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Resistance to Discontinuing Breast Cancer Screening in Older Women: A Qualitative Study

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Abstract

Objective—Screening mammography is associated with reduced breast cancer-specific mortality; however, among older women, evidence suggests that the potential harms of screening may outweigh the benefits. We used a qualitative approach to examine the willingness of older women from different racial/ethnic groups to discontinue breast cancer screening.

Methods—Women ≥70 years of age who reported having a screening mammogram in the past three years and/or reported that they intended to continue screening in the future were recruited for in-depth interviews. Participants who intended to continue screening were asked to describe how

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Conflict of Interest

The authors have no conflicts of interest to disclose at this time.

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the following hypothetical scenarios would impact a decision to discontinue screening: health concerns or limited life expectancy, a physician's recommendation to discontinue, reluctance to undergo treatment, and recommendations from experts or governmental panels to stop screening. Semi-structured, face-to-face interviews were audio-recorded. Data coding and analysis followed inductive and deductive approaches.

Results—Regardless of the scenario, participants (n=29) expressed a strong intention to continue screening. Based on the hypothetical physician recommendations, intentions to continue screening appeared to remain strong. They did not envision a change in their health status that would lead them to discontinue screening and were skeptical of expert/government recommendations. There were no differences observed according to age, race/ethnicity, or education.

Conclusions—Among older women who planned to continue screening, intentions to continue breast cancer screening appear to be highly resilient and resistant to recommendations from physicians or expert/government panels.

Keywords

aged; breast cancer; cancer; cultural diversity; early detection of cancer; race/ethnicity; oncology; qualitative; women

BACKGROUND

In the United States (U.S.), 63% of adult women aged 65 years and older report having had a breast cancer screening mammogram in the past two years.[1] Even among women 75 years and older, screening mammography is common, with over half (51.5%) reporting screening in the past two years. While breast cancer screening mammography is associated with reduced breast cancer-specific mortality in women aged 50 to 74 years,[2] evidence suggests that for older women, the harms of screening may outweigh the benefits.[3,4] Professional guidelines are inconsistent in how they address breast cancer screening in older women. Concerns about potential harms of screening (e.g., false positives, overdiagnosis, overtreatment) contribute to the notable differences in published screening guidelines for women over the age of 70.[3–7] For example, the American Cancer Society (ACS) offers a qualified recommendation to discontinue screening mammography for women aged 55 years and older when life expectancy is less than 10 years.[8] The U.S. Preventive Services Task Force (USPSTF) provides a Grade I (insufficient evidence) recommendation for women aged 75 years or older.[9]

Differences in U.S. breast cancer screening guidelines have led to contentious debate among experts, policy makers, and the general public. In 2009, the updated USPSTF mammography guidelines, which recommended screening every two years starting at age 50, was met with such public and political resistance that during the development of the Patient Protection and Affordable Care Act (ACA) a coverage exception was granted exclusively for breast cancer screening.[10,11] This dialogue surrounding screening coverage highlights persistent concerns regarding the challenges associated with communication about both the benefits and harms of screening.[4,10,12,13] As disagreement surrounding guidelines is hardly a new phenomenon, it may be particularly difficult for women over the age of 70 to determine their optimal

screening schedule as they may be susceptible to some of the effects associated with aging, such as multiple comorbidities, competing mortality causes, decreased physical functioning, and individual preferences based on quality of life factors.[10,14–18]

The current study used a qualitative approach to examine racially/ethnically diverse, older women's perceptions about breast cancer screening discontinuation. This is part of a larger project that investigated older women's motivations for either continuing or discontinuing screening, their understanding of the concept of overdiagnosis, and their preferences for communication about screening. Specifically, this project explored circumstances that might lead older women from diverse racial/ethnic groups who intend to continue screening to consider discontinuation of screening and possible resistance to discontinuation.

