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## Identifying Sociocultural Barriers to Mammography Adherence Among Appalachian Kentucky Women

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### Abstract

Despite lower breast cancer incidence rates, Appalachian women evidence lower frequency of screening mammography and higher mortality risk for breast cancer compared to non-Appalachian women in Kentucky, and in the United States, overall. Utilizing data from 27 in-depth interviews from women in seven Appalachian Kentucky counties, this study examines how Appalachian women explain sociocultural barriers and facilitators to timely screening mammography, and explores their common narratives about their mammography experiences. The women describe how pain and embarrassment, less personal and less professional mammography experiences, cancer fears, and poor provider communication pose barriers to timely and appropriate mammography schedule adherence and follow-up care. The study also identifies how improving communication strategies in the mammography encounter may improve mammography experiences and adherence to screening guidelines.

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Breast cancer is the most commonly diagnosed cancer among women. In 2012, approximately 226,870 new cases of breast cancer were expected to be diagnosed, and another 39,510 women would die from the disease (American Cancer Society, 2012a). In Kentucky, a largely rural state, an estimated 3,160 new cases of breast cancer were expected to be diagnosed in 2012 and an estimated 570 women would die from breast cancer (American Cancer Society, 2012a).

Across the population, age-adjusted invasive cancer incidence rates in Kentucky show that non-Appalachian women are more likely to be diagnosed with invasive breast cancer compared to Appalachian women (125.00/100,000 compared to 111.00/100,000; Kentucky Cancer Registry, 2013). This pattern holds true for noninvasive breast cancer rates as well, where non-Appalachian women are more likely to receive a diagnosis compared to

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Appalachian women (28.00/100,000 compared to 18.00/100,000 people; Kentucky Cancer Registry, 2013). Yet age-adjusted cancer mortality rates for breast cancer among Appalachian women are higher than for non-Appalachian women in Kentucky (24.00/100,000 compared to 22.00/100,000). One possible explanation offered for this difference is the statistically significant later stage at diagnosis for breast cancer among Appalachian women, compared to non-Appalachian women (chi-squared = 36.34,  $p < .0001$ ; Kentucky Cancer Registry, 2013). Among Appalachian women, 33% of female breast cancer cases were at a late stage (regional and distant sites), compared to non-Appalachian female breast cancer cases having 28% at a late stage.

Within the state of Kentucky, counties designated as “Appalachia” by the Appalachian Regional Commission are underserved by the health care system. From an epidemiological perspective, later-staged breast tumor diagnosis may be attributed to a disparity in the initiation, scheduling, and maintenance of appropriate mammography screening across the population that may produce disparate outcomes. Indeed, 69.9% [CI 67.7–72.2%] of women in Kentucky age 40 years and older have had a mammogram within the last 2 years, which is compared to Area Development Districts (aggregations of counties) in the Appalachian Kentucky region where this proportion varies from 61.7% to 68.4% [CI 55.0–74.8] (Kentucky Health Facts, 2012).

In the decades after mammography became widely available in the United States, researchers studied barriers to initial mammography use to develop appropriate mammography promotion interventions to enhance demand for services in “late adopting” populations. Research suggests external factors such as lack of access to imaging centers (Engelman, Cizik, & Ellerbeck, 2006) and internal factors such as personal modesty (Schoenberg, Howell, & Fields, 2012) may serve as barriers to mammography screening. To address these barriers, from a diffusion of innovations perspective, the Guide to Community Preventive Services (the Community Guide) recommends a range of evidence-based strategies to improve mammography rates. However, while the Community Guide assesses the evidence base for client-oriented and provider-oriented interventions, it does little to assess the difference in those strategies’ effectiveness in improving initial uptake of screening and adherence.

In the context of mammography, which is a less frequent health behavior, barriers to remaining “on schedule” and maintaining screening across multiple opportunities remains an understudied area of research. Yet regular use of mammography is critical to early diagnosis for breast cancer, when women have more treatment options and tumors are more localized, smaller, and can be cured (Cronin et al., 2005). Furthermore, Gierisch, Reiter, Rimer, & Brewer (2010) suggest that appropriate communication “interventions to encourage women who have lapsed from regular mammography use may be different from those needed to motivate women to initiate use” (p. 678).

In the context of mammography, a focus on adherence reflects the paradigmatic shift that has occurred in the United States, from the need to develop communications strategies to “promote” mammography, to informed decision making about the appropriateness and timing of screening. Breast cancer screening guidelines recommend biennial mammography

screening for average-risk women aged 50 to 74 years (U.S. Preventive Services Task Force, 2009); however, some organizations such as the American Cancer Society (ACS) recommend screening initiation at age 40 (American Cancer Society, 2012b). Despite these guidelines, it is common for U.S. women to experience mammography before age 40 years (Woloshin & Schwartz, 2010). For example, providers who detect breast abnormalities after clinical breast exams or breast self-exams in younger women go on to refer them for diagnostic mammography. The American Cancer Society (2012b) encourages women with a family history of breast cancer to begin annual mammography starting 10 years prior to the age of the youngest first-degree relative with breast cancer (but not before age 25, and no later than age 40 years).

