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Preferences for Communicating about Breast Cancer Screening among Racially/Ethnically Diverse Older Women

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Abstract

Differences exist across breast cancer screening guidelines regarding frequency of screening and age of discontinuation for older women (70 years) at average risk for breast cancer. These differences highlight concerns about the benefits and harms of screening, and may negatively impact older women's ability to make informed screening decisions. This study examined preferences for communicating about screening mammography among racially/ethnically diverse, older women. In-depth interviews were conducted with 59 women with no breast cancer history. Non-proportional quota sampling ensured roughly equal numbers on age (70–74 years, 75 years), race/ethnicity (non-Hispanic/Latina White, non-Hispanic/Latina Black, Hispanic/Latina), and

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education (high school diploma, >high school diploma). Interviews were audio-recorded, transcribed, and analyzed using NVivo 10. Thematic analyses revealed that rather than being told to get mammograms, participants wanted to hear about the benefits and harms of screening mammography, including overdiagnosis. Participants recommended that this information be communicated via physicians or other healthcare providers, included in brochures/pamphlets, and presented outside of clinical settings (e.g., in senior groups). Results were consistent regardless of participants' age, race/ethnicity, or education. Findings revealed that older women desire information about the benefits and harms of screening mammography, and would prefer to learn this information through discussions with healthcare providers and multiple other formats.

Keywords

breast cancer screening mammography; communication preferences; women; qualitative

Introduction

Among United States (U.S.) women, breast cancer is the most common type of cancer and the second leading cause of cancer-related death (Siegel, Miller, & Jemal, 2016). The goal of screening mammography is to detect cancers early, before they progress, when treatment is less toxic and the potential for cure is greatest. Differing recommendations for screening frequency and age of discontinuation for older women at average risk exist across published guidelines. The American Cancer Society suggests annual or biennial screening for women 55 years, and discontinuation of screening when life expectancy is <10 years (Oeffinger et al., 2015). In contrast, the U.S. Preventive Services Task Force suggests biennial screening for women 50–74 years, but makes an "I" Grade recommendation for those 75 years, citing insufficient evidence on the benefits and harms of screening (Siu & U.S. Preventive Services Task Force, 2016).

Little is known about the benefits of screening in older women, as most trials have not included women 75 years. However, the harms may outweigh the benefits, and evidence that screening adds to life expectancy or reduces mortality among older women is lacking (Walter & Schonberg, 2014). Potential harms include anxiety, pain, and complications from unnecessary follow-up tests (e.g., biopsies) after the detection of false-positive results (an abnormal finding that requires follow-up testing to prove that it is benign) or from unnecessary treatment due to overdiagnosis (detection of cancer through screening that would not have caused symptoms or death; Independent U. K. Panel on Breast Cancer Screening, 2012).

Differing guidelines and complex tradeoffs between the benefits and harms of screening might affect older women's ability to make informed decisions about whether or not to screen, frequency of screening, and when to discontinue screening (Pace & Keating, 2014; Walter & Schonberg, 2014). Moreover, women from underserved populations (e.g., racial/ ethnic minorities, low education) are at increased risk for misinterpreting screening guidelines (Peek & Han, 2004), and are thus, more likely to experience disparities in screening (Siegel et al., 2016).

Efforts are needed to explore strategies for communicating about breast cancer screening in diverse older women with varying education levels. Results will inform interventions focused on communicating about screening and will enhance older women's ability to make informed screening decisions. This is critical, as informed decision making considers empirical evidence and individuals' values and preferences (Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007; Volk, Llewellyn-Thomas, Stacey, & Elwyn, 2013). It is also related to better knowledge about screening guidelines and the benefits, risks, and limitations of screening; less decisional conflict and anxiety; greater satisfaction with the decision-making process and the decision; and active participation in decision making (Pace & Keating, 2014; Stacey et al., 2013; Volk et al., 2013).

This study was guided by the Integrative Model of Behavior Prediction (IMB; Fishbein, 2008), and used in-depth interviews with racially/ethnically diverse, older women with varying education levels to elucidate their communication preferences about screening mammography. This investigation is part of a larger study examining older women's motivations for screening, understanding of overdiagnosis, and preferences for communicating about screening.

