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Original article

Adjusting the frequency of mammography screening on the basis of genetic risk: Attitudes among women in the UK

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ABSTRACT

Purpose: To explore public attitudes towards modifying frequency of mammography screening based on genetic risk.
Methods: Home-based interviews were carried out with a population-based sample of 942 women aged 18–74 years in the UK. Demographic characteristics and perceived breast cancer (BC) risk were examined as predictors of support for risk-stratified BC screening and of the acceptability of raised or lowered screening frequency based on genetic risk, using multivariate logistic regression.
Results: Over two-thirds of respondents (65.8%) supported the idea of varying screening frequency on the basis of genetic risk. The majority (85.4%) were willing to have more frequent breast screening if they were found to be at higher risk, but fewer (58.8%) were willing to have less frequent screening if at lower risk ($t(956) = 15.6$, $p < 0.001$). Ethnic minority status was associated with less acceptability of more frequent screening (OR = 0.40, 95% CI = 0.21–0.74), but there were no other significant demographic correlates. Higher perceived risk of BC was associated with greater acceptability of more frequent screening (OR = 1.71, 95%CI = 1.27–2.30).
Conclusion: Women were positive about adjusting the frequency of mammography screening in line with personal genetic risk, but it will be important to develop effective communication materials to minimise resistance to reducing screening frequency for those at lower genetic risk.

Introduction

Breast cancer screening by mammography has been identified as reducing deaths from breast cancer; nonetheless, false positives, overdiagnosis and overtreatment have all been identified as potential harms [1,2]. Routine screening is usually recommended for women above age 50 [http://www.cancerscreening.nhs.uk/; http://www.who.int/cancer/detection/variouscancer/en/; http://www.cdc.gov/cancer/dcpc/prevention/screening.htm]; although women with a strong family history of breast cancer may be offered screening from an earlier age [3] http://www.cancerscreening.nhs.uk/; http://www.cdc.gov/cancer/dcpc/prevention/screening.htm). However, approximately 20% of all breast cancers occur in women younger than age 50 [4]; with a substantial proportion in women without a family history. These cancers tend to be aggressive with a poorer prognosis [5,6], and therefore early identification, irrespective of known family history, might be beneficial.

Given the number of genetic markers for breast cancer risk that have been identified [7–9], incorporating genetic risk assessment into current mammography screening has been proposed as one way to maximise benefits and minimise harms [10]. Modifying screening eligibility and frequency to account for genetic risk could make it possible to 'tailor' screening and risk management efforts to those at the highest risk, for example by shortening screening intervals, or by offering screening using alternative modalities such as Magnetic Resonance Imaging (MRI) and ultrasound. At the same time, it would minimise exposure to potential harms of screening

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for those at the lowest risk; for example by starting screening later or by making a recommendation against routine mammography screening in this group. Risk-stratified mammography screening based on genetic risk could therefore be superior to current age-stratified approaches [11,12].

However, implementation of genomic risk-stratified breast screening would require the support of the wider public. The public is generally very enthusiastic about screening [13,14]. Women perceive high benefits of mammography screening [15,16]; reflected in the high attendance rates (around 70%) across countries [17–19]; although lower socioeconomic status (SES) and ethnic minority status have both been associated with lower participation rates [20–22]. Perceived risk of breast cancer has been cited as encouraging some individuals to be screened, while deterring others [16,23,24]; so predicting the impact of giving genetic risk information on screening uptake is difficult. There has also been attention to public perceptions of a 'right to be screened', which may militate against the acceptability of reducing breast screening frequency for those at the lowest risk.

Few studies to date have investigated public attitudes to 'personalised' cancer screening, despite calls for empirical research on the topic [10,25]. One qualitative study in the Netherlands found that women were supportive of both increases and reductions in breast screening frequency, although there was an important proviso that any woman who was worried about breast cancer despite having low genetic risk, should still be able to access screening [26]. A small qualitative study in the UK found enthusiasm for risk-stratified ovarian cancer screening based on genetic risk [27], but these findings cannot be assumed to generalise to an existing and very popular mammography breast screening programme; especially given evidence from two studies that show that information on overdiagnosis is not a deterrent for mammography screening for most women [14,28].