METHODS

Study Design

Participants were identified and recruited using community outreach in Houston and Galveston, Texas between May 2013 and May 2015 as part of a larger study. Eligibility criteria were: female; at least 70 years old; and no personal history of breast cancer. A non-proportional quota sampling technique was used to ensure that the sample consisted of participants with roughly equal numbers in age (i.e., 70–74 years, ≥75 years), race/ethnicity (i.e., Non-Hispanic White [NHW], Non-Hispanic Black [NHB], Hispanic/Latina), and educational attainment (i.e., ≤high school diploma or GED, >high school diploma or GED). If participants were eligible based on screening criteria, research staff determined eligibility based on meeting targeted quotas for age, race/ethnicity, and educational attainment. Non-proportional quota sampling is useful when recruiting participants from populations that are traditionally underrepresented in research, such as racial/ethnic minorities or those with low education, and enables researchers to investigate differences by variables of interest.[19] Eligible participants were scheduled to participate in individual, in-depth interviews.

Procedure

This study was guided by the Integrative Model of Behavior Prediction (IMB), a behavior change theory suggesting that attitudes, perceived norms, and self-efficacy influence intentions, and intentions influence engagement in a particular behavior.[20] Semi-structured interview questions were developed iteratively and pilot tested by two researchers with extensive qualitative experience (KS and SW). Face-to-face interviews were conducted and audio-recorded at locations convenient for participants (e.g., senior living facilities, community centers, churches, a geriatric clinic) by a female research assistant with experience in conducting qualitative research. During the interviews, participants were asked whether or not they had ever had a screening mammogram and, when applicable, were probed on their intent to continue breast cancer screening in the future. Of the 59 total participants, 29 women who intended to continue screening were included, of which the majority had been screened recently (≤3 years; n=26). Interviews lasted approximately 60 minutes.

Participants were asked about circumstances, based on questions developed by Torke et al.,[16] that would lead them to stop having breast cancer screening mammograms, using eight scenarios: 1) having other medical conditions; 2) having severe memory problems; 3) living in a nursing home; 4) having a life expectancy of less than 5 years; 5) recommendations by experts or governmental panels; 6) if doctor said they would not live long enough to benefit; 7) if doctor said mammogram would not make them live longer; and 8) if they were not willing to undergo treatment for breast cancer (Table 2). In addition, participants were asked to rate their health as very poor, poor, fair, good or excellent.

The University's Institutional Review Board (IRB) approved this study (IRB Number: 13-0289). All study participants provided verbal informed consent to participate and were compensated for their time with gift cards.

Qualitative Data Analyses

Recorded interviews were transcribed verbatim using a professional transcription service and analyzed using QSR International's NVivo 10 software. Analysis used a qualitative descriptive approach, as described by Sandelowski.[21,22] This approach is rooted in principles of naturalistic inquiry and provides rich descriptive content from participants' experiences and perspectives.[23] Coding and analysis followed a deductive approach. Codes were defined using a structured codebook.

Perspectives on discontinuing mammography screening using the eight scenarios were coded by the research assistant and the study PI (MRP) into the following categories: *yes* (if the scenario would make them stop screening using a mammogram), *no* (if the scenario would have no effect on their continuation), *maybe* (if a particular scenario may stop them getting a screening mammogram based on any conditions they may have expressed in the interview), *I don't know* (if they were not sure if the scenario would stop them from getting a screening mammogram), and *not applicable* (if the participant did not answer the questions or the scenario was not presented to the participant).

Themes, subthemes, and quotations were checked for coding consistency by the study PI (MRP) and a coder (SK) by reviewing the transcripts and the coded data. Any coding disagreements were resolved through discussion until the primary coders (MRP and SK) and a third coder (SW) reached consensus. Moreover, the three coders performed coding and data audits to ensure qualitative rigor. Potential differences according to age, education, and race/ethnicity were examined.