Method

Procedures

Participants were recruited in Houston and Galveston, Texas via community outreach between May 2013 and May 2015. Eligibility criteria were: female; 70 years old; and no history of breast cancer. We used non-proportional quota sampling to ensure that the sample included roughly equal numbers in terms of age (i.e., 70–74 years, 75 years), education (i.e., high school [HS] diploma, >HS diploma), and race/ethnicity (i.e., self-reported Latina/Hispanic, non-Latina/Hispanic White, non-Latina/Hispanic Black). If women were eligible based on study criteria, research staff determined eligibility based on targeted quotas, such that five women were sought from each of the 12 categories related to age, education, and race/ethnicity. This approach is useful when recruiting underserved or difficult-to-reach populations, and facilitates the investigation of differences by sociodemographic variables (Morrow et al., 2007). Eligible participants were scheduled to complete face-to-face, individual, in-depth interviews. Of the 66 women who were screened, 59 were interested, eligible, and participated in an interview.

Interviews were conducted in English by a research coordinator using a semi-structured guide. Prior to the start of interviews, study procedures were described and participants provided informed consent. A co-author (a social scientist with over 30 years of qualitative experience) trained and supervised the research coordinator and ensured fidelity to the study protocol.

The larger study was informed by the IMB, a theory of behavior change suggesting that attitudes, perceived norms, and self-efficacy determine intentions, and intentions influence engagement in a behavior (Fishbein, 2008). The interview guide assessed key components of the IMB (i.e., attitudes [thoughts about screening and preferences for whether or not to engage in screening], perceived norms [beliefs based on others' expectations or others'

screening], and self-efficacy [ability to engage in screening and factors that influence screening]). Other factors (i.e., knowledge and skills to perform the behavior, importance of the behavior, environmental barriers, habits) that influence behavior were also included. Broadly, the guide assessed: 1) whether participants had ever had a screening mammogram; 2) knowledge about mammograms; 3) participants' decision-making process, including whether information about the benefits and harms should be communicated to older women; 4) preferences for discussing screening with healthcare providers; and 5) preferences for how the benefits and harms of screening, particularly overdiagnosis, should be communicated to older women. Participants were also asked to rate their general health as "excellent," "good," "fair," "poor," or "very poor." Interviews lasted between 30 and 60 minutes, and participants were compensated with \$25 gift cards. Study procedures were approved by the university's Institutional Review Board.

Data Preparation and Analyses

Interviews were audio-recorded, transcribed by a professional transcription service, and analyzed with QSR International's NVivo 10 software. Analysis used a qualitative descriptive approach (Sandelowski, 2000), which is rooted in principles of naturalistic inquiry, and provides rich descriptive content from participants' perspectives (Colorafi & Evans, 2016). Coding and analysis followed inductive and deductive approaches. An initial set of codes came from the interview topics, and additional codes were identified from concepts emerging from the data. The goal of coding was to capture as many concepts as possible and to explore patterns within and between transcripts to identify conceptual linkages or themes (Ryan & Bernard, 2003).

Two coders independently reviewed and coded all 59 transcripts. They met weekly with the second author (study PI) to discuss progress and to refine the coding scheme, as needed. Coding discrepancies were clarified and discussed to consensus. To ensure data dependability and confirmability, audits were performed regularly. In the current analyses, the following areas related to attitudes and preferences were coded: 1) preferences for whether or not information about the benefits and harms of screening mammography, particularly overdiagnosis, should be communicated to older women; 2) preferences for discussing screening with healthcare providers; and 3) preferences for how the benefits and harms of screening should be communicated to older women. In some cases, not all participants were asked all of the questions; our presentation of the results reflects these instances, with the denominator indicating how many participants were asked the question. Following thematic analysis, chi-square analysis was utilized to determine differences based on age, education, and race/ethnicity.

Results

Participant Characteristics

Fifty-three percent of participants were 75 years and 51% reported having >HS diploma. Regarding race/ethnicity, participants were 24% Latina/Hispanic, 41% non-Latina/Hispanic White, and 35% non-Latina/Hispanic Black. Only 5% of participants reported never having had a mammogram. Most (70%) reported either "excellent" or "good" health.

