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Mammography Screening: Gaps in Patient's and Physician's Needs for Shared Decision Making

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Abstract

As shared decision-making increasingly influences screening mammography, understanding similarities and differences between patients and physician perspectives becomes crucially important. This study compares women's and physicians' experiences of mammography shared decision making. Results reflect the critical gaps which exist between women's expectations and physicians' confidence in shared decision making regarding screening mammography.

Keywords

breast cancer screening; health communication; mammography; decision-making; risk communication

Introduction

Screening mammography plays an important public health role in improving outcomes and has contributed substantially to the national and statewide declines in breast cancer mortality over the past 30 years. The age to begin screening mammography is the focus of substantial policy debate. The United States Preventive Services Task Force (USPSTF) recommends individualizing screening for average risk women before age 50 based on personal risk of breast cancer and preference (1, 2). In doing so, the USPSTF has "mandated" both risk assessment and shared decision-making (SDM) without providing the necessary guidance

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and the operational mechanisms for patients and primary care physicians to respond to this directive.

SDM is a favorable means to provide evidentiary transparency and to help women make decisions about population health recommendations as they apply to individual risk and context (3). Yet, there is a dearth of evidence as to what women and primary care physicians need to make informed and shared decisions about screening mammography (4). A recent systematic review suggested that research about risk models and decision aids that promote patient centered SDM for breast cancer screening is needed (5). Davey discovered that there is disagreement between stakeholders (patients, primary care physicians, subspecialists, and advocates) in terms of the information that should be discussed at the outset of breast cancer diagnostic testing (6).

From a patient perspective, informed choice about breast cancer screening mammography requires the opportunity to weigh all possible favorable and unfavorable effects of screening. Accordingly, choice should be based on relevant knowledge and actual screening behavior should be consistent with attitudes and values regarding screening (7).

Critical elements of SDM fall on the primary care physician and include: identifying options; inviting patients into the decision process; presenting information about the benefits and harms of alternative options; and helping to make a decision that is concordant with personal values (8). Currently, mammography decision-making often lacks many of these elements.

We sought to understand patient and provider experiences regarding screening mammography decision-making and practices.

Materials and Methods

The University of Wisconsin-Madison Health Sciences Institutional Review Board approved this study.

Patient Focus Groups

Two patient focus groups were conducted in March and April 2013 at geographically distinct clinic locations. Each group consisted of 5 women aged 40–49 years who had previously received at least one mammogram. Participants were reimbursed $30.

We used the Critical Incident Technique to engage women in a discussion of challenges faced during mammography decision-making (9). Each woman was asked to describe personal experience of mammography decision-making, including fears, frustrations, uncertainties, barriers/facilitators, surprises). Women who indicated they did not have difficulties with past mammography decision-making were asked to recount how they made the decision for their initial mammogram. Focus groups were audio-recorded and a researcher took detailed notes during the group.

Physician Interviews

We interviewed a convenience sample of 17 primary care physicians in the UW Health system (6 Internal Medicine, 8 Family Medicine, 3 Obstetrics/Gynecology; 9 female, 8 male) who see female patients between 40 and 49 years. Researchers conducted either phone or in person interviews (February–March, 2013) based on a template of prepared questions. Physicians were asked what their current practice was counseling average risk women on mammograms, which guidelines they followed, how long they spent in counseling, and what they would like to see in a SDM tool. Each interview was audio-recorded. The interviewer took detailed notes during the interview.

Analysis

Detailed notes and transcripts provided content for analysis of focus groups and physician interviews. Content analysis was used to summarize findings, including similar and discordant themes from focus groups and interviews. A constant comparison technique was used to identify initial categories and subcategories and revised based on further evaluation of content within these frameworks. Discrepancies in coding were discussed until agreement was reached.