These early, first, and often irregular mammography experiences are important to consider as influential on women's maintenance or adherence to recommended screening protocol. Such protocol adherence is recommended because of the diagnostic value in comparing changes in breast tissue over time, which is important to achieve optimal early detection (U.S. Preventive Services Task Force, 2009). However, there is a paucity of assessments on whether and how patients perceive provider communication in the context of mammography, and how sociocultural barriers and communication practices may contribute to reluctance toward follow-up mammography behaviors, which, in turn, leads to later-staged breast cancer diagnosis and higher breast cancer mortality rates among Appalachian women.

From a communication perspective, understanding socio-cultural barriers to mammography adherence is an innovative area for research in Appalachia, given increasing evidence that patient-centered communication practices have important implications for cancer screening processes and patient outcomes (Epstein & Street, 2007). A qualitative investigation of barriers to cervical cancer screening in the context of Appalachian women's cervical cancer screening practices concluded that lack of patient-centered communication is related to perceptions of poor quality of care and distrust for the service technician (McAlearney et al., 2012). Beyond typical sociocultural barriers to mammography screening initiation such as lack of physician recommendation, lack of breast cancer knowledge, medical mistrust, and fear of diagnosis for women to surmount (Andrews, 2001; Avis-Williams, Khoury, Lisovicz, & Graham-Kresge, 2009; Engelman et al., 2006; Lyttle & Stadelman, 2006; McAlearney et al., 2012), there may be specific barriers and identifiable communication facilitators related to adherence to mammography screening protocol.

In the breast cancer context, research is needed to identify barriers to mammography screening maintenance and to determine whether these barriers are surmountable with communication practices. From a communication perspective, there is a well-established literature examining patient-centered communication (PCC) as an ideal practice to surmount barriers to cancer screening and care. Fundamentally, patient-centered communication occurs when providers "provide care that is concordant with the patient's values, needs and preferences, and that allows patients to provide input and participate actively in decisions regarding their health and health care" (Epstein et al., 2005, p. 1516). PCC is widely endorsed as a prerequisite to quality health care, and the Epstein et al. examination of PCC in the context of patient-provider communication established four domains relevant to its

examination: (a) the patient's perspective, (b) psychosocial context, (c) shared understanding, and (d) sharing power and responsibility. In the context of adherence to screening mammography, then, effective communication may be critical to ensuring that individuals surmount barriers to adhering to the mammography protocol by receiving linguistically accessible information about screening; helping patients to navigate through the healthcare system to follow-up on test results; and addressing patients' worries and concerns after they have an established basis for understanding mammography (Epstein & Street, 2007).

Although PCC is a health care ideal, its implementation in the mammography screening context has not been established. Many mammography technicians are fundamentally technologists, who may lack training in patient-centered care. Patients may exhibit limited understanding of the screening process, and the imaging center may have limited power and authority to provide interpretations of results. While mammography centers that are nationally accredited and located within community hospitals may include technicians trained to improve quality in the patient experience, other imaging centers do not have someone reading batches of screening mammograms and women frequently leave without having results (Clark, 2010).

The question remains, in the context of Appalachian women residing in medically underserved communities, of whether mammography experiences and communication with providers about breast cancer screenings are identified as barriers and facilitators to future mammography screening adherence. The purpose of this study is to determine what specific sociocultural barriers women residing in Appalachian Kentucky report to maintaining compliance with the recommended mammography screening protocol, and whether there are communication practices that may help women surmount these barriers.

## METHODS

A semistructured, qualitative interview approach eliciting women's mammography narratives was utilized to understand Appalachian Kentucky women's breast cancer screening knowledge and attitudes, communication practices centered on mammography, and breast cancer screening experiences. The study was conducted in collaboration with the Centers for Disease Control and Prevention-funded Rural Cancer Prevention Center (RCPC). Women were eligible for study participation if they were residents of eight underserved Appalachian Kentucky counties (county names omitted to protect participant identities), over age 40 years, and had experienced at least one screening mammogram. Prospective participants were ineligible for participation if they had experienced breast pathology (including breast cancer) up to the time of the study, with the exception of postpartum mastitis.

### Procedure

Recruitment began in September 2010 and lasted through August 2011; a local research coordinator recruited women with the assistance of the RCPC Community Advisory Board (CAB) members, many of whom worked with local health departments or in association with local cancer coalitions. RCPC CAB members asked women in their communities if

they might be interested in participating in a research study about perceptions of mammography screening. Interested women granted permission for the research coordinator to call them at home to further describe the study; all calls were expected and no cold calls were made.

