

Breast Cancer Screening in Primary Care: A Call for Development and Validation of Patient-Oriented Shared Decision-Making Tools

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Abstract

The latest recommendations on breast cancer screening in women from 40 to 49 years charge primary care providers (PCPs) with completing shared decision-making with women about screening mammography. However, there is a lack of supportive materials accompanying this directive. No easy-to-use risk assessment tool is available for PCPs to stratify women's risk. Neither is an evidence-based patient-centered way to assess values surrounding mammography available. To provide the highest quality care for women of 40–49 years, further research should clarify ways to apply risk assessment and values clarification to individual women.

Keywords: decision-making, mammography, primary healthcare, risk assessment, communication

Introduction

IN 2015, GUIDELINES for breast cancer screening began to focus on the benefit–harm balance of screening mammography and incorporate the patient-centered concept of shared decision-making. These guidelines increasingly began advising that patients and physicians weigh breast cancer risk and patient values in the decision to undergo screening. The American Cancer Society was the first to support shared decision-making when they published guidelines in October 2015, saying that women “should have the choice to begin screening mammography at age 40 or before age 45 years, based on their preferences and their consideration of the trade-offs.”¹ In January, 2016, the U.S. Preventive Services Task Force updated its 2009 recommendation for breast cancer screening, also recommending weighing risks and values saying,

“The decision to start screening mammography in women before age 50 years should be an individual one. Women who place a higher value on the potential benefit than the potential harms, may choose to begin screening every 2 years between the ages of 40 and 49 years.”²

In July of 2017, the American College of Obstetrics and Gynecology followed suit by publishing a bulletin that presented “recommendations for using a framework of shared decision making to assist women in balancing their personal values regarding benefits and harms of screening at various ages and intervals to make personal screening choices from within a range of reasonable options.”³

These new recommendations more definitively leave the decision to get a screening mammogram for average-risk women between 40 and 49 years up to the individual woman and her primary care provider (PCP).

Although these guidelines agree on shared decision-making, their recommendations in terms of initiation age and screening interval differ based on different interpretation of the evidence and weights given to benefits and harms. In general, younger women experience similar harms, that is, recalls for additional imaging and benign biopsies, but since there are fewer cancers found in this population, the balance of harms and benefits changes. For example, mammograms save fewer lives in younger women because the incidence of breast cancer is lower in women 40–49 years old as compared with women of ages 50 years and more, but screening results in more quality-adjusted life years gained in this population than older age groups.

Assigning different weights to different types of evidence supporting the efficacy of breast cancer screening with mammography, including randomized controlled trials, observational trials, service screening data, simulation modeling, and other study designs, influences the conclusions. The fact that organizations and experts who have access to the same data about screening mammography reach different and sometimes conflicting conclusions provides evidence that the data about benefits and harms of mammograms are complicated and determining the optimal balance is nuanced.^{1,4,5}

For PCPs, these guidelines are particularly challenging because they do not provide tools or supporting materials to

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help follow the recommendations for risk assessment and shared decision-making. Multiple studies document that PCPs are not only confused about the guidelines⁶ but also struggle to operationalize these important components.⁷ The new recommendations do little to help PCPs wade through the vast amount of sometimes conflicting data, evaluate risk, or explore and respond to patient values. PCPs are in a unique position to start the conversation with women about preventive screening due to their ongoing relationships and knowledge of other health risks. We advocate for the provision of more support to help PCPs approach this topic in a more effective manner and determine whether other resources or individuals could aid PCPs in this important activity.

Risk Assessment

The guidelines already noted were developed for average-risk women. High-risk women⁸ (e.g., women with a personal history of breast cancer, a family history of breast cancer, or high breast density) may benefit more from screening than average- or low-risk women based on the underlying increased incidence of disease in these women. Breast cancer risk tools available online or in the literature⁹ include the Breast Cancer Risk Assessment Tool—BCRAT (developed and improved by Gail et al.), the first tool to be used in this arena included demographics (age, race/ethnicity), reproductive history, menopausal status, family, and history (website: <https://www.cancer.gov/bcrisktool/>).¹⁰ The BCRAT model does not include known and modifiable risk factors such as obesity or alcohol use, nor does it consider extended family history.

