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Women's perceptions of personalized risk-based breast cancer screening and prevention: An international focus group study

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Abstract

Objective: Increased knowledge of breast cancer risk factors enables a shift from one-size-fits-all breast cancer screening to a risk-based approach, tailoring screening policy to a woman's individual risk. New opportunities for prevention will arise. However, before this novel screening and prevention program is introduced, its acceptability from a woman's perspective needs to be explored.

Methods: Women eligible for breast cancer screening in the Netherlands, United Kingdom, and Sweden were invited to take part in focus groups. A total of 143 women participated. Data were transcribed verbatim and analyzed using thematic analysis.

Results: Analysis identified five themes across the three countries. The first theme "impact of knowledge" describes women's concern of not being able to unlearn their risk, perceiving it as either a motivator for change or a burden which may lead to stigma. The second theme "belief in science" explains women's need to trust the science behind the risk assessment and subsequent care pathways. Theme three "emotional impact" explores, eg, women's perceived anxiety and (false) reassurance, which may result from knowing their risk. Theme four "decision making" highlights cultural differences in shared versus individual decision making. Theme five "attitude to medication" explores the controversial topic of offering preventative medication for breast cancer risk reduction.

Conclusions: Acceptability of risk-based screening and prevention is mixed. Women's perceptions are informed by a lack of knowledge, cultural norms, and common emotional concerns, which highlights the importance of tailored educational materials and risk counselling to aid either shared or individual informed decision making.

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KEYWORDS

acceptability, attitudes, breast cancer, oncology, prevention, risk prediction, risk stratification, screening

1 | BACKGROUND

Population-based breast cancer screening programs, adhering to a one-size-fits-all approach based on age, have successfully led to early detection and subsequent breast cancer mortality reduction.^{1,2} However, screening may become more effective if tailored to women's differing levels of breast cancer risk, potentially optimizing the benefit-harm ratio of screening.³ Breast cancer risk prediction models are becoming more accurate by adding, eg, breast density and polygenic risk score to classic risk factors.⁴ Risk prediction also offers new opportunities for breast cancer prevention, targeting women who would benefit most from reducing their risk through lifestyle changes or risk-reducing medication. Successful implementation of risk-based screening and prevention relies on women's participation. However, eligible women's perceptions of adopting this novel program have never been explored.

A risk-based screening and prevention program is inherently more complex than current age-based screening programs. Women need to reflect on participation at different stages (Figure 1). Although Figure 1 is an illustration which does not necessarily follow current

pathways of care, it shows that women need to decide whether they (a) want to know their risk, (b) are willing to change their screening strategy based on risk, and (c) are prepared to participate in preventative practices. Women's interest in knowing their breast cancer risk is high.⁵ However, knowledge of their risk did not lead to any consistent changes in screening or preventative behaviours.⁶ Additionally, although women generally appear in favor of increased screening for high-risk women, lowering screening intensity for low-risk women is more contested.^{7,8} Women are concerned about the accuracy of breast cancer risk estimates with some believing that risk-based screening is mainly motivated by a desire to save money.⁸ Their perceptions of prevention also seem mixed.⁷ However, risk-reducing medication has mostly been discussed with high-risk women who tend to be monitored outside of national screening programs, which potentially limits the generalizability of these results to the screening population.

Risk-based screening may bring about considerable benefits to healthcare policy by directing screening and preventative resources to women who are most in need.⁹ However, there is a lack of knowledge on the acceptability of an integrated risk-based breast cancer screening and prevention program from the perspective of