RESULTS

Participants

Of the 29 participants, 18 (62%) were between the ages of 70–74 years (Table 1). Most (41%) were NHB, approximately one-third (31%) were NHW, and one-third (28%) were Hispanic/Latina. Just over half (52%) were categorized as "high" education (>high school diploma or GED), and most (69%) stated that their health was either "excellent" or "good." For the purposes of this analysis, the eight scenarios have been clustered into four thematic scenarios: 1) health status and life expectancy, 2) doctor's recommendation, 3) preferences

for treatment, and 4) expert/governmental panel recommendation. It should be noted that there were no significant thematic differences according to age, race/ethnicity, or education.

Health Status and Life Expectancy Scenarios

Having other medical conditions—Nearly two-thirds of participants reported that they would continue screening even if they were diagnosed with a medical condition other than breast cancer. For example, one woman (P5, 73 years, NHB, High Education) stated, "Well I don't think anything would make me stop. I can't think of any ailments that would make me stop." Similarly, another woman (P50, 74 years, Hispanic/Latina, Low Education) said, "Would it [other conditions] stop me? No."

Experiencing severe memory problems—Participants reported that they would not consider discontinuing screening even if they began experiencing severe memory problems. Instead, they reported that they would continue screening and believed that their families would support this decision. One woman (P27, 75 years, NHW, High Education) stated, "… my daughter would insist [that I continue screening]. She is a nurse and she insists…" Another woman (P58, 80 years, Hispanic/Latina, High Education) said, "No [I would not stop mammograms] because [I would do] anything that is going to help me. Memory has nothing to do with… cancer." One woman (P51, 80 years, NHW, Low Education) noted that she already experienced difficulty with her memory, and that this did not keep her from getting mammograms. She said, "I have memory problems, they don't stop me from having them [mammograms], you know."

Living in a nursing home—More than half of participants stated that living in a nursing home would not prevent them from continuing to get screening mammograms. They cited that routine and family obligation were reasons to continue. One woman (P4, 78 years, NHW, Low Education) stated, "Yes, if they thought it [mammogram] was a routine, a precaution or early detection of anything. I wouldn't care if I was 100. If they thought well this [mammogram] is something we still do because it's [cancer] still happening to older ladies, I would say go ahead, do it." Another woman (P62, 71 years, NHB, High Education) said, "… I just hope that if I'm not able [to get a mammogram], if I have dementia or whatever, my daughters will help me, take me through that."

Life expectancy of less than five years—Participants stated that they would continue to get screening mammograms even if they had less than five years to live. For instance, one woman (P61, 70 years, NHW, High Education) said, "Knowing that there might be a possibility, no matter what age you are or what year it is, that it could… [be cancer]… I would still, I believe at this point, want to have it [a mammogram] done." Another woman (P49, 75 years, Hispanic/Latina, Low Education) expressed her motivation to continue screening as a way of preventing or delaying death, "You fight for your life… Any way, anywhere…"

Doctor's Recommendation Scenarios

Being told they would not live long enough to benefit—Participants were reluctant to consider changing their screening behaviors based solely on a doctors' recommendation

that they would not live long enough to benefit. One woman (P7, 72 years, Hispanic/Latina, High Education) stated, “No because they [doctors] don’t know. They don’t know when my expiration date… only that one [God] knows when my expiration date is up.” Moreover, another woman (P62, 71 years, NHB, High Education) said, “No. It wouldn't influence me, because nobody can't say who going to live and who not going to live. That's in God's hands.”

Being told screening would not extend life—Participants indicated that they would continue mammograms even if a physician told them that it would not increase their life expectancy. These participants said that they might even question the doctors’ advice. One woman (P61, 70 years, NHW, High Education) said, “Just because that doctor says it does not mean that's the gospel. If it's not going to hurt you, you're not taking any medicine, it's just someone examining you. I would want to have it done.” Another woman (P20, 73 years, NHB, High Education) stated, “I just cannot imagine a doctor saying that a test would not prolong your life.”

