

Appendix 9. Ways to Communicate Risk to Patients and Improve Patient Understanding of Risk

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INTRODUCTION

To intervene for screening and prevention of early onset breast cancer (EOBC), improved methods of communication of risk are necessary. This review evaluates the current information regarding communication tools, decision aids, and best practices for communicating risk of EOBC and the knowledge gaps in this area. Shared decision making is a key component of patient-centered health care, particularly because there is often more than one option for screening. Eliciting patient beliefs and values about the possible benefits and harms of screening and desire for screening or treatment, is important, because these things differ at the individual level.¹ Shared decision making has been endorsed by the American College of Obstetricians and Gynecologists (ACOG) for deciding the age at which to initiate breast cancer screening.² The literature search for this review was centered on the following questions:

1. What validated tools or best practices are available for communicating EOBC risk to patients?

P – Patient, Problem or Population. I – Intervention. C – Comparison, control, or comparator. O –

Outcome(s) (PICO)

P: Patients with normal and high risk for EOBC; all women aged 18–45

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I: Shared decision making tools, decision aids, risk communication tools, genetic risk assessments

C: Use of shared decision making tools versus no use of shared decision making tools, use of tools in high-risk populations versus low-risk populations

O: Use of early screening (mammography or ultrasonography), early diagnosis, stage of disease at diagnosis, accurate risk perception, value-choice agreement, decreased decisional conflict

2. What validated tools or best practices are available for communicating risk to patients in other areas that could be generalized to EOBC?

PICO

P: Adult women

I: Validated tools or best practices for communicating risk to patients in other areas

C: One tool versus another, a tool for one disease versus a tool for another disease

O: Accurate risk perception, value-choice agreement, decreased decisional conflict, early diagnosis, stage of disease at diagnosis

3. What are current major society or health services guidelines for communicating risk for EOBC, or from other areas that could be used for EOBC?

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PICO

P: Women aged 18–45

I: Major society or health services guidelines for shared decision making tools, decision aids, risk communication, genetic risk assessments

C: Use of shared decision making tools versus no use of shared decision making tools, use of tools in high-risk populations versus low-risk populations

O: Recommendations by the National Comprehensive Cancer Network (NCCN), U.S. Preventive Services Task Force, ACOG, American Cancer Society, or other specialized organizations

METHODS

Literature Review

Using the PICO criteria, a search was conducted for English-language articles, including systematic reviews, meta-analyses, cohort studies, case–control studies, and randomized controlled trials. In addition, major society and health services guidelines from organizations including NCCN, U.S. Preventive Services Task Force, ACOG, American Cancer Society Breast Surgeons, Society of Surgical Oncology, and the National Cancer Institute (NCI) of the National Institutes of Health were reviewed. The review further encompassed international guidelines, such as those from the Royal College of Obstetricians and Gynaecologists, National Institute of Health and Care Excellence (NICE), European

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School of Oncology, European Society of Medical Oncology, and European Society of Breast Cancer Specialists; their recommendations for the management of young women with breast cancer were reviewed.

- Guidelines included: USPTF, ACOG, NCI, NCCN, Centers for Disease Control and Prevention, NICE
- Guidelines excluded: Royal College of Obstetricians and Gynaecologists, American College of Radiology

A total of 136 titles and abstracts were reviewed. However, only 56 remained for deeper review. After further assessment, 13 titles were reviewed, and 5 additional articles were identified. In addition, multiple websites for proprietary and public-facing shared decision making models were identified using terms similar to those in the literature review.

Articles were excluded if they were not available in English, were case series or reports, or focused on the communication of risk-related treatment modalities after a diagnosis of EOBC or breast cancer.

RESULTS

While patient decision aids and risk calculators help enumerate risk and are key components to shared decision making, the process is more involved than use of these validated tools alone.¹ Many of the risk calculators are aimed at a certain population, such as the Breast Risk Calculator Tool (BRCAT) Gail Model (for women >35 years) and the Health Decision Breast Cancer Screening Tool. The ACOG Committee Opinion 587 references the partnership model of negotiation, but refers to no significant tools or

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decision aids that specifically address risk communication.³ In a small study examining barriers and facilitators of patient–provider communication when discussing breast cancer risk, time constraints, lack of knowledge, low health literacy, language barriers, and desire for personalization and autonomy were all cited as barriers to consider when developing a patient-centered decision aid (the authors performed this needs assessment to guide development of a new tool).⁴

Narrative risk communication may offer an improved way of influencing feelings about cancer risk.⁵ Narrative risk communication involves the use of stories and anecdotes, as opposed to statistical risk communication, which involves quantification of events and percentages. Narrative risk communication is thought to enable activation of personal feelings and values, which are important in making personal health care decisions.⁶ More specifically, narrative risk communication may represent a way of addressing disparities in screening for breast cancer. Trials in the African American community using video narratives demonstrated that, in the subpopulations studied, narrative risk was not associated with increased anxiety and was associated with objective subject matter retention and increased screening.^{7,8}

