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Informed Choice

Do women make an informed choice about participating in breast cancer screening? A survey among women invited for a first mammography screening examination

Heleen van Agt [a,*], Jacques Fracheboud [a], Annemieke van der Steen [b], Harry de Koning [a]

[a] Department of Public Health, Erasmus MC University Medical Center, Rotterdam, The Netherlands
[b] Screening Organization South-West, Rotterdam, The Netherlands

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ABSTRACT

Objective: To determine the level of informed choice in women invited for breast cancer screening for the first time.
Methods: To determine the content of decision-relevant knowledge, 16 experts were asked to judge whether each of 51 topics represented essential information to enable informed choices. To assess the level of informed choices, a questionnaire was then sent to all 460 invited women in the south-western part of the Netherlands who turned 50 in August 2008.
Results: Of all 229 respondents, 95% were deemed to have sufficient knowledge as they answered at least 8 out of 13 items correctly. In 90% there was consistency between intention (not) to participate and attitude. As a result, 88% made an informed choice. Sixty-eight percent of women responded correctly on the item of over-diagnosis. Even if all non-respondents were assumed to have no knowledge, 50% of the total group invited to participate still had sufficient knowledge.
Conclusions: Women were deemed to have sufficient relevant knowledge of the benefits and harms if they answered at least half of the items correctly.
Practice implications: To further increase informed choices in breast cancer screening, information on some of the possible harms merits further attention.

1. Introduction

Breast cancer screening has positive health effects in terms of reducing the risk of dying from breast cancer [1–3]. However, a negative effect of screening is that many women are advised to have a diagnostic assessment because of a positive screening result although they will never have breast cancer. The number of these women is of course much larger than those saved from a breast cancer death as a result of screening [3]. For population-based cancer screening programmes, at the population level the benefits should outweigh the harms [4]. However, individuals may still not want to be screened, because the balance between benefits and harms can be valued differently for their own personal situation.

In several Western countries, informed decision-making about participating in screening, also in cancer screening, has become an explicit purpose [5,6]. An informed choice about participation in breast cancer screening requires that invited women have opportunities to weigh all possible favourable and unfavourable effects of screening so as to enable them to form an opinion and subsequently make an autonomous choice, free from external pressures or barriers [7]. There has been a shift from promoting the benefits of screening towards providing comprehensive information to enable people to make an informed choice [7–10].

Following Marteau, we defined an informed choice as one that is based on relevant knowledge while the decision-maker's attitude is consistent with her actual screen behaviour [11]. Note that in applying the concept of informed choice, non-attendance can be a perfectly acceptable outcome of the deliberative process, if it is based on sufficient decision-relevant knowledge and consistent with the decision-maker's attitude towards participating in the screening programmes [11].

In the Netherlands, breast cancer screening is offered free of charge every two years to all women in the 50–75 age brackets through a governmental funded screening programme. Regional screening organizations invite women to participate by sending them a personal letter. Information about the screening is provided in a leaflet enclosed with the invitation letter. However, it was not known whether women invited for breast cancer screening are able to make an informed decision about whether or not to participate in the screening programme.

* Corresponding author at: Department of Public Health, Erasmus MC University Medical Center, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands.
Tel.: +31 10 7043718/7038460; fax: +31 10 7044724.
E-mail address: h.vanagt@erasmusmc.nl (H. van Agt).

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The purpose of this study is to determine the level of informed choice in a representative sample of women who are invited for breast cancer screening for the first time.

2. Methods

2.1. Study design, participants and data collection

In the Netherlands, women receive their first invitation to participate in breast cancer screening around their 50th birthday. To all 460 women in the regions of The Hague, Leiden and Delft who were newly eligible for the screening programme – mostly women who turned 50 in August 2008 – the screening organization (*Bevolkingsonderzoek Zuid-West*) sent an invitation letter, a standard information leaflet (version 2007) and the questionnaire to assess the level of informed choice. The content and presentation of information in the information leaflet was not based on decision-relevant knowledge for informed decision making about (non)participation in breast cancer screening. In a cover letter, women were asked to complete the questionnaire and return it to the screening organization; they were assured that not completing it would not have any consequences for their medical care. We did not send reminders.