Preferences for Treatment Scenarios

Not be willing to undergo treatment for breast cancer—Participants responded that they would continue screening mammograms even if they did not plan to undergo treatment. One woman (P34, 76 years, NHB, Low Education) said, “No, I don’t think it [not willing to undergo treatment] would [stop me from getting mammograms].” Another woman (P62, 71 years, NHB, High Education) said that even if she did not want to undergo treatment, “I would have the mammogram, yeah.”

However, others stated that they expected to undergo treatment if diagnosed with cancer; therefore, they had difficulty answering the question about how refusing to undergo treatment would influence their future screening behaviors. As one participant (P27, 75 years, NHW, High Education) said, “Well, I would have treatment… I can’t [answer if I would stop screening].” Another woman (P41, 79 years, NHB, Low Education) stated, “…If I had it [cancer], I would not be a person who would not want it treated.”

Expert/Governmental Panel Recommendation Scenario

Expert/governmental panel recommendations are to discontinue—Participants appeared to be somewhat skeptical of experts and governmental panels, and reported that they would continue screening, even if it conflicted with expert or panel recommendations. As one woman (P27, 75 years, NHW, High Education) stated, “Government panels aren’t always correct.” Another woman (P50, 74 years, Hispanic/Latina, Low Education) stated, “If I wanted to have it, and I felt that I needed it, I would have it.” A number of participants indicated that they “might” consider discontinuing screening due to expert or panel recommendations. One woman (P20, 73 years, NHB, High Education) stated, “It would probably depend upon the panel or whatever, because they wouldn’t know me personally. I’d still stick with my doctor.” Similarly, another woman (P21, 78 years, NHW, High Education) said, “I suppose [I would consider recommendations by experts or governmental panels], but I am not sure I trust [the experts or panels].”

DISCUSSION

This study adds to the growing body of literature on cancer screening discontinuation by exploring racially/ethnically diverse older women's perceptions about breast cancer screening discontinuation. Regardless of the scenario, participants who reported previously having had a mammogram and planned to continue having future mammograms reiterated that they intended to continue screening. Participants were asked to consider how they would react if a doctor said they would not live long enough to benefit from a mammogram and if a mammogram would not make them live longer. Based on their responses to the doctor's recommendation scenarios, most intended to continue screening. There were no differences observed according to age, race/ethnicity, or education.

Overall, participants were resistant to any scenario to discontinue screening mammograms. Existing literature shows that older adults plan to continue cancer screening for various reasons. For example, Gross et al. found that older men and women plan to continue screening even with multiple comorbidities.[24] Similarly, Lewis and colleagues reported that both men and women plan to continue cancer screening as they age, and that physicians can influence the decision making process through the use of individualized conversations with their patients.[25,26] Moreover, Schoenborn et al. found that older men and women seemed to be open to discontinuing cancer screening when given the opportunity to discuss it with a trusted clinician, and sought opportunities for individualized conversations about screening.[27] Schonberg et al. reported that older women expressed continued enthusiasm and commitment to breast cancer screening[18] and physician recommendation, habit, and reassurance motivated women to continue screening.[28] Our findings from a tri-ethnic sample of women further support the importance of physician discussions of screening discontinuation, specifically for breast cancer screening.

Physicians and other health care providers play a vital role in the breast cancer screening decision making process. Older adults often seek to engage in discussions with their physicians in order to weigh the potential benefits and harms of screening.[26] Emerging findings show that older adults frequently seek opportunities to discuss cancer screening with their physicians.[26,27] In a separate analysis of these participants, Hoover and colleagues found that older women wanted the opportunity to hear about the benefits and harms of breast cancer screening from their physician or another health care provider.[29] Additionally, Pappadis et al. found that older women demonstrated a limited understanding of the downsides associated with continued screening, like overdiagnosis[30] Our findings build on this prior work and highlight the role of physicians in screening decision making. Even though women intended to continue screening, they were willing to discuss breast cancer screening discontinuation in the two doctor's recommendation scenarios. Therefore, strategies that incorporate individualized, tailored conversations between physician and patient may not change screening intentions but may be a way to enable more informed, higher quality decision making.[26]

