Repeat Mammography Screening Among Low-Income and Minority Women: A Qualitative Study

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Regular mammography screening can reduce breast cancer mortality. Yet, low-income African American and Hispanic women underutilize mammography screening and are often diagnosed at a later stage, resulting in increased mortality. We used qualitative research methods to identify factors influencing regular breast cancer screening among African American and Hispanic women. Predisposing factors (including fear of mastectomy and lack of knowledge), enabling factors (including cost and social support) and a reinforcing factor were identified and categorized utilizing the PRECEDE framework. The study identified factors associated with the decision to complete regular mammography screening, and examined differences between African American and Hispanic women who participated in the interviews. Future research should seek to better understand the influence of family/friends, risk perception, and fatalistic beliefs on the decision to obtain regular mammograms.

Introduction

In the United States, African American and Hispanic women suffer disproportionately from breast cancer. Compared with non-Hispanic whites, they both have lower breast cancer survival rates. African American and Hispanic women are more likely than white women to be diagnosed with breast cancer at a later stage, resulting in lower breast cancer survival rates. Mammography is associated with reductions of breast cancer mortality and is most effective when women have regular screenings every 1 to 2 years. However, African American and Hispanic women underutilize regular, repeat mammography screening. Currently, the repeat screening rate in the United States is only 41% for African American women and 52% for Hispanic women, compared to 58% for non-Hispanic white women.

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general population of women is approximately 46% in the United States. Six studies with medically underserved samples found the repeat screening rates for these women to be 5% and 10%.

The ENCOREplus program, a breast and cervical cancer education program aimed at reaching older, low-income, and minority women through the YWCA community centers in over 78 YWCA sites in 30 states, has had considerable success in encouraging mammography screening among women previously nonadherent to screening guidelines. However, in a recent study of women who were initially screened through the program and were due for a repeat mammogram, only 28% had obtained a repeat mammogram screening.

Although studies have tried to identify the factors related to mammography screening, only a few have examined the determinants that are specifically associated with repeat screening. These studies show that women who are white, have higher levels of education, are born in the United States, have higher income, have regular physician visits, have a family history coupled with a perceived vulnerability to breast cancer, and receive physician recommendation are more likely to engage in repeat screening. Additionally, several studies report that anxiety, embarrassment, concerns about cost, fear of radiation, and low perception of breast cancer risk act as barriers to repeat screening.

The overall purpose of this study was to identify factors influencing repeat mammography screening among low-income African American and Hispanic women.

### Methods

Focus groups and in-depth personal interviews were conducted to assess ideas, opinions, and perceptions about mammography screening. Grounded theory, a method that creates theoretical categories out of collected data, was used to guide the focus groups and the personal interviews. With this approach, data collection, analysis, and interpretations are actually rooted in the observed data and not in predetermined hypotheses. An important element of grounded theory is that data collection and analysis occur simultaneously, allowing for the flexibility to follow-up on ideas as they develop during the research.

### Sample and Setting

Focus groups and in-depth interviews were conducted in San Antonio and Houston, Texas, and in Albuquerque, New Mexico, between August and December of 2000 (Table 1). For recruitment purposes, we collaborated with the YWCAs in San Antonio and in Albuquerque. Women over 50 years of age who had received a repeat mammogram within the past year (considered adherent) and those who were overdue for a repeat mammogram (considered non-adherent) were recruited to participate in the study. In Houston, we recruited participants from a senior center by placing announcements at a predominately African American apartment complex community center.

Fifty-eight women participated in this study (Table 1). We conducted five focus groups and two in-depth personal interviews with Hispanic women, and three focus groups and two in-depth personal interviews with African American women. Focus groups and interviews lasted approximately 1 hour. As an incentive, participants were offered a light meal and a payment of $15.00. We also obtained from each participant a written consent to participate.