Expansions and modifications of this type of model came to include additional variables such as breast biopsies and mammographic density, for example, the Breast Cancer Surveillance Consortium (BCSC) risk calculator (website: <https://tools.bscscc.org/bc5yearrisk/calculator.htm>).¹¹ The BCSC model is currently being used to test risk-based screening in the WISDOM trial¹²—the first prospective trial to evaluate the feasibility and efficacy of risk-based screening. The Tyrer–Cuzick model (also called the International Breast Intervention Study, or IBIS,) was tested in a screening program of average-risk women¹³ and achieved the highest discrimination—that is, how well a model predicts risk at the individual level—in a meta-analysis.¹⁴

Other models, such as the Claus, BRCAPro, are BODICEA, are either not appropriate or too cumbersome for use in a busy primary care practice. The key point is that there are no effective and externally validated tools with available infrastructure (integrated into clinical workflow) to assess women who are technically “average risk” but who may want to weigh their individual risk in their decision to undergo screening. In fact, there is no single, validated, easy-to-use tool for PCPs to efficiently and accurately counsel these women.¹⁵

PCPs would benefit from the development and dissemination of a validated, personalized risk assessment tool, integrated into the clinical workflow. Such a tool would include the standard risk factors such as family history and age at menarche and would also add more recently identified risk factors such as race, ethnicity, and breast density.¹⁶

After the mandate to discuss risk and engage in shared decision-making, risk assessment tools have become increasingly important. Ideally, risk assessment tools should

identify women who are not appropriate for guidelines meant for “average-risk” women and stratify risk in “average-risk” women. However, the definition of “average risk” is not clearly defined. Therefore, currently available risk assessment tools are not validated in screening populations, studied in terms of optimal use, nor tested considering communication principles such as framing. Tools are not available at the point of care (ideally integrated in the electronic health record) nor do they provide educational support for PCPs or patients. Finally, tools do not model possible complex interactions between risk factors and outcomes nor do they provide a context for decision-making in terms of the outcomes that are difficult to definitively quantify (e.g., radiation risk and overdiagnosis).

Incorporating Patient Values and Shared Decision-Making

Determining values about breast cancer screening is complicated and difficult to assess. How does the PCP assess values? Online tools have been developed that explore some of the value dimensions that may inform the appropriate decision to undergo breast cancer screening, including avoiding false positives, avoiding false negatives, peace of mind, catching cancer early, overdiagnosis, stress and fear, time and access, embarrassment and pain, radiation exposure, and cost.^{17–19} These tools are not extensively studied, validated, or easily available to most PCPs.

Constructing a tool that balances personal values and risk considerations is an important goal. For instance, a woman may make a different decision about screening mammography based on her personal risk of breast cancer and likelihood of benefit. Balancing the timing and relative emphasis of risk and values is yet another nuanced conversation for which little evidence or support is available. There is ample literature demonstrating that how risk is communicated (i.e., “framing”) may affect the screening decision. PCPs need more guidance on how to effectively relay individual risk to women.²⁰

Shared decision-making is an important part of patient-centered care, improves patient’s knowledge regarding options, and reduces the conflict surrounding their decisions.¹⁹ In relation to breast cancer screening, it is predicated on knowledge of benefits and harms of screening (which vary based on risk) and values about screening. Ideally, we would standardize the way shared decision-making is provided and thus enable women to make an informed, evidence-based, personalized, and value-concordant decision.

Challenges and Call to Action

To develop effective shared decision-making tools, the barriers faced by PCPs must be addressed. Most health maintenance examinations for women cover preventive topics, lifestyle modifications, supportive counseling, any chronic health conditions, screening tests, and physical examination—all within a short visit. There is little time to discuss the process of screening mammography, possible benefits and harms, individual breast cancer risk, and values about screening, yet that is what the updated guidelines suggest.

PCPs may not use currently available tools for several reasons. First, there are not many tools that are embedded into the electronic health record (EHR), making access cumbersome and time consuming. Second, most PCPs are not trained in shared decision-making and so do not feel comfortable

pursuing it in an office visit. And third, most PCPs are challenged to address all recommended preventive screening, as well as manage chronic conditions, and address acute concerns, all within a short period of time.

This article is meant to serve as a call to action for investigators to develop and validate tools that support risk assessment, values clarification, and communication about screening mammography for PCPs and women in their 40s that can be used in an efficient manner within the context of an office visit. Research should also elucidate the most efficient model for easy-to-use individualized shared decision-making tools that will enable PCPs to accurately identify high-risk women and counsel them accordingly. Ideally, well-designed and complementary educational materials and supportive services would increase effectiveness of the shared decision-making process and decrease the burden on PCPs.

Disclaimer

The content is solely the responsibility of the authors and does not represent the official views of the sponsor.

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