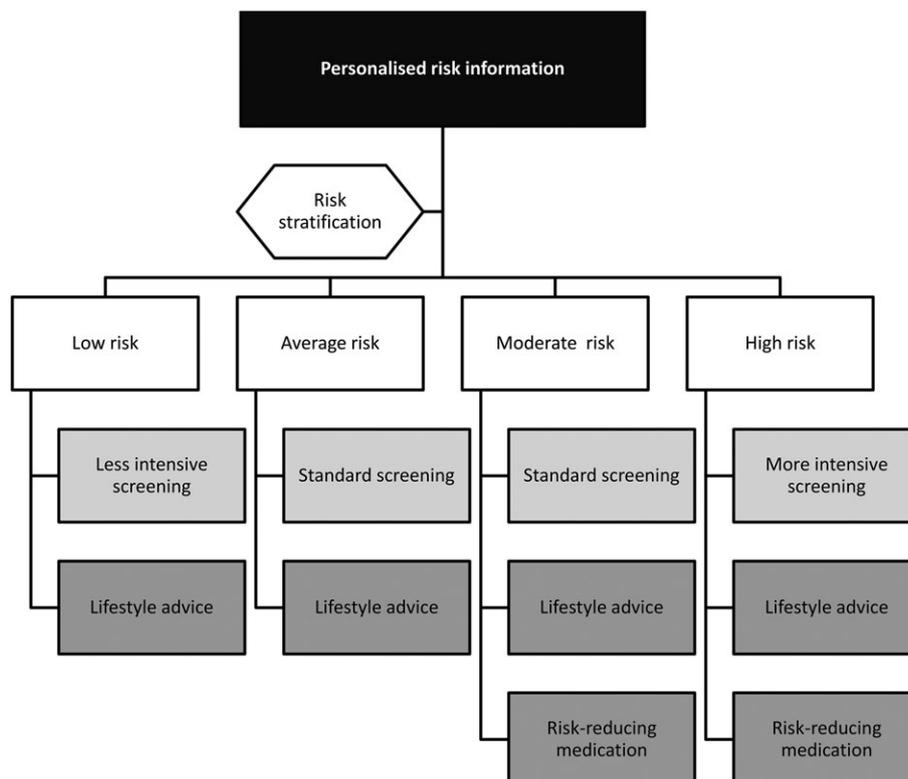


FIGURE 1 Illustration of a risk-based breast cancer screening and prevention program. *Current screening guidelines: Netherlands (NL): women aged 50 to 75 years old, screening interval 2 years; Sweden (SE): women aged 40 to 75 years old, screening interval 1.5 to 2 years; United Kingdom (UK): women aged 50 to 70 years old, screening interval 3 years

European women who would be eligible to participate, ie, women at population-level risk who meet current age criteria for screening. Therefore, this study aims to evaluate the adoption of risk-based breast cancer screening and prevention by exploring perceptions of women who participated in the well-established national screening programs of the Netherlands (NL), the United Kingdom (UK), and Sweden (SE). Screening eligibility in these countries is solely based on age, without access to additional risk information or screening modalities. Therefore, risk-based screening would be a considerable departure from current age-based screening practices in these three countries.

2 | METHODS

2.1 | Design

Focus groups (FGs) following a semistructured interview guide were performed to explore women's perceptions of adopting risk-based breast cancer screening and prevention in NL, UK, and SE. Ethics approval was acquired from the regional ethics committee CMO Arnhem-Nijmegen (2015-1773) in NL, London Central NHS Research Ethics Committee (16/LO/0925) in UK, and the Regional Ethical Review Board at the Karolinska Institutet Stockholm (2017/375-31/2) in SE. Written (NL and UK) or verbal (SE) informed consent was obtained from all participants prior to the start of the FGs. The participant selection process and procedure are described in Data S1.

2.2 | Data analysis

Data were thematically analyzed per country, independently by pairs of two researchers (L.R. and D.vd.W., L.R. and M.B., and Y.W. and A.J.) using an inductive approach.¹⁰ Six stages were adhered to during analysis, ie, familiarization with the data, coding, developing themes, reviewing themes, defining and naming themes, and final analysis.¹⁰ Consensus was reached through discussion when discrepancies arose. Descriptive analyses were performed with IBM SPSS version 22 (Armonk, NY: IBM Corp).