### Data Collection

The focus group guide included a series of open-ended questions and prompts about breast cancer, prior mammography experience, barriers, general health, and health care availability and experiences. After the initial interviews, the guide was modified for the subsequent interviews to include additional questions and explore the themes that had surfaced. All moderators were women of the same racial/ethnic background as the focus group participants and the interviewees. By request, all Hispanic focus groups were conducted in Spanish.

### Data Analysis

Audio tape recordings of the focus groups and of the in-depth interviews were transcribed and Spanish language transcripts were translated. We then entered the docu-
ments into the NUD*IST 4 computer software, which is a qualitative data management program, to facilitate data manipulation and retrieval during analysis (Non-numerical Unstructured Data Indexing Searching & Theorizing, QST International, Melbourne, Australia). Transcripts were independently reviewed by each member of the research team who identified initial themes. After initial identification of themes, the team reexamined the data and identified additional constructs, reorganized and labeled existing themes, and described relationships between themes. As analysis proceeded, certain themes emerged that were supported by current theoretical and empirical health behavior literature utilized to explain mammography screening and repeat screening.12,16,18,19 To assist in data-reporting, themes were categorized by types of factors that influence repeat mammography screening. We used categories of factors consistent with the PRECEDE model,20 which include predisposing, enabling, and reinforcing factors. Specifically, predisposing factors include knowledge, attitudes, beliefs, and perceptions, enabling factors include resources and barriers, and reinforcing factors are events that occur after the behavior and make the behavior more likely to recur.

Results

Themes emerged that revealed similarities and differences between adherent and nonadherent women and between African American and Hispanic participants. Table 2 shows themes by adherence status and racial/ethnic group.

Predisposing Factors

Knowledge About Mammography Screening: Compared with women who did not follow mammography guidelines, those who did knew more about mammography screening and understood the guidelines better, irrespective of race/ethnicity. To describe the purpose of mammography screening, adherent women made statements such as “for the early detection of breast cancer.” One Hispanic participant said, “I think they [mammograms] are very important, because without the mammogram you could have breast cancer and not know it. It could spread.”

Women who did not adhere to mammography guidelines were uncertain about screening recommendations. For example, a Hispanic participant said, “It’s only one time.” This statement was the typical belief of many

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<th>Theme</th>
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Table 2. — Major Themes by Racial/Ethnic Group and Adherence Status
women who had an initial mammogram but had not had a repeat screening. Additionally, they had more misconceptions about mammography screening. One Hispanic participant said, "I have also heard that you should not get the mammography, because of the squish." Some Hispanic women in the nonadherent focus groups said that since they examined their own breasts and never found anything wrong, they did not need a mammogram.

**Outcome Expectations:** All groups of adherent women believed that getting regular mammograms would help them stay healthy by enabling them to detect and treat cancer early. They expressed the belief that when found early, breast cancer was treatable and survivable. One African American woman said, "...the earlier you catch it, the better your chances of living." Conversely, nonadherent women did not mention the benefits of regular mammography or early detection.

**Cancer Beliefs:** The belief that breast cancer always results in death also emerged primarily among African American and Hispanic women who were nonadherent to mammography screening guidelines. Throughout our discussions with study participants, many women shared vivid experiences of watching family and friends die of breast cancer. These personal experiences influenced their beliefs and opinions about the survivability of breast cancer. One African American participant said, "They say that cancer is one of the number one killers in women. So when I think of breast cancer which is in women, then okay, if you get it, you die." Another African American woman said, "Basically you feel that once you get it [breast cancer], hey, I'm not going to be here long anyway." A Hispanic woman said, "Well, whether she knows it or does not know it, she is going to die." Nonadherent women also said that they would prefer not to know if they had cancer.

