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Medical Advocacy and Supportive Environments for African Americans following Abnormal Mammograms

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Abstract

African American women experience disproportionately adverse outcomes relative to non-Latina White women after an abnormal mammogram result. Research has suggested medical advocacy and staff support may improve outcomes among this population. The purpose of the study was to understand reasons African American women believe medical advocacy to be important and examine if and how staff can encourage and be supportive of medical advocacy. A convenience-based sample of 30–74 year old women who self-identified as African American/Black/of African descent and who had received an abnormal mammogram result was recruited from community-based organizations, mobile mammography services, and the local department of health. This qualitative study included semi-structured interviews. Patients perceived medical advocacy to be particularly important for African Americans, given mistrust and discrimination present in medical settings and their own familiarity with their bodies and symptoms. Respondents emphasized staff can encourage medical advocacy through offering information in general in a clear, informative, and empathic style. Cultural competency interventions that train staff how to foster medical advocacy may be a strategy to improve racial disparities following an abnormal mammogram.

Keywords

abnormal mammogram disparities; African American; communication; breast cancer screening; follow-up; qualitative; medical advocacy

Introduction

African American women experience greater delays in receipt of follow-up care after an abnormal mammogram result relative to their non-Latina White (NLW) counterparts¹⁻³. African American women's perceptions and experiences with medical providers contribute to this disparity⁴⁻⁷. Inadequate provider-patient communication about mammography results is more common among African American women relative to NLW counterparts (21% vs 11%)⁴. Distrust of providers and anticipated discrimination in medical settings are other barriers to adherence to follow-up in this population⁷. African American women also experience inadequate provider-patient communication during follow-up, such as a lack of detailed information about procedures and definitive diagnoses⁵. These negative experiences have adverse consequences, including lower likelihood of obtaining subsequent mammograms^{8,9}. There is thus a need to examine and promote factors associated with African American women's *positive medical experiences* during follow-up, defined as *situations wherein patients were satisfied with follow-up care*.

One factor is *medical advocacy*, defined as the "ability to seek, evaluate, and use information to promote one's health"¹⁰. Among African Americans, medical advocacy has been associated with adherence and positive medical experiences. Kerner and colleagues found African American women who asked questions and obtained information during the initial appointment were almost three times more likely to have timely adherence to follow-up¹¹. Allen and colleagues found that women who believed they had a personal responsibility to be engaged in their care (e.g., asking questions) to be more likely to have timely adherence to follow-up¹². These findings are in line with traditional African American values, which place an emphasis on self and non-medical sources (e.g., faith, family) to manage health problems¹³. Medical advocacy can further be conceptualized as one sociocultural strategy for African Americans to overcome discrimination and distrust in medical settings^{14,15}. Promoting medical advocacy among African Americans may be a culturally appropriate strategy to improve adherence and satisfaction with care. Although beneficial, some studies have indicated that African Americans are less likely to engage in medical advocacy^{10,16} and others have found no racial/ethnic differences^{17,18}. Work is thus warranted to understand how to encourage and support medical advocacy among African American patients.

The first step to understanding how to encourage medical advocacy is to examine reasons underlying its importance among African Americans. If African American women believe medical advocacy to be important to mitigate discrimination and receive high quality care^{16,17}, efforts should be made to build trust within communities and to discontinue discriminatory practices directed toward this patient population (e.g., microaggressions). Alternatively, medical advocacy may be perceived to be important, given patients' knowledge about their own bodies. Similar to other racial/ethnic groups, providers' attentiveness to patient concerns has been associated with satisfaction among African Americans¹⁹. Nonetheless, African American patients experience more physician-dominated visits than other groups²⁰. If African American patients perceive medical advocacy to be important to alert providers about symptoms and concerns, efforts should be made using

patient engagement approaches to increase shared-decision making processes and patient-centered care for this population.

Subsequent steps to understanding how to encourage medical advocacy include examining if and how social aspects of the medical environment can be supportive to medical advocacy. Active provider communication has been identified as another factor associated with positive medical experiences among African American women. Kerner and colleagues found African American women to be over two times more likely to be adherent to follow-up, if they received next-step information about the potential of needing follow-up during the initial appointment¹¹. Allen and colleagues found that women who received reminder phone calls and letters to be more likely to be adherent to follow-up after an abnormal mammogram and be satisfied with care¹². Both studies identified medical advocacy and provider communication as important, but did not examine how they may interact to influence satisfaction. Provider communication may facilitate medical advocacy among this population, if women feel they can trust providers and that providers are supportive of their participation in care. Neither study further characterized the specific aspects of communication that are associated with patient satisfaction. Understanding if, and the specific manner in which, providers can encourage medical advocacy may inform subsequent cultural competency educational programs and ultimately improve care given to African American women.