3 | RESULTS

3.1 | Participants

From the 1650 women invited to take part, 143 women participated across the three countries (8.7%). Participant characteristics are outlined in Data S2. Nine FGs were conducted in NL (54 participants), five in SE (38 participants), and six in UK (51 participants). Group sizes ranged from 5 to 10 participants. Swedish participants were considerably older than Dutch and British participants: median ages 67.0, 57.5, and 56.0, respectively. British women had fewer years of education (median: 15.0) than Dutch (17.0) and Swedish women (21.0). More British women had a first-degree family history of breast cancer (47.1%), than Dutch (16.7%) and Swedish women (21.1%). British

women showed a marked discrepancy between their perceived breast cancer risk and their actual risk as relayed by the PROCAS study team. Most British participants had a high risk of developing breast cancer (70.6%); however, only 23.5% of participants perceived their risk as high. No participants had a below average breast cancer risk.

3.2 | Thematic analysis

Dutch and Swedish women were generally positive about receiving breast cancer risk feedback. None of the British women expressed regret about finding out their risk. Women in all three countries emphasized, however, that participation should be optional, offering screening according to current country guidelines to women who do not want to adopt this approach. Figure 2 displays the themes representing perceptions of the adoption of risk-based screening and prevention of Dutch, Swedish, and British women. Data S3 provides a breakdown of the themes per country with relevant quotes. In general, there was extensive overlap in perceptions of women across the three countries. Therefore, we were able to identify five superordinate themes: (1) impact of knowledge, (2) belief in science, (3) emotional impact, (4) decision making, and (5) attitude to medication. Although the overarching themes showed similarities, subthemes sometimes differed per country. Both will be discussed below using FG data extracts.

3.2.1 | Theme 1. Impact of knowledge (NL, SE, and UK)

The superordinate theme "impact of knowledge" deals with women's perception that once they know their breast cancer risk, they feel the need to act upon that information. A moderate-high risk result in particular elicited either a beneficial response, ie, the subthemes perceived control, proactive attitude, motivation, and empowerment, or was perceived as a burden, ie, avoidance, guilt, and fatalistic view. As a Swedish participant put it, "A high risk result almost feels like it's close to a diagnosis." British participants, who had chosen to have their breast cancer risk relayed, generally perceived knowledge of risk as an opportunity: "Perhaps being more aware, and doing something proactively about your high risk, makes you feel more in control, and so you're less stressed." Although women in all three countries generally welcomed preventative options to manage their risk, they also mentioned the potential for stigma and guilt, eg, "It puts a lot of responsibility for health on women and not everyone is equally capable of maintaining a healthy lifestyle; financially or intellectually. It can't become a woman's own fault if she develops breast cancer" (Dutch participant).

3.2.2 | Theme 2. Belief in science (NL, SE, and UK)

The superordinate theme "belief in science" illustrates women's concerns regarding the scientific basis of the risk prediction model and the effectiveness of risk-reducing medication and lifestyle changes. Dutch women were particularly concerned about extending the

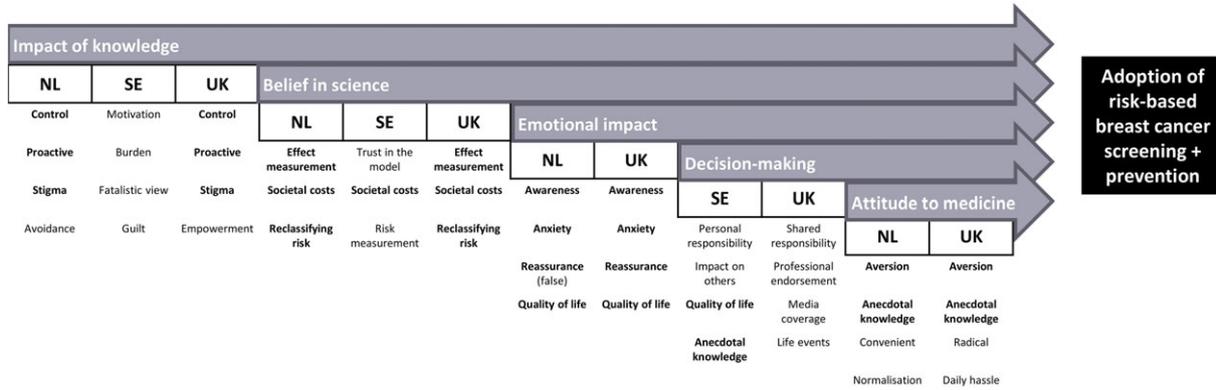


FIGURE 2 Overview of the themes associated with Dutch, English, and Swedish women’s perceptions of risk-based breast cancer screening and primary prevention. *Agreement in themes is displayed in bold. Figure adapted from Fritzell et al 2017¹¹

