



Original article

Assessing and managing breast cancer risk: Clinicians' current practice and future needs



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ABSTRACT

Decision support tools for the assessment and management of breast cancer risk may improve uptake of prevention strategies. End-user input in the design of such tools is critical to increase clinical use. Before developing such a computerized tool, we examined clinicians' practice and future needs. Twelve breast surgeons, 12 primary care physicians and 5 practice nurses participated in 4 focus groups. These were recorded, coded, and analyzed to identify key themes. Participants identified difficulties assessing risk, including a lack of available tools to standardize practice. Most expressed confidence identifying women at potentially high risk, but not moderate risk. Participants felt a tool could especially reassure young women at average risk. Desirable features included: evidence-based, accessible (e.g. web-based), and displaying absolute (not relative) risks in multiple formats. The potential to create anxiety was a concern. Development of future tools should address these issues to optimize translation of knowledge into clinical practice.

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Introduction

As we move towards more personalized medicine [1], it is possible to estimate a woman's risk of breast cancer (BC), and discuss appropriate prevention and screening options. It is important to identify and appropriately manage women at increased risk, but also to reassure the majority at population risk and thus avoid unnecessary interventions.

While many factors influence BC risk, the most important include family history, a personal history of proliferative breast disease, and mammographic density [2]. Mathematical models already exist to identify those at higher risk of BC [3], but most are designed for use by highly specialized physicians or researchers. None of these is a patient centered decision support tool with integrated educational content.

Patient decision support tools are evidence-based tools designed to help people participate in decision-making about health care options. They provide information on available options and allow patients to make informed, values-based decisions with their clinician. They do not advise people to choose one option over another, nor do they replace medical consultations; they merely assist the decision-making process [4].

Once women at increased risk for BC are identified, there are proven interventions that decrease BC incidence [5], including;

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surgery with risk-reducing bilateral mastectomy, premenopausal bilateral salpingo-oophorectomy and medication to prevent BC with tamoxifen, raloxifene or exemestane [6] and more recently anastrozole [7]. Lifestyle modifications, including weight loss and reducing alcohol intake have a smaller benefit. While screening does not reduce breast cancer risk, and remains unproven in high-risk populations, it may aid in early diagnosis and is recommended [8]. Appropriate uptake of these measures, especially medical prevention, remains low [9,10].

A tailored decision aid may help clinicians educate women about their personal risk and the options available to manage that risk. There is evidence that with informed decisions, realistic expectations, and active involvement in the BC risk decision process, women are more likely to persist with decisions and experience less distress with the consequences [11].

To enhance the likelihood that women receive BC risk management advice consistent with their estimated risk, we are developing a personalized, web-based, risk assessment decision support tool. This tool aims to assist health care professionals to easily and accurately assess a woman's absolute BC risk, and effectively convey tailored information about the risks and benefits of relevant risk management options for that individual.

One of the challenges in developing decision support tools is their integration with clinical practice, and many approaches have been suggested. Normalization Process Theory (NPT), for example, suggests addressing three core processes to achieve a lasting change in practice; implementation of the practice, embedding in routine use and integration of the practice in a sustained way [12]. In order to develop a tool that can be effectively implemented and embedded, we conducted qualitative research to understand the current practice of BC risk assessment and management, to inform the design of this decision support tool.

We identified that the clinicians most likely to use this tool in clinical practice were Primary care physicians (PCPs) (with support of practice nurses (PNs)) and breast surgeons (BSs). PCPs are often a point of first contact for women concerned about breast cancer risk, and breast surgeons would see women concerned about risk, including those diagnosed with benign breast disease, and those seeking prophylactic mastectomy.

Methods

Recruitment

Clinicians were identified and recruited through professional networks in Melbourne, Australia, including the Victorian Primary Care Practice-Based Research Network (VicReN) [13] and the Melbourne Breast Surgeons Group— a network for all breast surgeons working in Melbourne. Invitation emails were sent through these networks, those interested replied were then contacted by phone to confirm attendance. While participants were not reimbursed for participation, they were provided with a meal and refreshments during the focus group. The study was approved by the Human Research and Ethics Committee (HREC) of the University of Melbourne, and all participants provided written consent.

Data collection

Participants completed a short demographic questionnaire. Focus group discussions were guided by the use of a theme list and prompts, and other themes raised by participants were followed up and explored. The discussion was conducted in two parts within a single session, the first part explored the theme; current practice of risk assessment and risk management for BC, including knowledge, attitudes and experience. Information was then distributed to the

participants, which described and illustrated examples of a proposed BC risk assessment and risk management tool. During the second part of the focus group, further themes were explored; participants were asked to describe their reaction to the idea of the tool, specify particular desirable or undesirable features, and identify perceived barriers and enablers to its use in practice.

Data analysis

Focus group discussions were audio recorded and transcribed verbatim, de-identified and analyzed thematically by authors ES and LK. Based on several readings of all transcripts, a coding framework was developed, consisting of three main themes and a number of sub-themes. All data were coded to the level of sub-themes. Each sub-theme was analyzed in order to describe the variations and patterns present. QSR NVivo qualitative data analysis software [14] was used to manage the organization and analysis of the data.

Results

Twenty-nine clinicians participated in four focus group discussions (four to eleven participants in each). Table 1 summarizes participant characteristics. Unfortunately we were not able to identify the denominator for our sample and therefore cannot report a response rate. Two of these groups included only BSs, one group included only PCPs, and one group included PCPs and PNs. After coding, 3 main themes (Table 2) were analyzed; risk assessment in current practice; risk management in current practice; views on the proposed tool.

Participants identified difficulties assessing and managing BC risk and lack of available tools to standardize their currently inconsistent approach to risk assessment and management. Most felt confident identifying high risk women, but found differentiating women at population risk from those at moderately increased risk more difficult. They felt a tool would help them reassure anxious low to moderate risk women and better identify and refer or manage high risk women. They identified several key elements they would like to see in a tool. Each theme is illustrated with quotations, identifying participants by profession and number (Table 3).

Breast cancer risk assessment – current practice

On whom is risk assessed?

While most BSs indicated that all women attending their practice will undergo some BC risk assessment, PCPs reported BC risk

Table 1
Demographic characteristics of participants.

Characteristics		Number (%) n = 29
Gender	Male	13 (45)
	Female	16 (55)
Age (years)	25–35	8 (28)
	36–45	3 (10)
	46–55	13 (45)
	56–70	5 (17)
	>70	1 (3)
Type of clinicians	Breast surgeon	12 (41)
	Primary care physician	12 (41)
	Practice nurse	5 (18)
No. of years as a clinician	1–15	16 (55)
	16–25	12 (42)
	>25	1 (3)
Average no. of clinical sessions per week	1–5	8 (28)
	6–10	18 (62)
	11–15	3 (10)
Education about familial cancer in the past year	Yes	14 (48)
	No	15 (52)

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