**Perceived Susceptibility:** Generally, women who were adherent felt at risk for breast cancer, whereas those who were nonadherent did not. Women with previous family history of breast cancer or any other cancer felt at increased risk. In discussing her family history, one adherent African American woman said, "I think I'm at risk because it's in my family. It's right there for sure [points to her breast]." An adherent Hispanic woman said, "My mother had cancer. I am in more danger and I have to do them [mammograms] always. I have to take care of myself." Knowing someone who died of breast cancer was another factor that seemed to influence perceived risk. Adherent women discussed the deaths due to breast cancer of family members and friends. In an African American adherent focus group, a participant described her experience with a close acquaintance. She stated, "This lady had breast cancer and it took off her breast and then they took off the other breast and then that lady died. That is why I keep on getting my mammogram."

**Pain:** Women in both adherent and nonadherent groups made comments about the pain and discomfort associated with mammography. Pain was discussed as a significant barrier for repeat screening only among women who were nonadherent. They typically described the pain as excessive, whereas adherent women did not. In describing her experience, one African American woman said, "When I got in there and they were doing what they were doing, giving me some torture, I vowed never to go back again. It was really horrible. Horrible! Horrible!" Another nonadherent African American woman said, "It was very painful because they mash down on you, it mashes and pulls on you." Nonadherent Hispanic women also talked about the discomfort of having their breast "squeezed." Some said they had heard that this could cause breast cancer.

**Procrastination:** A central theme that emerged from participants who were both adherent and nonadherent was delaying or putting off mammography screening. Several participants said they had not had a repeat mammogram because they simply kept putting it off. A nonadherent Hispanic participant said, "It's just procrastination (desidia), thinking that you feel fine, that you are fine and you say tomorrow, then the next day, and the days go by ...."

**Fear of Mastectomy:** A discussion topic that occurred only in the African American focus groups, among both adherent and nonadherent women, was fear of mastectomy. One participant described the idea of having a mastectomy as "you are less of a woman." Other fears about mastectomy pertained to losing their intimate partner. One nonadherent participant said, "Well, you kind of wonder how you would look again. You know how you would feel because that's a part of being female. You kind of like wonder especially if you have a husband, how he would react, you know, how he would see you."

**Enabling Factors**

**Accessibility:** Hispanic women in both adherent and nonadherent groups described difficulty navigating the healthcare system and accessing mammography services. This was more pronounced among nonadherent Hispanic women who were confused about what was needed to get a mammogram. They were unsure about who to contact and/or whether a referral was needed. Among African American women these issues did not emerge. In general, adherent women described using both private health care and public clinics to obtain mammograms and usually obtaining repeat mammograms at the same clinic.

**Cost and Insurance:** Although participants in all focus groups discussed issues related to insurance for screening and cost of mammography, these factors emerged as barriers to screening primarily among nonadherent women. A nonadherent African American participant said, "Why would I go and have a mammogram and pay this amount of money when I'm trying to pay my bills? There's nothing wrong, you know, and it's like you go when you get sick. If you're not sick, then you don't go." Similarly, a Hispanic woman said, "I never had a mammo-
program because it was very expensive.” Other Hispanic women also talked about problems qualifying for programs offering low-cost mammograms. Several nonadherent women without insurance said they postponed screening because of lack of insurance. Women in nonadherent focus groups who had previously been covered by health insurance said they delayed getting a mammogram in hopes of obtaining insurance again. One Hispanic participant in the nonadherent group said, “I have to go again, but I don’t have insurance. I have to wait again for it before I can go.” Some women noted that they had had their previous mammogram because it was free (obtained at a local health fair or a visiting mobile van) and did not get a subsequent mammogram because they were not free. Adherent women were much more likely to have health insurance that paid for their mammogram. However, even some women with insurance expressed concerns about the rising costs of copayments. One adherent African American woman said, “I have insurance and it is still too expensive.”

Time/Conflicting Priorities: Some participants in the African American focus groups said they were too busy to have a mammogram. Women cited family obligations as an important factor in preventing them from having a mammogram. Even adherent women noted reasons for delaying mammograms. One adherent participant said, “Sometimes, you can’t go to the doctor because you got to go and take care of somebody else. We put it off and say I’m gonna do it next week, next week. “ The issues of time/conflicting priorities did not come up in Hispanic focus groups.