Each participant chose the day, time, and location for her enrollment meeting and study interview. Upon enrollment, each participant was provided an informed consent document that the interviewer verbally reviewed for understanding; two copies of the document were signed, one for the researcher and one for personal records. The informed consent document made participants aware that involvement was voluntary and could be terminated at any time and assured that there was no obligation to undergo mammography screening as part of the research study. Interviews were audiotape recorded and lasted 20–40 minutes. Audio recordings from the interviews were transcribed for analysis. Pseudonyms were used to facilitate in vivo quotation identification. All study procedures were approved by the university institutional review board, including providing a \$30 gift card to the women as compensation for participating in the study.

### Protocol

After informed consent was granted and preliminary to the in-depth interview, a brief questionnaire was used to acquire demographic information about participants and to determine when the participant's last mammogram was received. Women were then engaged in an in-depth interview probing their previous mammography experience, their adherence to mammography guidelines, and any difficulties they experienced with having a routine mammogram, including (a) work or school issues, (b) child or elderly relative care, (c) payment issues, (d) transportation issues, (e) personal issues, (f) scheduling issues at the hospital or mammography center, and (g) provider communication factors. Participants were asked to tell a story related to the factors that motivated them to undergo mammography screening, to describe their recent mammography experience and reasons for not maintaining the recommended mammography schedule, and to describe how having a mammogram could be a more positive experience.

### Sample Description

Descriptive demographic and mammography behavior data from women participating in in-depth interviews was elicited and recorded by the interviewer, and confirmed in the interview transcripts (by the first and second authors). Recruitment efforts resulted in 27 individual interviews of women who had experienced at least one mammogram and who resided in six Appalachian Kentucky counties (pseudonyms are used and the names of counties are omitted to protect privacy). All of the women reported living in the region since childhood. The women ranged from 41 to 70 years old ( $M = 55$ ). All of the women enrolled were non-Hispanic white, which reflected the dominant racial and ethnic composition of this Appalachian region. Fifty-two percent of the sample ( $n = 14$ ) had less than or equal to a high school degree or equivalent, including three women who received their GEDs and two women who had seventh- and 11th-grade educations, respectively. Thirteen of the women (48.1%) interviewed had received an "early" mammogram before the age of 40. Seven of the women reported that they had received a mammogram in the past year; two of these

seven were under 50 years of age. Five of the 23 women older than 50 years reported that they were current with their mammograms. During the interview, more than half of the women (51.9%) reported uncertainty or that they “were not aware” of the recommended guidelines for breast cancer screening for women over 40.

### Data Analysis Procedures

The goal of qualitative research is to continue to sample until researchers achieve informational redundancy or maximum “theoretical” or “practical” saturation, where no new insights can be expected from additional interviews or panels. As Sandelowski (1995) pointed out, “Determining adequate sample size in qualitative research is ultimately a matter of judgment and experience” (p. 179). In our experience with more homogeneous rural populations in eastern Kentucky, we found that such saturation can occur after as few as 15–20 interviews in narrowly targeted demographic groups (Cohen & Head, 2013; Head & Cohen, 2012). Here, we sought to achieve maximum variation in participant experiences until redundancy was reached, leading to the completion of 27 scheduled interviews.

Following standard approaches to qualitative data analysis (e.g., Cohen & Head, 2013; Cohen, Scott, White, & Dignan, 2013), after reading the transcripts, the researchers derived categories for content analysis by inductive reference. Transcripts were reviewed and annotated by the authors for key ideas and recurring themes. This undertaking was consistent with the constant-comparative methodology where “codes and categories were mutable until late in the project, because the research is still in the field and data from new experiences continued to alter the scope and terms” of the analytic framework (Lindlof & Taylor, 2002, p. 218).

The authors inductively read transcripts to identify attitudes related to mammography; knowledge of certain barriers to mammography and ways women problem-solved these roadblocks to continue with screening; communication problems with mammography technicians and providers; and related practices that affected their adherence to recommended breast cancer prevention strategies. The team members then, independently, descriptively assessed participant responses for women’s current mammography status from the transcripts and established a broad initial theme of coding categories of barriers derived from the research literature linked to “in vivo” quotations representing participants’ stories explaining the barriers to mammography. Then the second author placed quotations from the interviews into a master outline consisting of framework headings and subheadings (Ritchie & Spencer, 1994). The researchers then convened to compile and compare findings. The process was an iterative one, where after proposing an initial set of categories the research team met to “audit” the categories to organize major and minor themes of information seeking, and to examine whether categories were distinctive based on “feels/like and looks/like” (Lincoln & Guba, 1985). The team members then reexamined the annotated transcripts and clarified key focal constructs related to self-reported barriers to timely screening mammography, participants’ heuristics related to mammography screening, and other attitudes and reasons expressed by participants related to receiving and/or not receiving timely mammography. The lead author reviewed the charting and, where disagreements were found, negotiated the placement of in vivo quotations until the research team reached



consensus. This iterative work with an interdisciplinary research team (including a public health/cancer information specialist and a health communication specialist) was directed to establish the trustworthiness of interpretations (disagreements were resolved among the authors during and after this audit process) to satisfy methodological rigor.