We found that participants reiterated their beliefs and feelings of commitment to undergoing breast cancer screening, which may be in conflict with current guidelines. Thus, physicians may benefit from strategies that provide a way to discuss guidelines with patients as a way

to implement current clinical guidelines into practice.[31,32] This may be addressed by engaging women in a tailored strategy that incorporates their personal values and beliefs as they assess the benefits and downsides of continuing breast cancer screening as they age.[18] Using a shared decision making strategy can allow women to discuss their values and to weigh the complex tradeoffs between different, viable options.[33–40] Decision support tools have been found to support shared decision making in screening mammography in women aged 75 years and older.[17] These women reported improved screening knowledge, greater satisfaction regarding patient-provider screening communication, and lower screening intentions when life expectancy was considered.[17] However, discussions surrounding life expectancy are sensitive in nature and older adults may be reluctant to discuss life expectancy when making decisions about screening discontinuation.[27] As a result, developing tools that elicit an individualized discussion regarding guidelines, benefits and downsides of screening, and personal values may facilitate higher quality patient-provider conversations.

Study Limitations

This study has several limitations. First, this investigation included only English speakers. Thus, findings may not be generalizable to those who speak Spanish or other languages. Second, the sample may not be fully representative of women in the general population; however, our use of non-proportional quota sampling ensured that the sample was diverse in race/ethnicity and educational attainment. Third, although we assessed perceived health status, we did not assess whether or not participants had specific health conditions. It is possible that specific comorbidities may play a unique role in screening decision making of older women and may warrant further investigation. Finally, due to the iterative nature of semi-structured interviews, not all participants were asked all of the questions. Future work should assess the impact of randomly assigned screening discontinuation messages during real physician-patient exchanges among women who wish to continue screening. The use of hypothetical scenarios may provide insight into one’s beliefs, but is not a substitute to actually knowing how a woman would respond when faced with a discontinuation message by her physician.

Clinical Implications

Findings suggest that physicians or other healthcare providers should discuss the benefits and harms of screening with older women; however, older women may seek to continue screening mammograms even if they have a shared decision-making conversation with their provider. Intention to continue screening mammograms appears to be resilient among women who plan to continue screening as they age. Future efforts to identify how to best communicate screening discontinuation when the risks may outweigh the benefits in older women are needed.

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Table 1

Demographic Characteristics.

Demographic Characteristic n=29	Total n (%)
Age in years, Mean (SD)	74.5 (4.1)
70–74 years	18 (62.1)
≥ 75 years	11 (37.9)
Race/ethnicity	
Hispanic/Latina	8 (27.6)
Non-Hispanic Black	12 (41.4)
Non-Hispanic White	9 (31.0)
Education	
Low Education[†]	14 (48.3)
High Education[‡]	15 (51.7)
Health Status	
Fair	9 (31.0)
Good	16 (55.2)
Excellent	4 (13.8)

Note: All results are presented as number and percentage unless noted otherwise.

[†]Low education was defined as completing high school or less

[‡]High education was defined as education beyond high school

Abbreviations: SD=standard deviation.

Table 2

Hypothetical Scenarios about Discontinuing Mammograms.

What circumstances would lead you to stop having mammograms?
Health Status and Life Expectancy
1. Having other medical condition
2. Having severe memory problems
3. Living in a nursing home
4. Having a life expectancy of <5 years
Doctor's Recommendation
5. Doctor said you would not live long enough to benefit
6. Doctor said mammogram would not make you live longer
Preferences for Treatment
7. Not willing to undergo treatment for breast cancer
Expert/Government Recommendation
8. Screening recommendations by experts or governmental panels