This qualitative study sought to address gaps in literature described above. We provide preliminary data concerning: 1) reasons underlying the importance of medical advocacy among African Americans; 2) if provider communication can promote medical advocacy; and 3) the specific aspects of provider communication that can promote medical advocacy among African Americans.

Methods

Recruitment

The project's methods and materials were approved by the research center's Institutional Review Board. Between June and July 2013, African American women were recruited by two community advocates, one mobile mammography service, and the local National Breast and Cervical Cancer Early Detection Program grantee in Seattle, WA. African Americans represent 8% of the state's population²¹. Despite similar mammography use, African Americans residents are more likely to experience a late stage breast cancer diagnosis relative to NLW residents²².

Women met the following eligibility criteria: 1) self-identification as being African American, Black, and/or of African descent; 2) age between 30–74 years old; 3) receipt of an abnormal mammogram within the past four years; and 4) no previous personal history of breast cancer before the abnormal mammogram experience. Women then met with one of five African American community advocates who were trained in qualitative interview techniques. Interviews occurred in participant homes or in public settings (i.e., libraries, coffee shops), depending on the participant's preference. Each audio-recorded interview lasted 30–60 minutes. Participants signed an informed consent and received \$35.

Qualitative data collection and analysis

The study team developed a semi-structured interview guide, including questions and statements such as: “What were some ways you felt the doctor and staff supported you during your follow-up appointment” and “Describe what and how the doctor told you he/she wanted you to return for follow-up tests.” Interviews were transcribed verbatim, checked for accuracy, and uploaded into ATLAS.ti version 7 (Berlin, Germany). Two authors independently read each transcript. The team applied a combined deductive and inductive analysis approach, in which themes from different samples were explored and new themes were identified from raw interview data²³. First, the study team, which included researchers and community advocates, adapted a codebook from a previous analysis of similar interviews with Latina and NLW women who had experienced an abnormal mammogram²⁴. For example, the original codebook included direct informational and empathic communicative styles. We next adapted the codebook by adding codes that addressed unique experiences of this sample. For example, medical advocacy emerged as salient for the current study’s sample of African American women, but not for Latina and NLW women. During this analysis, coders met regularly to review codes and coding strategies and to maintain inter-rater reliability. The coders clustered similar concepts together into categories representative of each emergent theme and discussed preliminary findings with the study team.

Results

Descriptive information for our twenty-eight participants is provided in Table 1. The majority of women elucidated positive medical experiences more often than challenging experiences. Emergent themes were grouped accordingly: 1) reasons underlying the importance of medical advocacy among African American women; 2) provider communication can promote medical advocacy; and 3) specific aspects of provider communication that can promote medical advocacy among African Americans.

Reasons underlying the importance of medical advocacy among African American women

The importance of medical advocacy among African American women was strongly emphasized, as illustrated by this respondent, “Black women need to really assert themselves to ask questions and get the answers.” Women highlighted two key reasons medical advocacy is integral to a positive medical experience for African American women. First, respondents said it is important that African Americans in particular engage in medical advocacy to address historic and ongoing medical mistrust and experiences with racism in medical settings. One participant noted:

We got to reach out and go over the boundaries...especially African Americans with cancer, because we’re going to be paranoid otherwise...we’re automatically going to assume that we’re not going to get the best care. Sometimes- a lot of times it has happened, even in modern medicine.

Second, respondents said engaging in medical advocacy was an important strategy for women to assert their awareness and familiarity of their body and symptoms with providers.

Several respondents, such as this one, held themselves accountable to document and share perspectives about their symptoms with healthcare staff:

Just to advocate, advocate, advocate... Each individual, you are your best doctor in a sense. You know your body the best... You can describe what you're feeling to them and they can give a name to the symptoms. Be very honest. Don't hide any information in terms of symptom information that you might give to your doctor or behaviors that you're engaging in that might cause these symptoms.