## FINDINGS

Collectively, the research team identified major and minor themes in the interviews and present findings around the three specific themes from the data analysis: (a) women delay mammography due to pain and embarrassment, (b) impersonal and unprofessional mammography experiences are a barrier to timely and appropriate mammography, and (c) the fear of detection, compounded by poor provider communication, becomes a barrier to mammography guideline adherence. The first theme generally explained individuals' reticence to go back for mammography, and is commonly identified in the breast cancer screening literature across populations as a barrier to mammography even when individuals express positive attitudes and are knowledgeable about the importance of mammography. However, the second and third themes relate to the construct of patient-centered communication and care, which seems to take on specific, socio-cultural meaning for Appalachian women. Women, already pained and embarrassed by mammography procedures, in the absence of patient-centered care and communication are reluctant to receive timely and appropriate mammography. Women's reticence is entangled with and often overrides beliefs about the benefits/risks to screening and with logistical or practical (i.e., financial) barriers to care.

### Women Delay Mammography Due to Pain and Embarrassment

Women understood the importance of breast compression, and even pain and discomfort, to yielding an adequate screening necessary to detect breast cancer. They described coping strategies, including talking with their technician about the pain, to overcome their concerns about the procedure; however, participants admitted disrobing for mammography was a source of personal embarrassment and that they delayed mammography to have fewer of such moments.

Women's reticence to receive timely follow-up screening stems from their past experience and intimate knowledge regarding the exposed nature of the procedure as not just painful and invasive, but also embarrassing. As Jackie identified:

Well, it's a machine ... and they take your breast and put it in there ... and they lower it down and they lower it down higher and it squeezes ... it squeezes. They're painful. I mean, it's tolerable. I mean the biggest part to me isn't the pain; it's the embarrassment.

This identification of mammography with personal embarrassment was found across women without differentiation to their age or status of having children. As Lynn expressed:

I think that's the reason that I don't [continue to] go have them. Everyone says once you've had a baby, it shouldn't be that embarrassing ... but it is embarrassing.

Remembering her last mammography experience, Sue said:

I find them embarrassing ... I think if it was more of a pleasant experience I wouldn't care to really have one every so often ... but where ... that just hurt me so much the time I had it done that I just ... when I think about it, I hate it with all my heart ... I don't like it.

Aside from noted access barriers in terms of cost, provider access, and caregiving responsibilities (as assessed via the demographic questionnaire), pain and loathing of the procedure was a central recurring reason women offered that they did not receive timely screening. Kamea admitted that she received her mammograms irregularly, "about one every five years ... I don't want to go any more often because of the degree of pain that I have with them ... that's the reason I don't go every year."

Despite these embarrassing and painful experiences, these women also recognized how communicating the benefits of mammography could help them surmount their fears of embarrassment. When asked how they would persuade other women to get their mammograms, Katie offered that she'd be candid and say:

Well, "You'll live." ... It's something that you have to go through and you'll work through it ... but you know ... you will live ... and I would tell them if you are embarrassed and you're back there ... just tell them, "Ouch, it hurts," and, "I'm embarrassed ... just explain to me everything that you're doing. I want to know what's going on."

However, even when the mammography technician explained each step of the procedure, women expressed personal embarrassment and pain with the screening. As Katie indicated:

If I can remember correctly ... they explained everything to me and told me what they were going to do and why they were doing it and where to stand and all that ... you know ... each of the things ... but still you kind of ... as they're doing the initial process ... and as they're squeezing it and all that, you just kind of lose some of your self-respect ... that's just how it is ... and it does hurt ... there's just nothing more you can do ... say about it.

Women who were able to describe the procedures technicians would take to give them privacy also expressed discomfort and loathing toward mammography. As Linda explained:

I went in and they put me in a private room to put on the sheet. They walked me over to the other room where the mammogram is at, the mammogram machine. And they put my breast in the "smash cup" as I call it. And they done that ... it hurt! But the overall procedure, you know, was okay, I guess.

Linda's concern for the pain and privacy, however, was balanced by her expressed belief that mammography for early breast cancer detection was "important."

Many women who reported painful mammography experiences also explained that they experienced mammography early in adulthood. Women who remembered having their first mammogram when they were in their 20s and 30s due to a lump they called a "caffeine cyst" or a "fatty lump" expressed particular concerns and mammography fears. As Leah recounted:



I did have a lump in my breast once ... and they sent me down there ... and it worried me because I didn't know what was going to be the outcome ... I told them I didn't think I wanted to go ahead and have one ... but they scheduled me for it and I went ahead and had it. But I didn't really want to go have one; because I thought, "Well I don't think there's anything wrong with me" ... so I thought, "Well now, I don't think I'll go ... " but I went ahead ... it was fine ... it was just a caffeine cyst.