2.2. Outcome measures

2.2.1. Knowledge

The content of decision-relevant knowledge was determined in an expert consultation which aimed at the development of comprehensive, balanced and fair information about the favourable and unfavourable effects of breast cancer screening. Following the model of Irwig et al. [4], (1) we differentiated between essential information that is required for all women invited for breast cancer screening to make an informed choice, and (2) additional information that only some groups of women require to make an informed choice. Sixteen (out of 18 invited) experts participated in this consultative group, including the director of a screening organization, two general practitioners from the Dutch College of General Practitioners, one radiographer from a screening organization, one pathologist from a university medical centre, one radiologist from a general hospital, one radiologist from a university medical centre, one cancer surgeon specialist, one epidemiologist from the national cancer registry, one member of the Health Council of the Netherlands, one policymaker from the Ministry of Health, Welfare and Sport, two epidemiologists from a university medical centre, one psychologist specialized in risk communication from a university medical centre, one ethicist from a university ethics institute. The consumer perspective was included by a representative of the Dutch Breast Cancer Association representing Europe Donna in the Netherlands. This organization stands up for optimal quality of care for all people who have or had breast cancer, including the breast cancer screening programme, by stressing the patient perspective and by supporting patient's self-management. A questionnaire was sent to the participating experts containing a list of topics compiled from national and international information materials [12] for a number of generic content domains [13,14] (Appendix I). Each topic was given a brief description based on recent evidence (Appendix II).

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First, experts were asked to judge whether each topic represented information that was (1) essential, namely minimally required information that each woman need to make an informed choice, (2) additional, namely information that is not essential for all women, but only for those who need additional information to make an informed choice or (3) unnecessary. To illustrate this, we explained that the essential information should be included in the national information leaflet provided to all invitees of breast cancer, and that the additional information might be presented elsewhere for example on a website. The standard leaflet should mention how to access the additional information. Secondly, they were asked whether the information in each category was sufficient. According to the experts, most of the topics contained essential and sufficient information for all invited women (Appendix II). In general, the experts recommended the use of simple texts without numerical values to present information on difficult topics such as false positives and over-diagnosis.

The content of the knowledge measure was based on the essential information (third column of Appendix II). The aim was to develop a short and simple knowledge questionnaire, usable for large-scale assessment of informed choice, in a similar way as the knowledge measures developed for prenatal screening [13,15]. Items were formulated for generic content domains [14]. In consensus meetings among the researchers, the items were discussed, – if necessary – revised and ranked. Finally, 13 items were chosen, concerning the purpose of the screening (3), voluntariness of the screening (1), the disease being screened for (1), the likelihood of detection (1), the testing method (2), the meaning of a positive test result (1), the meaning of a negative test result (1), the unfavourable effects of the screening (1), the options following a positive diagnosis (1), and the possible findings after diagnostic assessment (1). Each item of the knowledge questionnaire consisted of a statement with response options 'True', 'False' and 'Don't know'. A score of 1 indicated a correct answer; a score of 0 indicated an incorrect answer. The correct answer was 'True' for items 1, 2, 3, 5, 8, 9, 11 and 12 and 'False' for items 4, 6, 7, 10 and 13. Invalid and 'Don't know' responses were considered to be incorrect. The total score ranged from 0 (no correct answers) to 13 (all answers correct).

There are still no agreed external criteria for the definition of 'sufficient' knowledge and 'insufficient' knowledge [16]. Therefore, following earlier research [16–18], we used the midpoint of the scale, being the most often used threshold to define sufficient knowledge. This means that scores above 7 (at least 8 correct answers) were classified as indicating sufficient knowledge about breast cancer screening and scores of 7 and lower were classified as indicating insufficient knowledge. In addition, to assess the effect of the chosen threshold on the percentages of sufficient knowledge, we used five alternative thresholds, requiring correct answers on 9, 10, 11, 12 or all 13 items respectively, to calculate these percentages.

2.2.2. Attitude and intentional screening uptake

Attitudes towards attending the screening were assessed by four items based on a recent version of the Multidimensional Measure of Informed Choice (MMIC) in prenatal screening [19]: women were asked to rate their current response to 'I feel attending the screening for breast cancer will be' by using scores from 1 to 7 for four items anchored by 'A bad thing/Not a bad thing', 'Beneficial/Not beneficial', 'Harmful/Not harmful', and 'A good thing/Not a good thing'. Responses were recoded (items 2 and 4) and summed up resulting in a score range of 0–24, with higher scores indicating more positive attitudes. The internal consistency of the attitude scale was 0.77 (Cronbach's alpha). Scores >12 were classified as indicating positive attitudes towards undergoing the test, and scores ≤ 12 were classified as indicating negative attitudes towards undergoing the test [11,16].

Intentional screening uptake was assessed by the question 'Do you intend to attend breast cancer screening?