A 2017 Cochrane review of patient decision aids demonstrated enhanced understanding of the disease process when decision aids were used, without increasing anxiety for screening and treatment.⁹ A subanalysis specifically looking at the use of patient decision aids for cancer screening and treatment found increased knowledge, improved accuracy in risk prediction, congruency in value-choice, decreased decisional conflict, and fewer clinician-controlled decisions. Use of screening was found to be effective and applicable specifically to breast cancer, as well. This study highlights the need to develop

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additional patient decision aids for underrepresented populations (only four were included).¹⁰

Unfortunately, there still exists some controversy as to the value of decision aids. For example, the systemic review by Martinez-Alonso et al demonstrated increased knowledge in the percentage of women making an informed decision regarding screening, but called into question decisional conflict and confidence in the decision because of the heterogeneity in the study.¹¹

Regardless of use or development of decision aids or mode of communication, using absolute rather than relative risk in counseling reduces bias in decision making. Furthermore, absolute risk rather than numbers needed to treat was similarly more effective for understanding.¹² There is also concern for framing bias—whether risk being presented in a positive or negative way influences uptake in screening and treatment (eg, presenting breast cancer lifetime risk as one in eight women, rather than stating that seven of eight women will not develop breast cancer). Positive framing has been associated with less uptake in screening, which should be taken into consideration while counseling and in the development of future tools.¹³

Various organizations discuss the importance of shared decision making in communicating risk assessment and selecting treatments and further testing. However, specific references evaluating tools to facilitate this conversation for providers and patients at risk for EOBC are lacking. While decision aids exist for facilitating decision making regarding treatments once a diagnosis of breast cancer is made (genetic testing, use of adjuvant therapy), there is little that specifically addresses enhanced understanding for women at risk for EOBC. How best to tailor this risk communication remains an open question. Depending on a woman's numeracy capability, this can be more difficult and require multiple

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types of decision aids.¹⁴ Additionally, many of the existing tools are directed towards special populations or women with known hereditary risk, and are not applicable to the general population. Other disciplines (eg, colorectal screening) have begun tailoring shared decision making aids to individual preferences.¹⁵

Specific Validated Tools for Communicating Risk for EOBC

While not specific to EOBC, the NCI Breast Cancer Risk Assessment tool can predict 5-year risk of breast cancer. This calculator is only available for women aged 35 and older, however, and its utility is limited in women carrying a pathogenic mutation in BRCA 1 or BRCA 2, women with previous history of breast cancer, and women in certain subgroups. The tool may underestimate risk in black women with previous biopsies or Hispanic women born outside the United States.¹⁶ Families Sharing Health Assessment and Risk Evaluation (Families SHARE, a product of the National Institutes of Health's National Human Genome Research Institute) includes a specific decision aid useful for shared decision making for individuals of varied age groups, but it is not directed to any subpopulation of patients at risk for EOBC. Nevertheless, the tool may raise awareness of an individual's risk and can be used within and outside of an office setting.¹⁷ Additionally, individuals at average risk of EOBC may benefit from the decision aid Breast Screening Decisions, which is directed to women aged 40–49 and was developed collaboratively with Weill Cornell Medical College and Sloan Kettering Cancer Center.¹⁸

A number of interventions are available for women at high risk of hereditary breast and ovarian cancer.

The Cancer Risk Education Intervention Tool is a web-based (noninteractive) adjunctive tool to be used

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in a low socioeconomic setting for ethnically diverse women at high risk for genetically-associated EOBC and ovarian cancer. This tool demonstrated variably improved knowledge of risk; patients appreciated the narrative format.¹⁹ Additionally, Metcalfe et al evaluated the use of decision aids for breast cancer prevention in BRCA 1 or BRCA2 mutation carriers.²⁰ Cancer-related distress was reduced in the decision aid group, but decisional conflict did not change with use of the aid (though decisional conflict decreased in both groups over time). More recently, a randomized controlled trial had similar findings regarding overall improvement of knowledge without reduction in decisional conflict.²¹

Furthermore, there is no evidence that communicating results via phone is inferior to in-person sharing of results. As such, telephonic or virtual communication may provide an opportune time to begin the shared decision making journey.²²

The Stanford shared decision making tool for women with BRCA 1 or BRCA 2 was developed using the Montecarlo method to guide decision-based treatment incorporating calculated risk. This tool may represent a best practice for a decision aid to support patients with BRCA 1 or BCRA 2 mutations and their providers in screening and treatment decisions.²³

For minority groups, one education program was reviewed. The Health Belief Model was used as a construct for developing a school-based tool educating African American women aged 20–39 on risk of breast cancer. Both the classroom and online model resulted in increased knowledge regarding breast cancer risks.²⁴

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The ACOG Committee Opinion 729 references the importance of screening for social determinants of health in all patients (not just those at risk for EOBC), as these factors may play a role in decision making and communication.²⁵

Tools That Can Be Generalized

The Breast Cancer Screening (PDQ®) tool is not specific to women at risk for EOBC but is directed to women in the general population. The format for explaining screening benefits and harms may serve as a template for shared decision making in women at risk for EOBC.²⁶ The Breast Cancer Screening (PDQ) tool has the advantage of offering both a patient tool and a provider tool, which may be used as companion documents.