The pain of women's first mammogram lingered, as they remembered their first mammography experience was fraught with uncertainties and they lacked adequate knowledge about the procedure. Allison recounted:

From what I remember, it wasn't a very pleasant thing ... and it may have been from where it was my first time, it was a little scary ... in that sense ... just because you didn't know what to expect from the test. And I think if they had explained fully, the test, beforehand ... that it might have been less scary. But as far as now ... it's more of like a dread to go ... because you know that you're going to have to be a little uncomfortable and stuff.

Ann told a similar story of her early mammography fears, explaining:

Well, I was only 38 so it was scary ... because I thought ... you know ... because they don't normally recommend them until you're forty ... but I just had the fibroid cysts ... and that's why he wanted me to go have them checked ... so it was a kind of scary feeling when you're young and you have to have one.

More importantly, when Ann was asked by the interviewer how "did the mammogram go ... can you kind of describe what they did?," she remembered the pain of her first procedure but also remembered a technician who provided comfort: "Like I said ... they really hurt you ... they squeeze ... that's the worst part ... where they have to squeeze so tight. But other than that, it went well ... you know ... because the people that done it was great." Similarly, Marie had an early first mammogram and reported her "first mammogram ... It was kind of embarrassing" but mentioned that the technician was able to make her feel at ease:

Once the technician made me feel comfortable, you know, it just ... the embarrassment kind of left. I was okay with it. I knew he was there to do his job ... so, it was at first ... and he just did a really professional job.

Alternatively, a few women were referred to early screening because of a family history with a breast abnormality reported that their provider often assumed that they were knowledgeable about the procedures. As Mary explained: "My very first one ... I guess I was scared to death because of them machines." And when the interviewed asked, "And did he explain to you what it was for ... or what to expect?," she responded, "No, my doctor never did explain it to me." These women expressed surprise regarding the awkwardness and discomfort of the procedures. As Sarah explained:

They had me to stand almost on my tiptoes (I'm short) ... and they put my breast on a plate ... and they took another plate and mashed it down on top of it ... like really, really far ... and that was the uncomfortable part ... but other than that it

wasn't bad ... it wasn't painful ... just uncomfortable standing on my tiptoes ... and the pressure.

Women's feelings of pain and embarrassment were also explained by their stories of unprofessional and impersonal health care, which was a unique theme of these interviews among Appalachian Kentucky women.

### **Less Personal and Less Professional Mammography Experiences Are Barriers to Timely Mammography**

Women expressed concern that mammography technicians did not always account for their perspective and context in receiving screening. Women expressed difficulty communicating openly with the mammography technician, and appreciated when mammography technicians took responsibility to explain the procedure. Lacking open communication, women would rely on nonverbal signals from technicians that did not adequately address their concerns during the procedure. Furthermore, women's negative experiences during screening, including painful and embarrassing moments with technicians who they perceived made the procedure less personal and professional, made them reluctant to return.

Participants expressed confusion about the procedure, uncertainty regarding the need of the technician to position and reposition their breasts, and the impersonal nature of their technician's approach to the procedure. Ann reported a story of her first mammography experience, where she felt rushed and objectified in the process:

I had to go check in at the x-ray department ... and then they made me sit out in the lobby for maybe about maybe 20 minutes because they were very busy that day ... and then they took me back and took me to this room ... and gave this little gown thing and told me to put it on ... change my clothes ... so I did ... it's like a half-jacket thing ... and I went out and spoke to her ... and she said, "Well, this lady's going take you in and do it ... " and so we went in the room to have it done ... and then she went in and it was already on and everything ... and she told me to step up to it ... and told me to, "Do this [lay it up closer to it]" and everything ... then she pushed down on it and took a picture ... and she said, "Well, it's not quite right ... " and she come over and pulled my breast over and pushed it down ... and pushed it down again and did it again ... so it wasn't very pleasant ... I guess I object to being touched ... that's what I guess I really didn't like ... I didn't like the part where she dragged me and pushed me down and touched it ... you know ... I think that's what I mostly objected to.

Although women understood the need for repositioning the breast in mammography and that mammography technicians were trained to get a clear image, the women felt uncomfortable about their lack of power and control of their body during the procedure.