screening interval for women at below average risk, wondering whether it is financially motivated rather than evidence-based. Swedish women displayed a greater trust in the scientific evidence behind any new screening policy, eg, “Yes, personalised screening intervals are acceptable provided you know how they are developed and what the criteria are: why some women are asked to go for a screening more often than others.” Dutch women also described the role of perceived breast cancer risk in the acceptability of a personalized screening plan. They believe that if their relayed risk does not correspond to their perceived risk, they will be less likely to accept the accompanying screening and prevention advice. Both British and Dutch women were skeptical about the scientific link between lifestyle changes and breast cancer risk. The acceptability of risk-reducing medication depended on the magnitude of the effect, with women balancing the potential for adverse effects and risk reduction. Moreover, women would like to monitor the effect of preventative measures to determine potential reclassification of risk: “So, I think, if you can really see, find out that you have made a difference through prevention, then you could potentially screen less frequently. Particularly if you have changed your risk” (Swedish participant).

3.2.3 | Theme 3. Emotional impact (NL and UK)

The superordinate theme “emotional impact” describes how women think risk-based screening and prevention will affect their psychological wellbeing, with the subthemes: awareness, anxiety, (false) reassurance, and impact on quality of life. These themes were more prevalent in Dutch and British women’s perceptions, whereas Swedish women phrased their perceptions in more rational terms, with fewer references to emotional states, eg, “But, if they determine you have a higher risk of developing breast cancer, surely, that doesn’t mean you’ll definitely get it. Because there are other contributing factors too.” The main difference between British and Dutch women’s perceptions concerned the level of reassurance. The majority of Dutch women did not perceive the hypothetical message of below average-average risk to be particularly reassuring: “It remains a risk and it is never no risk; even if you tell me I have a 95% chance of not developing breast cancer, I might still be in the 5%; it doesn’t provide real

reassurance.” However, British women who actually received their risk, indicated that receiving a letter stating that you have an average risk of developing breast cancer was very reassuring, filing the letter and forgetting all about it. Dutch women worried that they would become preoccupied: “I don’t want to know my risk, because it will make me worry about every little ache or change in my breast.” Some British women at high risk described needing professional help: “It has massive impact, because I’m still undecided with the treatments I’ve been offered, what to do. So I’m seeing a clinical psychologist.” Women from both counties worried about the impact that risk-reducing medication would have on their current quality of life due to potential adverse effects.

3.2.4 | Theme 4. Decision making (SE and UK)

“Decision making” is a superordinate theme that received specific attention during the British and Swedish FGs. Swedish women emphasized individual decision making, considering the process a personal responsibility, balancing anecdotal knowledge of breast cancer and preventative options, and the impact that the risk assessment and subsequent recommendations may have on the quality of life of others and yourself: “I don’t think I’d consult anyone about the actual decision, because the decision is for me to make. It’s my responsibility.” British women on the other hand emphasized a shared decision making process with family, friends, and professionals, taking into account responsibility to oneself and family, and potential life events that could influence decision making, eg, divorce and illness. Professional endorsement appeared particularly elementary in the adoption of risk-reducing medication, with British women who were at first adverse to the idea of medication changing their mind due to professional advice: “Well, for me it was a no-brainer because, I mean, I don’t like the idea of taking tablets constantly, I just don’t like it. But the doctor said it was a no-brainer for me personally, you know, because of the advantages.” British women were also influenced more by media coverage about breast cancer, speaking of the perceived ubiquitous nature of the disease: “Not through being told, but I think because it’s constantly in the media, breast cancer, I don’t think even if you’re average you feel safe.”