Patient decision aids for colorectal cancer screening have been shown to improve knowledge and interest in screening compared with no information. However, these aids are no better than general colorectal cancer screening information, according to a systematic review and metaanalysis.²⁷

Healthwise is a nonprofit organization founded in 1975 with the intention of guiding patients to make better health decisions. In the 1990s, this organization created Healthwise Knowledge Base, an evidence-based interactive platform for patients. It offers decision support tools, including one on breast cancer screening starting at age 40. Many insurance companies and health care systems use it to provide decision support on their own websites. Healthwise also has a shared decision making tool for women aged 40–50, which may facilitate understanding for women who are at risk for EOBC at age 40.

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However, it does not address at-risk patients or patients younger than 40. A series of questions weighs patient worries, desires, and fears in response to evidence provided about the risks and benefits of screening. The tool provides a score denoting which way the patient is leaning at that time, and calculates how ready they are to act (see [University of Wisconsin Health](#)).²⁸

Decision analytic models can improve estimation of benefits and risk for patients undergoing thrombolysis, with the added benefit that the results can be embedded in a computerized decision aid.²⁹ This interesting approach of incorporation into the electronic health record could lead to innovations for tools and calculators, such as the Gail or Families SHARE model within a primary care or women's health record. Similar innovations related to genetic testing and screening would have applicability for those patients at risk for hereditary breast and ovarian cancer. Similarly, the University of Wisconsin School of Public Health has created Health Decision[®], a tool that includes a breast cancer screening module that can be integrated within some health records.³⁰ This web-based tool had previously been developed and implemented in the breast cancer prevention program at University of California San Francisco,³¹ and was found acceptable when tested for usability with 6 patients and 28 providers.³²

Major Society and Health Services Guidelines for EOBC and Other Topics

The USPTF does not specifically address EOBC in its guidelines, except to state that the recommended screening guidelines do not apply to women with prior chest radiation or known underlying genetic mutations such as BRCA 1 or BRCA 2. There is no professional society with any recommendations regarding how to communicate risk for women at risk of EOBC. The NICE guidelines address providing

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information and support for decision making in the Clinical Guideline no. 81, Advanced Breast Cancer: Diagnosis and Treatment.³³ However, no specific tool or decision aid is recommended. The NICE Clinical Guideline no. 164, Familial Breast Cancer: Classification Care and Managing Breast Cancer and Related Risk in People With a Family History of Breast Cancer, similarly stresses shared decision making and the use of “materials,” decision aids, and standardization of the discussion.³⁴

DISCUSSION

While multiple guidelines address breast cancer screening for a population at normal risk, there is little information on communication of those risks. Calculators such as the BRCAT model quantify the risks and generate a statistical risk, but guidance is lacking on how to best customize and communicate risks to individual patients based on their personal risk, health literacy, numeracy capabilities, and understanding of benefits and harms of screening. Moreover, for the woman at risk of EOBC, there is even less information on the best communication strategies. More work has been done in communication of risk of BRCA 1 and BRCA 2 testing and treatment for woman who are at increased risk of hereditary breast and ovarian cancer syndromes. In addition, when asked, young women perceive communication with health care providers regarding breast cancer, risk, and prevention to be limited.³⁵

While many clinicians believe they are performing shared decision making with their patients, what commonly happens is a discussion of the risks and benefits, solicitation of patient opinions, and sharing of the clinician’s opinion based on their knowledge of the evidence. This process does not really represent shared decision making. Shared decision making entails helping patients make a decision that

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is in line with their beliefs based on the available medical evidence. It should include the following three components:

1. Communication of clear, accurate, and unbiased medical evidence about reasonable alternatives, including no intervention, as well as the risks and benefits of each option.
2. Clinician ability to tailor the evidence to the individual.
3. Clarification of patient values, goals, preferences, and concerns in light of the evidence presented.³⁶

It is important to develop a breadth of tools for communication of EOBC risk so that, depending on factors such as numeracy capability and health literacy, the most appropriate tools can be selected for the individual patient. No tools for individualized assessment were identified in the literature review, however. If developed, such tools might guide tailoring of tools, aids, and communication strategies to an individual patient.

Online tools such as the Healthwise Knowledge Base may offer additional benefit in facilitating the process. The ability to embed a tool in the EHR (such as Health Decision) may be optimal for providers. Additionally, the ability to create companion tools similar to those in the Breast Cancer Screening (PDQ) tool that can be used by the patient and provider—as well as creating educational materials demonstrating the use of these tools—could be beneficial in communicating information related to risk and screening, thus ultimately decreasing mortality related to EOBC. Tools and aids that include narrative risk could be developed that can be administered via video vignettes, aiding efficient administration for the health care provider.

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