Related to this point, participants reported a lack of knowledge about the mammography steps, and also were unsure about what they should do if the procedure was too painful or they detected a nonverbal cue from the mammography technologist. Paula explained that although most of the women who take her mammograms are professionals, she tried to

watch their facial expressions. However, she also remained reticent to object to pain during the procedure:

**Paula:** You go in ... you disrobe ... they come and get you ... they take you in to a machine ... and I'm very short, so I have to stand on a stool ... because the machine is not low enough for me ... so it is kind of more uncomfortable for me than it would be for a taller person. They place your breast in the machine and it just kind of squishes it ... from both sides and from the top ... and they take pictures ... and usually, you can tell ... I have noticed the girls that have done mine ... you can tell if they think there's a problem ... because they look at it after it's taken ... so you can pretty much tell by their demeanor if anything's wrong. I've kind of figured that out in the last four years I've had it ... I've had some girls that did it that were very gentle ... and then I've had one that's been really rough [laughter]!

**Interviewer:** And what was your reaction when she was rough?

**Paula:** Nothing, really, because I know that it has to be done that way ... I just told her that it was a little tender ... and she apologized.

Other women, however, reported circumstances where they spoke up about the pain of the procedure and felt ignored. This lack of patient-centered care and communication led women to put off and fear follow-up mammograms. As Shannon reported:

I don't like some of the touching and pulling around that they do on you ... so I think the technicians need to be taught to do it gently ... to not be in such a hurry ... and if your patient says, "This is hurting me ... " then you release and let them be loose ... because I was really hurt ... and I told them to stop ... and they didn't ... and that was my bad experience ... and that's why I dread even the thought of it ... truthfully, I do.

Ramona also recognized the mammography technician's communication practices as often problematic, by inciting her worry and apprehension during the mammography experience. She explained how the technician's reaction was more unbearable than the discomfort of the procedure itself:

Yes, it was uncomfortable ... it wasn't unbearable ... but the thing that would bother me was because I'm real bad to watch the technician's expressions and pauses ... and I knew something wasn't right ... and that's the worst part of it ... because I knew something wasn't right ... it was all over their faces ... something's wrong [laughter].

Such comments from women led them to believe that they were receiving less personal, less professional care. Indeed, participants reported that some technicians appeared to be less experienced, and their previous negative experiences or beliefs about the mammography technician's incompetence made them less likely to adhere to the recommended follow-up mammography guidelines. Delia recounted her first mammography experience in her "late 20s":

I remember well. My breasts at that time were extremely small ... and they said the smaller the more painful ... and it's true ... it's very true. The machine ... I guess back then was probably a lot rougher than they are today ... they've come a long way. But the first one almost scared me away from ever having it done again ... because I think the little girl that did it was new ... and I was bruised up to my chin.

Women were also reluctant to identify the technician's conduct as unprofessional. As Shannon indicated apologetically: "I don't really want to blame the young woman who did it ... I'm just saying she was just ... she wasn't polite ... and she was very rough ... and I didn't like it. I'm sorry; but I didn't." Similarly, Jennifer reported that she had "been bruised before ... but this last one I went to ... she told me ... 'Tell me when you can't stand it anymore' ... so that wasn't hardly as much squeezing." Women who were experienced with the procedure and had past pain experience often would try to pre-empt pain and trouble, as Kami indicated:

I'd had other mammograms so I anticipated the pain and the problem with my large breasts ... and I just tried to relax with it ... but then after I got in the machine ... then I was having the pain and the difficulty ... so I told her ... I said, "Can you please hurry? Can you please hurry?" And she tried her best to do what she could do.

Women related that these first experiences changed over the course of their life span. Clearly, mammography technology has improved, but women also reported seeking out more experienced mammography technicians. As Delia reported:

Well, I think the first one was very traumatizing because it was a bad experience. I think she probably squeezed too hard or something ... where she was new. I would advise anybody ... I do now ... when I have mammograms ... ask the one that's doing it ... how long had they been doing this. I know everyone has their first time ... but it was really, really painful. And now ... I guess the new machines and the extra training that they give these people ... I don't dread them at all. They're not near as painful ... and it's over in just a few minutes.

The belief that the technician is important and can make a mammography experience more pleasant was a salient belief commonly held by women. As Marilyn opined:

Depending on the technician ... sometimes they can do it and it's nothing ... and then sometimes another one will do it ... and it's like ... squeezes ... it really pinches ... and fortunately the last one I had ... it really was not uncomfortable ... because I think now we have a really, really good technician.

Finally, women also reported "shopping" for the best facility. They described how their local health centers were not staffed to read mammograms on site, nor were they as professionally experienced and equipped compared to facilities in larger cities. Jane shared that her health care provider located a lump and sent her to a local facility for a mammogram, an experience that she described as "excruciatingly pain[ful] ... I refused to go back there ... so I asked, myself, to be sent somewhere else to a breast center." When asked to expand, Jane described her feelings about her local facility:

I just ... sometimes I feel like that locally ... maybe it's because of our rural area ... and maybe it's because we don't have an area that focuses totally on breast health alone ... and they're not as experienced I just think it would be an awesome thing if we did have a place like that here locally ... where they focused totally on breast health ... and we didn't have to travel for 2 ... 2 1/2 hours to get a good exam.

