriously ill (according to their family) and could not be interviewed and four refused to answer any questions. The 33 remaining women participated in a semi-structured interview. The following areas were covered:

- sociodemographic information;
- personal or family history of breast disease;
- use of ambulatory care services (general practitioner or gynaecologist), including female cancer preventative services;
- perceived state of health;
- attitudes and beliefs related to health, mammography and breast cancer;
- awareness of the information campaign and discussion about the programme with a physician or with the social network; and
- explicit reasons for not participating.

RESULTS

The non-participants have a low level of education (almost 80% elementary school only) and a low use of preventative services (within the past two years only 22% had had a Pap smear and, by definition, none a mammogram).

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In all, 24 of the 33 women in the sample clearly remembered and understood the invitation; the rest only vaguely recalled or understood it (4) or thought it was an advertisement (4) or misunderstood it (1).

Four of 20 non-participants who consulted their physicians in the months preceding the interview discussed the programme with them: two were encouraged to participate and two were dissuaded (because they were symptom free).

The interviews revealed a wide variety of reasons for a refusal to participate. *Table 1* classifies the refusals into three types (refusal due to external circumstances, conditional refusal or definite refusal) and several subtypes (depending on the woman, the programme, the examination or the physician).

Eight women who did not participate because of *external circumstances* reported transient obstacles, mainly acute personal or family illnesses and hospitalization. Even those who mentioned inconvenient aspects of the programme expressed no serious criticism of it. They clearly understood its aims and mostly acknowledged its benefits, despite some apprehension about the results.

In 17 cases the refusal was *conditional*; these women might reconsider participating if their circumstances changed, e.g. in the case of abnormality or pain, but also if their physicians firmly advised participation. They had a positive attitude about their health. They were unclear about the aims of mammographic screening, believing that a woman does not need a mammography unless she notices something herself and that cancer cannot be detected if it is not palpable, visible or painful. They doubted the efficacy of periodic screening examinations and criticized several practical aspects of the programme. The fear of a mammography was relatively strong: the imagined consequences such as radiation-induced cancer and pain associated with the examination were mentioned. However, despite expressed criticisms and distrust of the medical profession, seven of the 17 women in this group would have participated had their physicians requested them to do so.

Eight women explicitly and *definitely* refused participation. These women were fatalistic about their health, dreaded the thought that they could have cancer, which would be, to them, a disgrace and did not want to know about their health. Besides reservations about mammography (pain and lack of efficacy) or distrust of the medical profession, they largely believed that nothing could be done if cancer were to be discovered.

Table 1 Reasons for non-participation[a]

Type of refusal and main reasons	Number of women
Due to external circumstances (n=8)	
Woman dependent	
Severe illness in the family, hospitalization	5
Personal problems, other preoccupation and	2
Too busy at the moment	2
Programme dependent	
Difficulty in getting to the hospital, does not know where it is and	2
Difficulty in understanding the invitation	1
Conditional (n=17)	
Woman dependent	
Feels in good health	5
Sense of positive protection, feeling of invulnerability	3
Difficulty in getting to the hospital	2
No family history of breast cancer and	1
Other obligation has priority	1
Programme dependent	
Does not understand/know the aims of the programme	13
Doubts about the programme's efficacy	3
Prefers to attend a private physician	3
Programme increases health costs	2
'Infantilization' of women and	1
Programme resembles industrial process	1
Examination dependent	
Painful examination	5
Dangerous (irradiation, and compression of breast may cause cancer)	4
Self-examination of breast is sufficient	1
Confuses mammography with chest X-ray	1
Bad previous experience and	1
Embarrassed about exposing breast	1
Physician dependent	
Would have accepted if private physician had suggested and	7
Does not trust medical profession	7
Definite (n=8)	
Woman dependent	
Strong anxiety about learning of possible problems	3
Has no fears because of advanced age	2
Does not feel concerned	2
Feels in bad health, and prefers not to think of such matters	2
Feels in good health and refuses to think of such matters	1
Fear of the results because of existence of risk factors	1
Does not fear death	1
Refuses health care or surgery and	1
Believes breast cancer cannot be prevented	1
Examination dependent	
Will be able to detect an abnormality	1
Painful examination and	1
Examination does not prevent cancer	1
Physician dependent	
Does not trust the medical profession	1
No appropriate relation with physician and	1
Personal physician against mammography	1

a: Multiple answers given

DISCUSSION

The participation rate crucially affects the population impact of screening for breast cancer[5,6] and it is essential to examine the reasons for non-participation carefully. The programme achieved 42% coverage. Even taking into account the fact that an additional 21% mentioned having a mammography outside the programme, this rate is lower than for similar programmes elsewhere in Europe.[7,8] This qualitative study is based on a small number of interviews. However, the literature on screening for

breast cancer contains relatively few reports of in-depth interviews with non-participants and it is likely that the types of reasons for non-participation are mostly covered by the 33 women interviewed.

It is noteworthy that no fewer than 21 women of the sample of 70 were discovered at interview to be ineligible, so it may be that participation rates have been underestimated.

The low proportion of definite refusals suggests that there is much room for improving participation by offering more practical arrangements, such as mobile screening (for refusals due to external circumstances) or more convincing arguments (for conditional refusals). At the same time, the diversity of reasons given for not participating suggests a need for a corresponding diversity of measures to convince the whole range of non-participants of the value of participation.

The largest group consists of women who did not understand the aims of screening for breast cancer; they are convinced that mammography is meaningless unless there are symptoms. This seems to reflect a general attitude towards medical care, characterized by the need for acute symptoms and a neglect of preventive services such as those related to female cancers.[9,10] However, their refusal is not definitive; a more explanatory information campaign and, above all, counselling by medical practitioners might convince these women of the value to them of this specific preventive action. Practitioners can play a crucial role because of their credibility and the nature of their relationship with their patients.[11–15] Practitioners' attitudes towards the screening programme can be improved: few non-participants reported discussion with their physician, even fewer reported explicit encouragement to participate and some reported their physicians' advice not to participate. Practitioners should be an essential target of promotional messages.

Another group of women reported external reasons. In general they seem to be willing to participate. The fact that they failed to note that they were welcome to make an appointment at a later date is a cause of concern about the ability of the programme to inform prospective users adequately.

Non-participants tended to be of lower educational status and to have a lower use of cancer prevention services than participants (data not included here).[16] If the distributive efficiency of a screening programme is to be assured (i.e. its ability to distribute the benefits of screening among social classes), a substantial and specific effort should be made in the direction of less-advantaged women; there is evidence that even in a population with a low sociocultural level a good participation rate can be attained if a campaign's information strategy takes account of minority values.[17,18]

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