Cues to Action: Moderators asked focus group participants if a reminder or prompt was important for mammography screening. Both African American and Hispanic adherent women said they received either a telephone call or a written reminder (letters or postcards) to have a mammogram. They said reminders were “helpful.” These reminders came from physician offices, health insurance companies, or mammography facilities where they had obtained their last mammogram. One focus group participant summarized the thoughts of many: “One of the reasons why I am good about getting the mammogram is because I get a letter in the mail telling me that I am due. If that letter had not come to me, I probably wouldn’t have a mammogram.” Hispanic women also said that having a friend or family member remind them also served as a cue. Nonadherent women said that they had not received any reminders.

Health Care Provider Recommendation: Participant discussions showed that interactions with a physician or a nurse played an important role in having initial and repeat mammograms. This occurred for both adherent and nonadherent women. An adherent Hispanic participant stated, “The nurse from the clinic spoke with me and asked...she told me that she was going to set up the appointment.” Other adherent participants made statements describing the influence of health care providers, such as, “I didn’t want to go until my doctor just insisted that I go.”

Social Support: Study participants described various levels of support or encouragement provided by family and friends. Findings showed that adherent participants were comfortable about discussing health issues with female relatives and friends and had received support from them. Conversely, among nonadherent women, the discussion revealed that women felt that personal health issues were private and should not be discussed. An issue emerged in Hispanic focus groups (but not African American focus groups) regarding husbands who do not want their wives going to the physician for preventive examinations. One participant stated, “My husband is jealous and says that I will not go, but I do go. I’m sorry, but I do go.” Another participant said, “My husband gets mad for a while but one way or another I tell him it helps.”

Reinforcing Factors

Peace of Mind: In general, women who followed recommended screening guidelines said that they returned for a repeat mammogram because they wanted to have “peace of mind.” Although African American women generally expressed relief after receiving negative results, they did not specify “peace of mind” as a motivator for repeat screening. However, several Hispanic participants who followed screening guidelines noted that the peace of mind they felt after receiving negative results from their prior mammogram motivated them to have repeat mammograms.

Discussion

Since repeat screening rates for African American and Hispanic women are less than adequate, the identification of factors influencing repeat screening is an important area of continued research and intervention.7,8 Our findings indicate that a broad set of cognitive and attitudinal components, as well as interpersonal, community, and societal level factors, are involved in the decision to have a repeat screening examination. These factors greatly influence both the decision to seek screening and the ability to access screening services.

Although African American and Hispanic women shared many influencing factors, some notable differences between the groups existed. The fear of mastectomy and such barriers as lack of time and conflicting priorities were themes that surfaced solely among the African American focus groups. Factors discussed only among Hispanic women were difficulties in navigating the health care system and a lack of social support from husbands or male partners.

Hispanic women also discussed “peace of mind” after a mammogram as a reinforcing factor. Intrinsic and extrinsic reinforcement is important for continued behavior.21
The fact that most women failed to mention any sense of personal satisfaction or external reinforcement (eg, providers/family reinforcement, rewards/incentives) needs further investigation and may indicate an important strategy to include in future screening interventions.

Several themes seemed to differentiate the adherent from the nonadherent women. Adherent women were more likely to feel comfortable discussing mammography and have a greater knowledge about mammography screening, more positive outcome expectations regarding early detection, and higher perceived susceptibility to breast cancer. By contrast, nonadherent women were more likely to have cancer misconceptions, to believe that cancer would result in death, and to not want to know if they had breast cancer. Enabling factors mentioned among adherent women included receiving cues to action by mail or telephone about obtaining a mammogram and receiving social support from friends and family. Nonadherent women were more likely to delay screening due to cost and/or a lack of insurance.

Provider recommendation was another factor that clearly differentiated adherent and nonadherent women. An integrative review of mammography screening barriers found that a major barrier (identified in 8 of the 13 studies) was lack of physician recommendations. Interventions aimed at improving patient-provider communication and encouraging providers to recommend regular screening have been shown to be effective in other populations.