Participants shared the belief that traveling to a larger city, or a facility with a breast center, would provide a higher quality experience. Randy described her preference for facilities in larger cities by explaining:

Well, the little local hospitals ... it's nothing against them ... but if I'm gonna have something done, I'd rather have it done at [large hospital with a cancer center in big city], at [large hospital in big city] where if they do find something, the oncologists are right there ... because if they do find something at the small hospitals, they're sending me to Lexington anyway. So, I'd rather see one group as to have to jump 15 different places.

Lynn echoed the sentiment of Jane and Randy. She explained that her local facilities are overcrowded and require long waits, where bigger facilities in larger cities provide a higher level of care: "I go register ... and like within just minutes I go back ... prepare myself for the mammogram ... I mean I'm not there probably 30 minutes ... so it's a much better experience."

Women in this study often described a clear preference for receiving mammographic services in larger cities, and at facilities with more experienced technicians; this preference is based on their belief that certain facilities provided a higher quality exam and a better overall experience. Thus, though some women reported more impersonal and less professional, patient-centered approaches to mammography, other women reported success with strategies for hastening their mammography experience, communicating with mammography technicians about pain, and taking control of managing their screening experience to ensure that they see a competent technician, to the extent that they were able to do so.

### **Cancer Fear and Poor Provider Communication Complicates Mammography Adherence**

There were pragmatic reasons women avoided returning for a mammogram and talking to their provider about mammography. Women reported fearing cancer detection out of concern that cancer was a death sentence. Against the backdrop of fear, lack of insurance and lack of health care were identified as chronic barriers to maintaining their screening schedule. While not a clear barrier to mammography, as women initiated mammography screening despite these fears, women would postpone and deprioritize timely screening so as to avoid discussing cancer or to not burden themselves or family members with thoughts of cancer detection.

Women reported reticence to return for appropriate mammography screening due to fear of cancer diagnosis or detection at a time when they saw other friends or family members troubled by cancer diagnosis, treatments, or death. As Anna, who was more than 2 years

overdue for a mammogram, expressed: “I’ve been thinking about it for two years ... especially since my friend had hers removed ... So it’s been more on my mind; but I haven’t brought myself yet to go get it done ... If you don’t find out, you don’t have to deal with it. I don’t want to deal with it.” Even women who understood the importance of mammography expressed the certain and fearful belief that diagnosis with breast cancer was a death sentence. Moreover, women reported the pervasive nature of cancer in Appalachia Kentucky, with the number of relatives who they knew had died from cancer or breast cancer, and expressed their belief that a cancer diagnosis could be a “death sentence.” As Abigail opined:

Because it’s a lifesaver and I think that everybody should have them. I know there’s a lot of discussion about not doing them as often ... I think that’s wrong. I think that early detection is the best cure and the best defense. And my understanding ... what I’ve been led to believe ... what I’ve seen is that they’re not making any progress with breast cancer. It’s like they’ve gone two steps up and five back. I don’t know if the research has stopped on it or what ... but it seems like they’re not as successful ... now, I don’t have a thing to base that on ... other than the fact of what I read or what I hear ... but I do know that a lot of my friends have died with breast cancer. I have one that’s survived. But ... it’s almost a death sentence if you get it now.

And although every participant in this study reported that mammograms are an important tool in the early detection of breast cancer, they often would “put it off.” As Leah explained:

Well, I think it’s important ... because you need to go and have everything checked ... just in case there is something in there ... even though you take a [self] breast exam every month ... but you might be missing something. I think it’s important that you go ahead and have everything checked ... just in case. I know I haven’t had that done ... but I’ve had a lot of things going on in my life ... and I kind of put it off.

Women reported that although they intended to follow their doctor’s recommendations, they often were not accountable for their screening behavior if the provider didn’t proactively monitor their adherence. As Anna indicated:

I wish my doctor would insist on it. I have a tendency to try to do what my doctor tells me to do... . He would tell me to have one but they didn’t ever, ever asked me, “Did you have it?” He knows I’ve not had it; but he’s never looked me in the face and said, “Did you follow through with a mammogram?” So I don’t have to deal with looking him in the face. I’m not accountable.

Even when insurance was not an obstacle and women knew the importance of mammography to early detection, women reported remembering the pain of the procedure and “lagging behind” recommended screening protocols. As Abigail indicated:

Well, I mean, them branches [the mammography machine arm] hurt me; that was the worst part. But the lady that done mine, she was real nice; I mean, I would advise anybody to have one. I would. I mean, there’s no excuse for me not to have one every year; because I’ve got insurance that pays one hundred percent. So,



there's no excuse for me not to have one every year. I mean, I just lag behind and don't.