Given that research is under way to test the feasibility of 'personalising' mammography screening based on individual risk factors, including genetic risk [29], the primary aim of this study was to investigate public attitudes towards amending the frequency of breast cancer screening based on genetic risk in the current UK National Health Service Breast Cancer Screening Programme. Data were from a large, population-based study, making it possible to identify demographic and personal predictors of support for raising or lowering frequency of cancer screening based on genetic risk.

Methods and procedure

Sample

Data were collected by adding a question module on 'genetics and screening' to the 'Opinions and Lifestyle' survey, which is conducted monthly by the UK Office of National Statistics (ONS) on behalf of government departments, non-governmental agencies and academic institutions. Each month, 2010 households are identified from the Royal Mail's Postcode Address File using stratified random probability sampling. Selected addresses are contacted up to eight times at different times and days of the week to maximize response rates. One person aged over 16 from each household is randomly chosen to complete a computer-assisted face-to-face interview with trained researchers. Questions on the 'genetics and screening' module were included in two data collection waves, January and March 2014. Although questions were read out, we used the Flesch Reading Ease formula and the Flesch-Kincaid Grade Level formula to estimate comprehension. This produced a score of 68; conferring a reading level expected in grade 6 (age 12).

Measures

The module was introduced with a short explanation about genes and risk-stratified cancer screening that had been agreed with ONS: '*Genes contain the 'instruction manual' of life, called DNA. Genes are passed from parents to their children.* Nowadays, it is possible to predict whether someone is likely to develop certain diseases by looking at their genes. This is called genetic testing'. No information was given on current breast cancer screening approaches or potential harms of screening.

Outcome variables

One question addressed attitudes to risk-stratified breast cancer screening: *'It is possible that breast screening frequency could be varied depending on whether a woman is at higher or lower genetic risk of breast cancer. What do you think of the idea of varying the frequency of breast screening' ('very bad idea'; 'bad idea'; 'not sure'; 'good idea'; 'very good idea')*. Responses were dichotomized into very bad idea/bad idea/not sure vs. good idea/very good idea to reflect not supporting vs. supporting personalized risk-stratified breast cancer screening.

Personal acceptability of modified breast screening frequency was assessed with two questions: *'Would you personally be happy to have your breast screening more often if you were found to be at higher genetic risk of breast cancer', and 'Would you personally be happy to have your breast screening less often if you were found to be at lower genetic risk of breast cancer' ('very unhappy'; unhappy'; 'not sure'; 'happy' and 'very happy')*. For some analyses, very unhappy/unhappy/not sure were combined for comparison with happy/very happy to reflect low and high acceptability of varying the frequency of breast cancer screening.

Attitudes towards genetic testing generally were assessed to be sure that acceptability of stratified screening was not influenced by views about genetic testing, using the question: 'Based on what you know, do you think genetic testing will do more good than harm, or more harm than good? Response options were 'Do more good than harm', 'do more harm than good', 'not sure/it depends' and 'I have never heard of genetic testing'. Responses were coded as *'Do more good than harm'* vs. *'do more harm than good/it depends'*. Participants who responded that they had never heard of genetic testing were excluded from further analyses (n = 14). This question was taken from previous surveys that investigated public attitudes to genetic testing [30,31].

Predictor variables

Perceived relative risk of breast cancer was assessed with one question: '*Compared with other women of your age, what do you think are your chances of getting breast cancer*' with response options of: '*much lower than others*', *'lower than others', 'the same as others', 'higher than others'*, *'much higher than others'*. For the current analyses, we treated this variable as continuous, so as to not lose power.

Demographic data were provided by ONS from their standard survey items (http://www.ons.gov.uk/ons/%20ons/index.html). Age was coded as ≤50 vs. >50 years; women >50 years could have already been invited for breast screening, as part of the national breast screening programme in the UK. Ethnicity was classified as 'White' vs. 'ethnic minority' because the individual ethnic minority sub-groups were small. Educational attainment was classified as university degree or equivalent vs. below university degree level. Marital status was coded as married/cohabiting vs. single/widowed/divorced. Unfortunately, we had no information on past uptake of screening; or family history of breast cancer.