Thematic Results

Older women want to hear about the benefits and harms of screening—Most participants (80%, 45/56) reported that rather than being told to get mammograms, they wanted to hear about the benefits and harms of screening, as this information would inform screening decisions. One woman (75 years, non-Latina Black, HS diploma) said, "I'd rather for you to give me the information. Then, I'll decide. I don't want nobody to tell me nothing." Another (70–74 years, Latina, >HS diploma) stated, "I think I like the pros and cons. You know, I think we need to know that. Everyone has to decide on their own what they want."

Some (16%, 9/56) said that they preferred to be encouraged to have a mammogram rather than hearing about the benefits and harms of screening. One woman (75 years, non-Latina Black, HS diploma) said, "For now, I would prefer to just get the mammogram – to be encouraged to get it, and do it." Another (75 years, non-Latina White, >HS diploma) thought that older women be encouraged to get mammograms to "be on the safe side."

Older women should be given information about overdiagnosis—Most

participants (86%; 44/51) believed that women >70 who are considering screening mammography should be given information about overdiagnosis. One woman (75 years, Latina, HS diploma) said, "It [overdiagnosis] is very, very, very important." As a whole, participants noted that information about overdiagnosis may help older women make decisions about screening. For example, one woman (70–74 years, non-Latina White, HS diploma) stated that older women should hear about overdiagnosis so that they can "weigh all the options." Another woman (75 years, non-Latina Black, >HS diploma) said, "Well, I think they should be told [about overdiagnosis]. Because it might help them make decisions [about] whether or not to have any mammograms or not. That it could be more harmful than helpful."

Some (12%, 6/51) stated that older women should not be given information about overdiagnosis, as it might keep them from getting mammograms. One woman (70–74 years, non-Latina Black, >HS diploma) said that if women were provided with this information it might "scare somebody into not getting a mammogram." Another (75 years, non-Latina Black, >HS diploma) stated, "Don't be trying to tell people that they don't need help."

Older women want to learn about benefits and harms of screening from healthcare providers and through multiple other formats—Participants were asked about their preferences for hearing about the benefits and harms of screening. Although they listed various formats, most preferred to have this discussion with their physicians (69%, 35/51). Yet, many realized that their physicians were usually quite busy, and suggested that other healthcare providers could facilitate this discussion. One woman (75 years, non-Latina Black, HS diploma) stated, "I think it should always come from your doctor or a nurse or someone who's knowledgeable in that field." Another (70–74 years, non-Latina White, >HS diploma) said, "Probably through doctors… When you get older, you're not on a first name basis with your doctor, but you just see them more. I would think that the older people… they should trust and have confidence in their doctor."

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A number of participants (29%, 15/51) recommended that information about the benefits and harms of screening for older women be communicated via reading materials (e.g., brochures, pamphlets), and some suggested that this material be made available in physicians' offices. One woman (70–74 years, Latina, HS diploma) said, "Probably [brochures] at the doctor's office because if I want to know something that I read and I didn't know it, I could ask the doctor and he can explain it to me." Similarly, another woman (75 years, non-Latina White, >HS diploma) said, "I think by the doctor or by brochures – brochures that's easily read because most women – you mention breast cancer [and] they're gonna read it."

Some participants (14%, 7/51) expressed interest in learning about the benefits and harms of screening mammography through seniors' groups held in their physicians' offices, churches, or in senior living or community centers. For instance, one woman (75 years, non-Latina Black, >HS diploma) said, "Yeah, a church group would be great."

Many recommended that this information be communicated via multiple formats (e.g., discussions with healthcare providers, reading material, groups). One woman (70–74 years, non-Latina Black, HS diploma) suggested that it should be communicated through "doctors or the pamphlets that they pass out" or "those little health classes for seniors at the different senior groups – even at the nursing homes and then at the senior daycares." Another (75 years, non-Latina Black, >HS diploma) said, "If the pamphlets are there, it is fine, but if you're doing multiple ways of communicating and you're having a little seminar in the community, then a nurse can... certainly answer questions and give the information out."

Sociodemographic differences—Although potential differences according to age, education, and race/ethnicity were examined, thematic results did not differ on these variables.