Results

Patient Focus Groups

Sixty percent (60%) of the women reported European descent; forty percent (40%) were African American and Latina. While many women reported some ease of mammogram decision making, they still identified three critical areas that impact their screening mammogram decisions: (1) Physician characteristics (e.g. level of involvement in decision-making, knowledge of guidelines and risk factors, relationship quality including trust, communication and history); (2) Patient risk awareness (desire for risk education and awareness from personal stories of family and friends); and (3) Mammogram process (negative experiences during the mammogram itself or with receiving results and next steps).

Physician Interviews

Physicians reported struggling with the discussion about screening mammography. Accordingly, one stated “I’m not really adept.” Four critical areas where identified that impact communication with patients and shared decision making regarding screening mammography: (1) Time constraints; (2) Risk (lack of adequate knowledge of risks and ability to communicate risk in an effective format); (3) Guidelines (confusion related to conflicting and changing guidelines); and (4) personal preferences (addressing patient preferences that contradict guidelines and addressing physician’s own biases).

Women and Physician Discordance

We compared findings from the patient focus groups and physician interviews to determine areas of both concordance and discordance with respect to the most important areas of screening mammography SDM (Table 1). Overall patients and physicians share ideals including: the women’s participation in SDM at the level they prefer, the importance of

physician understanding of the relevant risks and guidelines to inform SDM conversations, and preparing women for the mammography experience, including the potential for positive results.

However, critical discordance occurs in perceptions of enacting these ideals, especially regarding the degree of expertise physicians have to guide the SDM process. Whereas women trust that their physicians know the risk factors for breast cancer and screening guidelines and direct them accordingly, physicians are reporting less confidence in their ability to know or consider all risk factors for an individual's risk calculation as well as difficulty making sense of ambiguous, contradictory or changing guidelines. Furthermore, physicians perceive time constraints as a barrier to thoroughly considering all risk factors and making individual recommendations. Further, both women and physicians identified the importance of preparing women for the potential mammography outcomes; however there is discordance in the perception of whether this occurs. Several physicians described they have brief conversations about potential outcomes, yet the women uniformly reported receiving limited or no information about the mammography process and felt ill-prepared for understanding results or next steps.

Discussion

Patients and physicians identified similar critical factors for consideration in facilitating screening mammography SDM. There is recognition of the need to understand a woman's individual breast cancer risk factors and associated screening guidelines based on this individual risk. However, whereas women trust their doctor's expertise in assessing these risk factors and applying associated guidelines to inform their recommendations, physicians reported using only minimal risk factors (most likely first degree relative history of breast cancer) to determine screening recommendations. This discrepancy reveals a critical gap in women's health care. As new SDM tools which incorporate risk estimates are developed and tested (10, 11) attending to this gap will be an important advance for population based mammographic screening. In the recently released American Cancer Society (ACS) guidelines for breast cancer screening of women at average risk, the authors highlight the fact that for women who are not in the highest risk group (known genetic mutations, prior personal history of breast cancer and prior chest wall radiation) but in an intermediate risk group there are no currently available risk based screening recommendations. (12). Moving to close these gaps in patient (13) and provider education on those with the highest, intermediate and low risk of breast cancer development will likely improve the shared decision making process for patients and providers.

While some women are comfortable being directed by their physician, many women expressed a desire to understand more about their individual risks, seeing this as important information in determining their personal need for screening. Physicians were in accordance with this objective, as they too want patients to know and understand their risks for breast cancer. Both the women and the physicians indicated that while familiar with common risk of family history, they have less familiarity with additional risk factors (e.g., breast density, smoking, obesity). Our study reinforces findings that better understanding of relevant risk

factors and how to evaluate them is warranted for physicians to be able to inform their patients (14).

While risk awareness can be a motivator, it can also be a barrier to screening. Understanding that a mammogram is important for your health by potentially detecting a serious health condition is a motivator; however associated fears of breast cancer can also be a deterrent. Physicians identified fear as a barrier to screening and women shared stories confirming that fear of cancer impacted their decision making. Striking a balance between knowing the importance of the screening and how to reduce the impact of fears is essential for implementing mammogram decisions. Such a balance relies on good communication, understanding the individual woman's fears (15) and values (6) and reflecting on the personal impact of the decision to address any avoidable barriers.

