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Original article

Women's perceptions of breast cancer screening. Spanish screening programme survey

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ABSTRACT

Objectives: Participants in breast cancer screening programmes may benefit from early detection but may also be exposed to the risks of overdiagnosis and false positives. We surveyed a sample of Spanish women to assess knowledge, information sources, attitudes and psychosocial impact.
Materials and methods: A total of 434 breast cancer screening programme participants aged 45–69 years were administered questionnaires regarding knowledge, information sources, attitudes and psychosocial impact. Scores of 5 or more (out of 10) and 12 or less (out of 24) were established as indicating adequate knowledge and a positive attitude, respectively. Psychosocial impact was measured using the Hospital Anxiety and Depression Scale and the Cancer Worry Scale.
Results: Only 42 women (9.7%) had adequate knowledge. The mean (SD) knowledge score was 2.97 (1.16). Better educated women and women without previous false positives had higher scores. The main sources of information were television, press, Andalusian Health Service documentation and family and friends. Most participants (99.1%) had a positive attitude, with a mean (SD) score of 3.21 (2.66). Mean (SD) scores for anxiety, depression and cancer worry were 1.86 (3.26), 0.72 (1.99) and 9.4 (3.04), respectively.
Conclusion: Women have a very positive attitude to breast cancer screening, but are poorly informed and use television as their main information source. They experience no negative psychosocial impact from participation in such programmes.

Introduction

Women participating in breast cancer screening (BCS) programmes involving mammography need to understand the benefits and risks [1]. The main benefit is a reduction in breast cancer mortality, generally agreed to be around 20% [2]. The main risks are a false positive finding and overdiagnosis. False positives, which affect 10% of all women screened over 10 years [3], may cause lasting psychological damage [4]. Overdiagnosis refers to found cancers that would never have been detected or become clinically apparent during the woman's lifetime. In such situations, women unnecessarily become patients and receive treatments that have quality-of-life repercussions [2]. A recent expert review suggested that the frequency of overdiagnosis was around 11% from a population perspective and 19% from the perspective of a woman invited to screening [2].

Women usually accept the invitation to participate in screening programmes, yet receive little information. They tend to overestimate the benefits [5] and may be unaware of the physical or psychological risk implied by overdiagnosis or false positives [6,7]. Studies indicate that information may not be provided effectively [8–10], with most women deciding to participate on the basis of convenience, gratitude or trust in the welfare state, rather than on the basis of a benefit-risk assessment [11].

This study attempts to answer three main questions: (1) Are Spanish women adequately informed about BCS programmes? (2) Where do Spanish women obtain their information? (3) What attitudes, levels of anxiety/depression and fears of cancer are expressed regarding screening?

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Materials and methods

The breast cancer prevention programme was launched in Cádiz in 1995 to offer women aged between 45 and 69 years a mammography every 2 years. Women are invited to participate by letter, undergo dual-view mammography interpreted by two radiologists and receive the result by mail: if abnormal, the women are referred for consultation and if normal, they are invited back again after 2 years.

Women living in the Bay of Cádiz-La Janda Healthcare District (Spain), aged between 45 and 69 years were recruited to this study between January 2011 and September 2012. Exclusion criteria were a personal history of breast cancer and participation in the last mammography examination. The women were evaluated for eligibility over 28 afternoons, at an average rate of 17 interviews/day held at the programme headquarters (Bay of Cádiz-La Janda District Health offices, 19 Avenida Ramón de Carranza, Cádiz).

After undergoing a mammogram, the women were informed about the study and their written consent was obtained. Identity data were collected and knowledge levels, attitudes, anxiety/depression levels and cancer fears were analysed using specific questionnaires. Data was collected via written questionnaires administered in face-to-face structured interviews.