3.2.5 | Theme 5. Attitude to medicine (NL and UK)

The superordinate theme “attitude to medicine” reflects the apparent controversial nature of risk-reducing medication for breast cancer, which was mostly addressed by British and Dutch women. Swedish women tended to have a more pragmatic approach to medication, stating that they preferred lifestyle changes but that they would be willing to try medication to determine the level of adverse effects. Most Dutch women, however, expressed an aversion to medication, perceiving it to be a radical and unnecessary daily hassle when dealing with a risk instead of a diagnosis. Anecdotal knowledge of particularly tamoxifen as a breast cancer drug induced worry and anxiety. Some Dutch women argued that preventative medication is normalized, referring to, eg, cardiovascular medication, reasoning that medication is a convenient and easy solution to lower your risk. A considerable number of British women who participated in the FGs had been advised to take risk-reducing medication. Although the British women's attitudes to medicine were very similar to Dutch women's, they generally opted to take it, with one participant stating: “Most of us think it's worth the risk.”

4 | DISCUSSION

The present study provides an overview of British, Dutch, and Swedish women's perceptions of adopting risk-based breast cancer screening and prevention. To our knowledge, this is the first study of its kind that has been performed in a population-based European screening setting. It showed that, overall, women appear in favor of finding out their breast cancer risk, although the acceptability of subsequent screening and preventative strategies is mixed. Importantly, women emphasize that strategies should be evidence-based and participation voluntary. There is considerable overlap in the perceptions of women across the three countries. This suggests that the variation in hypothetical (NL and SE) versus “actual” (UK) risk scenarios did not hinder women's ability to participate in the discussion. However, Swedish women experienced more difficulty than Dutch women relating to both the concepts of risk and hypothetical risk scenarios, requiring more clarification and encouragement to start a discussion.

The superordinate themes associated with women's perceptions of risk-based screening and prevention across the three countries are rooted in behavioral theory. Women's perceptions seem to be best reflected by the “health belief model” and “self-determination theory”.^{12,13} These two theoretical frameworks assume a cost-benefit analysis of particular health behaviors, whereby a person takes into account perceived severity and susceptibility to disease, psychological factors, social context, autonomy, and personal competence. The relevance of these two frameworks to the adoption of this novel screening and prevention paradigm by women has previously been demonstrated.⁷ However, the way in which the underlying constructs of the theoretical frameworks are represented in women's perceptions sometimes differs across the three countries, potentially pointing to culture-specific attitudes or customs.

Cross-cultural concordance was seen in the themes “impact of knowledge” and “belief in science”. Women from all three countries deliberated that breast cancer risk information may not be without consequence, enticing activity, or potential emotional turbulence. The importance of perceived competence in health behavior decision making is highlighted. Dutch and Swedish women reported a great need to understand the scientific basis of the risk prediction model and subsequent screening and prevention recommendations. They appear to perceive a greater sense of control when more knowledgeable. However, research shows that risk information is difficult to understand.¹⁴ A comprehensive information leaflet, which meets all of women's perceived information needs, may therefore hinder informed decision making. This is in accordance with the attitude of British women in this study who only received a basic level of information at every stage of the program but did not report a perceived lack of information or knowledge. The theme “belief in science” also highlighted some women's skepticism about the accuracy of risk estimates and the rationale behind risk-based screening, suspecting a financial motive. These concerns were previously mentioned by US women who professed a reluctance to change current screening habits, fearing missed breast cancers with a changed screening interval.⁸

The emotional impact of risk assessment was hypothesized by Dutch women and reported by British women about a year after receiving risk feedback. Some British women who were classified as moderate-high risk reported a decrease in psychological well-being with some women seeking professional help. These findings are tentatively confirmed by a survey study among PROCAS participants who received breast cancer risk feedback and PROCAS participants who were awaiting their risk feedback.⁶ Women who had received their risk feedback reported lower levels of anxiety but higher levels of cancer worry than women awaiting their risk feedback. Additionally, women with a moderate-high risk of developing breast cancer reported higher anxiety than women with a below average risk. However, overall anxiety levels were still relatively low. This is in line with previous research showing no significant long-term impact of genetic risk estimation on psychological outcomes.¹⁵