Women and physicians recognized that screening pros and cons can be a complicated discussion which can (and from a patient's perspective, should) require a significant amount of time during the clinical visit. Both women and physicians perceived value in the mammography discussion including preparation for the mammography experience itself and the aftermath (e.g., results, call-backs, positive findings). While some physicians described ways they educate their patients about such possibilities in the short time period allotted in a clinic visit, the women unanimously felt ill-prepared when called back for further imaging, echoing findings in the literature (15). Our findings reinforce research that women overwhelmingly wanted to know this possibility beforehand and felt understanding that false positives are a possibility would serve more as a reassurance when called back rather than a deterrent to initial screening (16, 17). These discrepancies between women's expectations for their healthcare providers and the provider's time restricted ability speaks to another critical gap. Furthermore, the decision for mammogram and satisfaction of that experience goes beyond the screening appointment and needs to include the consequences of getting results and potential for further imaging and even a cancer diagnosis.

There are some important limitations to consider in generalizing these findings. These findings represent a small sample size with a potential for sampling bias towards those who are aware of breast screening and potentially favor it, which was the general position of our participants. Therefore we are missing the perspective of those who do not know about screening or those who hold the perspectives that screening is unnecessary or prohibitively risky. Even so, this sample of women who are in favor of screening still gives rise to gaps in decision-making, and we can presume that women with less understanding would likely experience increased gaps.

This population represents a geographically and somewhat demographically limited sample. The women are insured (although many participate in the Wisconsin well-woman program, the Center for Disease Control supported screening program for under or uninsured women) and receiving care in an urban/suburban academic medical center clinic with an established primary care physician. The physicians are from an academic medical center, thus their perspectives may not be representative of community care center perspectives. However, even within this academic center, there is confusion of guidelines and low confidence in the ability to engage in individual risk recommendations. The gap may be even larger among

community physicians. Accordingly, these preliminary findings, albeit only part of the full picture, are clinically meaningful.

It is noteworthy that the screening mammography guidelines (USPSTF and ACS) have changed since data collection. However, perspectives regarding shared decision making and understanding of guidelines continue to have strong relevance as changes in guidelines are more likely to lead to increased confusion rather than clarity. Further, changes will spark a need for educating both physicians and their patients about what they are and why any changes were made in order to facilitate understanding of risks and best practices for any individual. Our result reinforces the need for easily accessible tools that increase provider awareness and facilitate the process of utilizing risk factors (14), guidelines and patient values in clinical practice for improved shared decision making at the point of service.

Conclusion

Our findings illuminate a critical gap in care delivery. Notably, with regard to individual risk factors and guidelines for mammography, patients expect primary care physicians to be experts, yet these physicians lack competencies and resources. Women want information on the logistics of the test and what to expect from results (especially false positives) and physicians rarely address this. Findings highlight the need not only for a shared decision tool to identify individual risk for breast cancer and clarify recommendations based on multiple individual risk factors, but also to facilitate a time efficient conversation between physicians and patients for true shared decision making.

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Table 1

Concordance and discordance in women's and physicians' perspectives on screening mammogram decision making.

Critical Area of Decision-making	Summary of Perspectives
Patient/Provider Concordance	
Preferred level of involvement in decision-making	Both identify and support patient preference for varying degrees of involvement in decision-making
Patient risk awareness	Both desire women to understand their risks
Patient/Provide Concordance and Discordance	
Preparation for mammogram process	Both see the value in preparing women for potential call-backs and next steps, however women report this does not happen whereas many physicians reported that they do discuss this
Patient/Provider Discordance	
Physician risk awareness	Many women trust their physicians are aware of risk factors; physicians are not always aware of all risk factors or using all risk factors in their discussions
Physician knowledge of guidelines	Many women trust their physicians understand guidelines and use them in directing their decision; physicians identify ambiguity regarding guidelines
Time and relationship issues	Women identify need for physicians to take time to listen to their concerns and answer questions; physicians report concern for time constraints and desire for efficiency in decision discussion