Finally, women also explained that as a backdrop to their fear of diagnosis and reluctance to rescreen the anxiety associated with the amount of time from the mammography screening and receiving of their results increased their apprehension. When asked how long they waited for results from their screenings, participants' responses varied from immediately (for a first diagnostic ultrasound) to never receiving word or hearing that they were "normal" more than a month later. However, all women who reported long wait times or not ever receiving results indicated that this behavior increased anxiety and fear. Sophie reported that this was a common experience that bothered her. She explained that "most of the time ... you don't hear anything about it ... unless they find something wrong ... they don't even call you ... and the only time you do hear anything about it is if they do find something wrong ... otherwise you assume it's normal ... which they should either tell you 'yes' or 'no.'" Other women reported never knowing whether or not their mammography was normal, and a total lack of communication with their health care team. When the interviewer asked whether they received communication from their provider when it was normal, Abigail related that she's received a phone call, but often weeks after the mammogram:

I think you just more or less ... I don't think I've ever gotten any written thing that I had a normal ... no, I think I was called ... I think I got a phone call. I can't really remember now; but no, I've never received any written thing that I had a normal mammogram... . It was almost like ... you forgot you even had your mammogram before you heard from it.

Given that women know that their mammography experience is an embarrassing, painful, and often impersonal one, when women fear a cancer diagnosis and at the same time may not hear normal results for weeks, these findings suggest that clinicians should not be surprised to see irregular, infrequent, and inconsistent mammography screening habits among this population of Appalachian Kentucky women.

## DISCUSSION

An important lesson from this study is that many Appalachian women with a history of mammography screening report feelings of reticence about timely routine follow-up screening, despite their knowledge of the importance of such screening. To adhere to screening requires that they confront sociocultural barriers to screening maintenance, including their personal embarrassment and worries about pain and impersonal mammography technicians, and that they consider fears about a breast cancer diagnosis. Open communication with health care professionals can help women surmount these barriers. These observations and relevant theorizing about patient-centered cancer communication can be practically applied to suggest strategies to improve adherence to routine mammography screening.

### Opportunities for Future Research

One implication of this study and opportunity for future research is to study whether and how mammography technicians should be trained in patient-centered communication strategies sensitive to their clients' experiences and fears. Mammography technicians are an understudied population of health care professionals, and often receive technical training outside of traditional academic medical center settings where interprofessional health communication training is becoming more common. Beyond consideration of a patient's pain or understanding of the mammography procedures, mammography technicians need to be trained on appropriate patient-centered nonverbal communication. Similarly, attention needs to be given to informing the patient of standard follow-up procedures; for example, technicians should disclose how patients may receive their results. Researchers may work with mammography professionals to find communication strategies to help women cope with the discomfort, embarrassment, and pain of the procedure, yet allow technicians to get clear images. Clearly, patient-centered mammography screening requires that mammography technicians match relevant, patient-focused communication strategies to their patients' understandings of the mammography experience.

### Opportunities for Health Communication Practitioners

The findings from these interviews suggest that women develop coping strategies when confronting a less-than-optimal mammography experience (fear and avoidance). These strategies at the same time might lead them to delay screening, exacerbating their risk for late-stage cancer diagnosis and potentially missed early treatment opportunities. Thus, there are clear opportunities for improving health communication practice.

One suggestion from this research is that health care providers and mammography technicians avoid simplifications about the mammography procedure with women who express worries about mammography pain. These fears are valid, as well as their personal worries about the meaning of a breast cancer diagnosis in their everyday lives. Medical professionals also need to be cognizant of the limitations of information-seeking or social resources for women in medically underserved communities. Appalachian women clearly need help confronting their mammography screening and breast cancer fears, which may be accomplished through messages about the ways in which women can reduce their pain and embarrassment. This formative research, consistent with Cohen's (2009) prior research, suggests the likely inappropriateness of "loss-framed" messages and fear appeals focused on the disparate burden of late-stage breast cancer diagnosis among Appalachian women. Instead, one promising area for future research is to develop strategies for assisting Appalachian women to cope with their uncertainties and emotions in the mammography screening and follow-up care context. The implication for clinical communication is that technicians and providers should sensitize themselves to women's multifaceted resistance to regular mammography screening recommendations.

## CONCLUSION

These in-depth interview conversations revealed challenging opportunities for mammography communication. Although extant scholarship has explored barriers to

mammography in medically underserved populations, this research sheds insight on the formative influence of women's nascent mammography experiences on their understanding of mammography maintenance and mammography outcomes. Awareness of breast cancer is high in the Appalachian study population under consideration, and fear is prevalent in women's communication regarding the prospect of confirming a breast cancer diagnosis. Given the pervasive knowledge about the importance of mammography, but inconsistent mammography practices in the region, these interviews demonstrate the next step for researchers: to develop culturally appropriate communication interventions to improve adherence to mammography scheduling by addressing obstacles to effective patient-centered communication related to mammography and follow-up care.

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