A pronounced difference between Swedish and British women's perceptions was visible in the decision making process precipitating participation. Swedish participants favored a more autonomous process than British participants, who emphasized a shared approach. Previous studies have found that medical decision making is affected by gender, age, and education, with younger, highly qualified women being most likely to desire higher levels of autonomy.¹⁶ This partially corresponds with our findings since Swedish women were, on average, more educated than British women. However, Swedish women were also considerably older on average than British women, contradicting previous findings. Moreover, a qualitative study of Swedish people's values regarding participation in colorectal cancer screening showed a similar need for autonomy, pointing to a potential societal attitude.¹¹

The superordinate theme “attitude to medicine” shows a general reluctance of women to try risk-reducing medication. Particularly

noteworthy is the reliance of British women on professional endorsement in the decision making process. Although our British participants were generally not in favor of medication, professional endorsement changed their views almost unanimously. This is in concordance with previous research suggesting that people look to physicians for decisions on medication use, because of their perceived superior knowledge.¹⁶ It is unclear whether the unfavorable opinion of Dutch and Swedish women regarding risk-reducing medication is related to the hypothetical nature of the risk scenarios. However, Dutch women are known for their reluctance to take medication,¹⁷ which is supported by the relatively low number of women reporting current/past HRT use in this study. Breast cancer risk reduction through medication is notoriously difficult to achieve, with few women showing willingness to commit to a 5-year preventative treatment regimen.^{18,19} The use of tamoxifen as a preventative drug elicits a strong response from women because of the association with breast cancer treatment.²⁰ Additionally, the perceived adverse effects often deter women,^{19,20} which was confirmed in the present study. Currently, studies are being undertaken, eg, KARMA Intervention Study (KARISMA) in SE (<https://karmastudy.org/ongoing-research/>), to determine the lowest effective dose of tamoxifen to potentially increase its applicability as a preventative drug.

5 | CONCLUSIONS

5.1 | Study limitations

The present study is the first exploration of European women's perceptions of adopting an integrated risk-based breast cancer screening and prevention program. The large number of women from three European countries allowed for an extensive cross-cultural exploration of the acceptability of this new paradigm from the perspective of potential future participants. However, we have to be careful in our interpretation of the results and culture-specific variations cannot be assumed. Selection bias is likely to have affected group composition in all three countries. In general, FG participants were relatively highly educated women who had previously participated in breast cancer screening and scientific research. They were more likely to have had favorable perceptions of screening, potentially limiting the generalizability of our findings to women who do not currently participate in screening. Moreover, an unequal number of British women were invited per risk category, which led to an overrepresentation of high-risk women. Below average risk women were not at all represented, although some women reported a low perceived breast cancer risk. Moreover, perceptions of Dutch and Swedish women could have been affected by the hypothetical nature of the risk scenarios with inherently lower stakes. Additionally, FGs were moderated by different researchers due to a language barrier. Although we relied on a semistructured interview guide to standardize discussion, variation is plausible. Future research is required to confirm the identified perceptions in a larger group of women. We are therefore currently performing a survey study aiming for equal representation of women

with below average, average, and above average breast cancer risk who are eligible for screening.

5.2 | Clinical implications

Acceptability of risk-based screening and prevention is mixed. More intensive screening for women with above average breast cancer risk was generally welcomed. However, screening pathways for the other risk categories and general prevention strategies were met with some skepticism. This has implications for clinical practice that need to be addressed by stakeholders and policy makers before implementation. Women's perceptions seem to be informed by a lack of knowledge, cultural norms, and common emotional concerns, which highlights the importance of tailored educational materials and risk counselling to aid either shared or individual informed decision making.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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