Discussion

This study, which was guided by the IMB (Fishbein, 2008), examined attitudes and preferences for communicating about screening mammography in a racially/ethnically diverse sample of older women with varying levels of education. Rather than having physicians tell them to get mammograms, most preferred to hear about the benefits and harms of screening, including overdiagnosis, as this information would help inform their screening decisions. Participants suggested that this information be communicated via physicians or other healthcare providers, but indicated that it could also be included in brochures or pamphlets or presented in groups for seniors. We investigated whether results differed according to participants' age, education, or race/ethnicity; however, no differences were detected. Future research should investigate whether other factors such as health literacy influence communication preferences. Nevertheless, these results have critical research and practice implications, and could be used to inform strategies for communicating about screening mammography with older women.

Most women expressed interest in learning about the benefits and harms of screening mammography, rather than being told to get a mammogram. Little work has explored

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optimal ways of conveying information about screening harms and benefits to older women. In a recent review, Walter and Schonberg (2014) found that older women are typically not adequately informed about the benefits and harms of screening mammography, as these discussions can be difficult and are often time-consuming. When discussions are held, they often focus more heavily on the benefits rather than the potential harms of screening, a finding consistent with patients' reports of cancer screening discussions in general (Hoffmann & Del Mar, 2017). Thus, older women may overestimate the benefits and underestimate the harms of screening. Walter and Schonberg (2014) suggested that screening discussions focus on the fact that screening is a choice; healthcare providers should describe the benefits and harms of screening and elicit older women's values and preferences about screening. This will ensure that older women are equipped to make more informed screening decisions. Our results are in line with this work, but also suggest that older women may value some autonomy in decision making about screening. It is notable that some women reported a preference for being directed to get mammograms; efforts are needed to understand what might set these women apart.

Women expressed particular interest in learning about overdiagnosis as a potential harm of screening, citing that it would help inform future screening decisions. Notably, overdiagnosis is a principal harm of screening mammography in older women, because life expectancy decreases due to comorbid health problems, and there is a higher proportion of slower growing cancers in older adults (Welch & Black, 2010). Even so, it is difficult to accurately estimate the magnitude of risk of overdiagnosis in older women due to varying study designs. Efforts are needed to determine optimal ways of communicating this information to older women, as prior work suggests that this information is hard to explain and to understand (McCaffery et al., 2016).

Participants expressed interest in learning about the benefits and harms of screening from their physicians, but recognized that their physicians may be too busy to discuss this information with them. Thus, they indicated that they would be willing to have these discussions with other healthcare providers. The use of decision aids could be used to assist with shared decision making and communication about the benefits and harms of screening. Notably, training efforts to improve effective communication skills typically target physicians. While this is important, it is encouraging that women were amenable to receiving information about screening benefits and harms from other healthcare providers. Prior research supports the use of health professional team members to deliver high quality decision support (see Stacey et al., 2013).

In addition to learning about the benefits and harms of screening through patient-provider interactions, participants expressed a preference for learning this information via multiple other formats (e.g., reading material, classes, senior groups). These results have implications for the implementation of programs to engage older women in making decisions about screening, and highlight the possibility of leveraging existing infrastructure, such as community partnerships. As McCaffery et al. (2016) suggested, mass media or direct-to-consumer campaigns might be fitting, as these efforts can influence large numbers of people simultaneously and promote long-lasting behavior change.

This study has several limitations. First, since participants were from southeastern Texas, results may not represent the views of all older women; yet, the sample was large and diverse, consisting of roughly equal numbers in terms of age, education, and race/ethnicity. Second, we only included interviews conducted in English. English- vs. Spanish-speaking Latina/Hispanic women may have different communication preferences. Third, some participants were not asked all of the questions due to changes in the interview guide, the interviewer overlooking a question, and because one question was a probe; this occurred in less than 14% of the interviews.

Conclusions

Racially/ethnically diverse older women with varying levels of education were interested in receiving information about the benefits and harms of breast cancer screening, rather than being directed to have screening mammograms by their physicians. Ensuring that clinicians and other healthcare providers are prepared to have these conversations with older women is a priority for future research. Similarly, efforts are needed to consider strategies such as involving community groups or working with churches, as they may represent a more feasible approach to engaging older women in decision-making about breast cancer screening and prepare them for conversations with their healthcare providers.

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