Provider communication can promote medical advocacy

Participants perceived a supportive healthcare team and overall environment as critical to enabling African American women's medical advocacy during the appointment. Upon initial receipt of results, women said they appreciated detailed information concerning how to proceed and what to expect, as described by these respondents:

They gave me the information to where I needed to go [and what] to write down. "Get a pencil and write this down and call this number and make an appointment over there. We're going to send your film over there."

They give you an idea of what's going to happen, so you know you're going to go on the machine or you know that this is going to happen and you're going to have take your top off and stuff like that.

During the follow-up appointment, participants said good providers offered a supportive space for questions, as described by this respondent:

When he came in he was very knowledgeable and he was thorough... gave you the chance to ask him whatever you wanted to ask him and you felt a sense of relief because the information just kind of flowed out. I think that helped tremendously.

Another woman further explicated, "They had excellent eye contact and gave you the opportunity to ask whatever questions you wanted to and they gave you an answer at that time."

Women said they appreciated providers who engaged them in care and offered agency. This respondent described a doctor who allowed her to make the ultimate decision, "He didn't pressure me. I don't like the doctors to pressure you and dictate, 'You have to do this, you have to do that', so he won me over." Other respondents, such as this woman, echoed the importance of a team-based approach to their care, saying, "I felt good about it because I felt like... [Provider's name] is my partner in [my] body. He's my team captain and I'm the team leader."

Specific aspects of provider communication that can promote medical advocacy among African Americans

Notably, the women in our sample were largely satisfied with the follow-up care they received in part because of their ability to engage in medical advocacy. Respondents offered several specific aspects of provider communication to enable patient medical advocacy. For example, respondents said clear communication was particularly important in situations

wherein providers openly recognized the limits of their expertise and asked patients how they would like to proceed. A respondent described a good doctor as “a doctor that (sic.) is not afraid to say that he doesn’t know, but he can find somebody that will help in that area of specialty.” Women further indicated they had received direct, detailed information about recommendations for subsequent care. One woman offered, “They said it was benign...then he told me that if something should change...or you start having pain, come back and see us. If not then, come back in six months.”

Women reported that providers who delivered information in an affective, warm tone instilled confidence and comfort. Further, they said using this type of tone allowed women to engage in medical advocacy, as illustrated by this respondent:

They were very comforting...he was very soft spoken... He just told me to watch, continue to do my own breast exams and make sure...if I see anything abnormal to give them a call. They were very supportive and then when I called to make my appointments, it was very comforting.

Another respondent remarked, “They supported me by making me feel comfortable and not stressed, because I told them I was stressing out about it.” Empathic communication was furthermore often couched in the context of personable care, as illustrated by this participant, “They’ll call you over the phone and it’s a nice letter that they send. It’s personalized.” Another respondent reported, “It makes you feel very warm to know that your doctor really does care. You’re not just another dollar in their pocket.” Another woman reported, “You’re not treated like a number, you know, they actually act concerned when with knowing that you’re there for a second screening.”

Many women primarily discussed their interactions with providers (doctors, radiologists, and nurses). Nonetheless, they also reported personable, engaging support from receptionists and other staff handling administrative aspects of care was just as important to their positive experience. Women noted:

Everything that they did was wonderful. They were very comforting...they give you privacy to change, a place to put your things...you went to a private, changing room and when you came out, you know there was someone waiting for you. So it was nice.

They give you your labels to go on all your clothes and everything. They tell you step-by-step. They ask you your name, your social security, and your birthday, over and over and over, so you don’t get mixed up with anybody. Do I need warm blankets? The person who’s with me: ‘Do you want a bed, do you want some covers, you want some cookies?’

Discussion

The current study addressed medical advocacy and supportive aspects of provider communication for African American women following an abnormal mammogram. This work builds on earlier research indicating medical advocacy and staff support contribute to timely adherence to recommended follow-up among African American women^{11,12}. Our

study offers important information for the development of cultural competency interventions, including African American patient perspectives on the importance of medical advocacy and aspects of provider communication that promote medical advocacy. African American women reported medical advocacy was important to mitigate mistrust and discrimination in medical settings and to offer accurate, detailed information about their symptoms. Supportive environment and staff were perceived to be integral to patients engaging in medical advocacy. Specific aspects of supportive environment that were associated with medical advocacy and patient satisfaction included direct and empathic communicative styles.