Data were collected at baseline by two doctors and a nurse. The women were then randomized to a clinical trial (ClinicalTrials.gov Identifier: NCT01335906) designed to assess the influence of the provision of suitable information regarding mammography benefits and risks on women's knowledge levels, attitudes, decisions to participate, anxiety/depression levels and cancer fears. The participants received either the information contained in the Nordic Cochrane Centre document on BCS published in 2008 (Spanish translation available from www.screening.dk or www.cochrane.dk) or our standard BCS programme information. Women in both randomized groups received a standard invitation letter containing their appointment details and information on the mammogram. The letter noted the importance of early breast cancer diagnosis, but did not mention the risks, and included recommendations on hygiene, the documentation to bring and the clothing to wear. Prior to the study, research procedures and materials were reviewed and approved by the Clinical Research Ethics Committee of the Hospital Universitario Puerta del Mar de Cádiz (PI-0315-2010).

Knowledge of BCS

The knowledge analysis questionnaire was adapted from a questionnaire developed by the Health Decision Group of the Sydney School of Public Health, Australia (www.health.usyd.edu.au/shdg/resources/decision_aids.php), and was further modified to take into account BCS benefits and risks as described in a 2008 document (available in several languages, including Spanish) created by the Nordic Cochrane Centre based in Copenhagen, Denmark (www.cochrane.dk).

The questionnaire had 4 multiple choice questions, each with 3 possible answers scoring 1 point each, and 3 free-response questions, each with 1 possible answer scoring 2 points. Minimum and maximum scores were 0 and 10, respectively. Women were considered to be reasonably well informed for scores of 5 or more. All women were scored, but any questions left blank were not scored.

The multiple choice questions and their possible answers were as follows:

1. "What is a mammogram for in a screening programme?" "A mammogram is for women who are healthy", "A mammogram is for women who detect a lump or other changes in their breast" and "Not sure."
2. "Can mammogram screening detect all breast cancers?" "Yes", "No" and "Not sure".
3. "Are all mammogram-detected cancers genuine malignancies that would result in death if not diagnosed and treated?" "Yes", "No" and "Not sure".
4. "Are all women with some anomaly in their mammogram diagnosed with cancer?" "Yes", "No" and "Not sure".

The free-response questions and their correct answers were as follows:

5. "For 2000 women who are regularly screened for breast cancer for 10 years, how many deaths will be prevented by early detection? ..... in 2000" (1 death).
6. "For 2000 women who are regularly screened for breast cancer for 10 years, how many will be diagnosed and treated unnecessarily for a pseudo-cancerous lesion that never develops into a tumour? ..... in 2000" (10 women).
7. "For 2000 women who are regularly screened for breast cancer for 10 years, how many will be affected by a false alarm requiring additional tests but will ultimately not be diagnosed with cancer? ..... 2000" (200 women).

Information sources

Women were asked how often they had obtained information from friends and family, experts (primary care physician, pharmacist), the media (television, radio, press), healthcare services or institutions (Andalusian Health Service, Ministry of Health, insurance companies, consumer and self-help association pamphlets and information), books and online healthcare and medical websites. The response options were "Never", "Seldom", "Sometimes", "Often" and "Don't know".

Attitude to screening

Attitude was calculated as per Marteau et al. [12] for 4 questions, each scoring between 0 (most positive) and 6 (most negative), for a maximum score of 24. The questions were as follows: "For me, breast cancer screening is (1) a good thing/bad thing, (2) beneficial/harmful, (3) important/not important, and (4) pleasant/unpleasant". Scores of 13 or more denoted a negative attitude.

Mood and cancer worry

Mood and cancer worry were measured using the Hospital Anxiety and Depression Scale (HADS) [13] and the Cancer Worry Scale (CWS) [14], respectively. The HADS has two subscales consisting of 7 items each: the anxiety subscale (odd-numbered questions) analyses emotional stress, nervousness and anxiety, whereas the depression subscale (even-numbered questions) evaluates joy, excitement and enjoyment. Participants score their answers using a 4-point Likert scale (0–3, indicating never/no intensity to most of the time/great intensity, depending on whether the answer referred to frequency or intensity). The final score (maximum 21 for each subscale) was interpreted as follows: 0–7 points, normal; 8–10 points, borderline; and 11–21 points, abnormal. Abnormally anxious/depressed women were referred to their primary or mental healthcare physician.

The CWS has 6 questions as follows: "In the last month, how often have you thought about your chances of getting cancer?"; "In the last month, has thinking about the possibility of getting cancer affected your mood?"; "In the last month, has thinking about the possibility of getting cancer interfered with your ability to do daily