Social support is another factor that may affect regular mammography screening. Our findings show that women who openly discussed mammography with family and friends were more likely to have had a repeat mammography screening.

A considerable number of predisposing factors identified in our study are consistent with previous research on initial and repeat mammography screening. A predisposing factor that clearly distinguished adherent and nonadherent women among our participants was knowledge. Past studies have found that African American and Hispanic women had lower levels of knowledge and more misconceptions about screening, which were associated with underutilization of mammography.

Consistent with the construct of perceived susceptibility, as defined in the Health Belief Model, our study findings suggest that risk perception was an important factor distinguishing regularly screened women from those who were not following recommended guidelines. These findings also support a number of other studies describing the relationship between perceived risk and mammography screening among women. More health communication research is needed to improve our understanding of how to communicate the concept of risk, particularly to minority women with low educational levels.

Research has also focused on pain and embarrassment as potential barriers for mammography screening. In this study, adherent and nonadherent women both discussed experiencing pain and embarrassment during the mammogram, but nonadherent women were more likely to describe the pain as severe. Unlike other studies that have also described embarrassment as a factor influencing mammography screening, women in our study did not say that feeling embarrassed had prevented or would prevent them from getting screened. However, some women mentioned a preference for a female provider/technician.

The issue of fatalism as a factor influencing cancer screening is wrought with problems related to both the conceptual and the operational definitions of the term. Formally, fatalistic beliefs include the idea that one’s future is predetermined. In previous research, authors have suggested that minority women hold fatalistic beliefs about cancer. Many of these researchers, however, have defined “fatalism” as the belief that if one gets cancer, he/she will die. In our study, we explored this concept and found that “fatalism” represented at least two separate beliefs. While most women, particularly Hispanic women, believed that a diagnosis of cancer usually meant death, when asked specifically about their belief in fatalism (ie, what is supposed to happen will happen) none of the women agreed with this concept. The belief, then, that cancer often means death is most likely related to personal experience (ie, many women said they knew few cancer survivors) and lack of knowledge about early detection and treatment. This is good news for intervention researchers because negative outcome expectations and low levels of knowledge about the possibility of cancer survival are more amenable to change than are those of strong fatalistic beliefs.

In our study, the belief that breast cancer would result in death was a major reason why nonadherent women did not participate in repeat screening. Intervention efforts should focus on creating messages that emphasize the availability of treatment and the good chance of survival, and they should include role model stories and the testimonials of survivors.

For most women, the use of preventive health care services was an uncommon activity and one of low priority. This was noted in several other studies. Women often postponed and procrastinated having a repeat mammogram. The lack of importance given to prevention is a central theme that health promotion efforts must target.

While a number of psychosocial factors must be addressed, our findings indicate that access barriers such as cost, lack of insurance, and difficulty navigating the health care system greatly contributed to failure to obtain a repeat mammogram. Continued efforts are needed to ensure that medically underserved women have access to routine mammography screening without encountering cost and insurance issues.

Results of this study are affected by certain limitations that must be acknowledged. One limitation involved the recruitment of participants; although efforts were made to maintain separate groups for adherent and nonadherent...
women, there was a mix of adherent and nonadherent participants for four of the groups. For these mixed groups, moderators kept notes on whether a participant was adherent or nonadherent, and this was also taken into account during the analysis. Another limitation was the ability to make inferences about ethnic group differences. Although the findings may indicate true differences in barriers to screening according to ethnic group, these findings should be interpreted with caution due to the qualitative nature of the study.

Additional research is needed to improve our understanding of the perception of breast cancer risk, fatalistic beliefs, and family/partner influences on the decision to obtain regular mammograms among low-income African American and Hispanic women. Intervention development, implementation, and evaluation must include a focus on external (enabling) factors. Specifically, intervention strategies must be developed to influence providers, family members, the broader community, and health care policy to increase both the motivation for screening and access to screening services.

References