Women emphasized that medical advocacy was particularly important for African Americans. The importance of medical advocacy was tied to medical mistrust, discrimination, and women's interests in offering detailed, accurate information about their bodies. This is in line with earlier work that has indicated African American women who perceived themselves responsible for their health and advocated for themselves were more likely to have timely adherence^{11,12}. African American's mistrust and anticipation of discrimination in medical settings should be understood in light of the historic and contemporary racism this population has faced in this context¹³⁻¹⁵. Sociocultural responses to this oppression have included a greater reliance on non-medical sources over healthcare, including self-advocacy, community, and faith^{13,15}. Although medical advocacy is associated with healthcare use among African Americans, this population has equivalent or lower levels of medical advocacy relative to other racial/ethnic groups^{10,16-18}. Our data and other work suggest that increasing levels of medical advocacy may increase African American patient satisfaction and use of healthcare services.

Previous research has suggested staff support is integral to patient satisfaction and adherence to care^{11,12}, whereas medical mistrust, racial/ethnic discrimination and inadequate provider-patient communication can be deleterious for African American patients^{2,5,25}. The current study adds to existing literature by indicating *if* and *how* staff support may encourage medical advocacy among African Americans. Offering detailed, clear information in an empathic style was perceived to promote medical advocacy. Our results suggest that this is important throughout the abnormal mammogram experience, from delivery of abnormal results to receipt of a definitive diagnosis and subsequent steps. Respondents often discussed empathic communication in the context of personable care, suggesting patients may appreciate and respond to personalized care and efforts by staff to recognize their unique needs. Our findings are similar to research on other populations^{19,24} and suggest these communication strategies are necessary across racial/ethnic lines. Given this, efforts should be made to increase the use of these strategies among African American populations, who are less likely to receive such care²⁰.

This study had several limitations. The main focus of the current project was patient-provider communication. Nonetheless, multiple factors contribute to ethnic disparities in timely adherence and patient satisfaction following an abnormal mammogram result. For example, a recent study including low-income African American women demonstrated the importance of societal context in the ability to seek follow-up care, including co-morbidity, major life stressors, insurance and access issues, and competing social (e.g., family,

caretaker), and work policies when understanding difficulties associated with follow-up care after an abnormal mammogram result⁶. Second, the current study focused on the experiences and needs of a small convenience-based sample and may not be representative of all African American women. Future larger, population-based studies are needed to examine associations of medical advocacy, staff support, and patient satisfaction. The average time between the abnormal mammogram experience and the interview was about a year; this amount of time may have affected women's perceptions of their care, potentially due to factors such as recall bias. Our project did not ascertain the influence of the abnormal mammogram experience and perceptions of follow-up care in relation to screening among women diagnosed with cancer and screening among women not diagnosed with cancer. Future longitudinal research is needed to determine the long-term consequences of medical experiences. Finally, this current project focused on the specific needs and experiences of African American women, who face a number of societal, interpersonal, and intrapersonal barriers to healthcare. These emergent themes may also be important factors to consider with other medically underserved populations and should be further studied.

Conclusions and Implications

Our work offers several target areas for provider educational outreach and cultural competency training to improve quality of care for African American women who receive an abnormal mammogram. Future educational interventions and programs may choose to target factors promoting patient medical advocacy to improve the early detection of breast cancer among African American women. Staff may benefit from training in historic and contemporary instances of racism within medical settings, as this may help providers understand and address their African American patients' anticipations and previous experiences. Staff training may further help to increase the use of communication styles that are helpful for several patient populations. For example, beginning with the delivery of the results, staff may encourage medical advocacy among African American women by providing clear, detailed information in an empathic and personable tone. Offering patients a space to respond to information during appointments may enable greater trust as well as allow providers to understand any symptoms and concerns African American women have. In conclusion, our work suggests that supporting and encouraging medical advocacy among African American women may be essential to patient satisfaction with follow-up care after receipt of an abnormal mammogram.

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Table 1

Study sample characteristics (n= 28)

Variable	<i>M (SD)</i>
Age	52.39 (7.58)
Income	\$20–29,999 (\$20,000)
Age at first mammogram	37.61 (9.12)
Time between abnormal result and interview	1.13 (1.36)
Number of mammograms within the past 5 years	4.22 (2.28)

Variable	<i>n (%)</i>
At least some college	20 (71)
Unemployed	7 (25)
Insurance status	
No insurance	7 (25)
Medicare/Medicaid	14 (50)
Private	7 (25)
Procedures	
% received a diagnostic mammogram	21 (75)
% received an ultrasound	10 (36)
% received a biopsy	15 (54)
% diagnosed with cancer	5 (18)