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Multi-Pronged Solutions Addressing Barriers to Breast Screening Access in Appalachia

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ABSTRACT

Annual mammography screening is recommended by the US Preventive Services Task Force (USPSTF) and American Cancer Society (ACS) to reduce mortality through early detection of breast cancer. In rural Appalachia, rates of later-stage breast cancer incidence and mortality are higher than national averages. We explored the ways that providers and staff at breast cancer screening facilities employed novel approaches to overcome patient- and facility-level barriers to access to breast cancer screening in the Appalachian region. We conducted 23 semi-structured interviews with 28 clinical providers and staff of breast health facilities in Appalachia. Themes reflect how limiting features of breast screening facilities influenced access to care; the way patient-level barriers presented challenges to access to breast screening; and that external and regulatory forces presented obstacles to access to care. In addition, the unique geographical and geographical attributes of the Appalachian region shaped access and adherence to mammography screening recommendations. Thematic findings highlight that facilities implemented patient-centered strategies to overcome access-related barriers. Results may inform the ways breast cancer screening facilities address suboptimal access to breast health screening. They may also

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inform future resource allocations to enable facilities to reach breast cancer screening performance goals.

KEYWORDS: rural health, breast cancer, preventive health care, women's health.

The American Cancer Society (ACS, 2023a) recommends, for those with an average risk of breast cancer, mammography screening to reduce mortality through early detection of breast cancer. Indeed, the guidelines stipulate that women[2] age 45 to 54 should be screened annually, and that women 55 and older should transition to biennial screening. The US Preventive Services Task Force (USPSTF) draft recommendation statement stipulates that those ages 40 to 74 years should receive biennial screening mammography (US Preventive Services Task Force, 2023). Yet, trends in mammography screening remain flat or have declined slightly over the last decade after years of increase (Sprague et al., 2014). The medican age of breast cancer diagnosis is 62, with a recent decrease in death rates occurring due to screening and improved treatments. However, that decrease has has slowed in recent years (American Cancer Society, 2023b).

In rural Appalachia specifically, rates of later-stage breast cancer incidence and mortality are higher than national averages (Blackley et al., 2012; Wingo et al., 2008; Yao et al., 2017). Women in the Appalachian region often experience suboptimal population screening rates, which are especially pronounced among those residing in rural areas (Anderson, Yang, Matthews et al., 2014; Brown et al., 2009; Lyttle & Stadelman, 2006). Appalachia-residing women also experience a relatively higher proportion of diagnosed later-stage tumors than women in other regions (Anderson, Yang, Matthews et al., 2014; Brown et al., 2009; Lyttle & Stadelman, 2006). Factors associated with poor outcomes like these may include an undersupply of mammography facilities (Elkin, Atoria, Leoce, Bach, & Schrag, 2013; Elkin, Ishill, Snow et al., 2010; Elting et al., 2009), as well as long appointment wait times and variable facility operating hours (Collie-Akers et al., 2012; Elkin, Snow, Leoce et al. , 2012).

National data on receipt of screening show that about 70% of women reported receiving screening for breast cancer (Gorina & Elgaddal, 2021). Prior research on patterns of underutilization of screening mammography in Medicare-insured women in Appalachia found that economically-distressed counties showed lower rates of biennial mammograms (42%) compared with those in more affluent counties (54%) (Anderson, Yang, Matthews et al., 2014). Furthermore, in spite of reporting similar levels of self-efficacy and positive beliefs related to breast cancer screening relative to urban-residing women, rural-living women reported lower levels of education and screening overall (Davis et al., 2012). . One of the most important barriers to breast cancer screening among patients in rural settings is geospatial access (Davis et al., 2012).

While research has enabled an understanding of women's needs for better access to preventive health services, less is known about the relationship between features of breast cancer screening centers and disparities in screening. Disparities may include those related to range of mammography services offered, levels of staffing, equipment and technology, and policies and practices intended to promote screening, such as marketing, advertising, and other forms of community outreach. These features are important, since mammography center characteristics may affect both recall rates and cancer detection (Grabler et al., 2017; Lehman et al., 2015; Oeffinger et al., 2015; Rosenberg et al., 2011). A better understanding of them may enable increased uptake

[2] In this article, we refer to our population of interest as women, largely to mirror the language used by study key informants. As we acknowledge that individuals who receive screening and diagnostic examinations for breast cancer may include individuals who identify as any gender, information reported is intended to include people of all genders.

by way of improved access to screening among populations with low rates of screening, and/or with high rates of tumor diagnoses.

Still, services reflecting patient-centeredness, such as reminders sent to patients reminding them of upcoming screening appointments (Feldstein et al., 2009), may encourage appointment-making or -keeping. Other approaches that motivate patients to adhere to appointments may include extending facility hours of operation (Engelman et al., 2004), and offering same-day results (Dolan et al., 1999). Research also illustrates that mobile screening units, (Reuben et al., 2002) promotion of screening services via marketing, advertising, and outreach (Schmid et al., 2008), and staff training (Remennick, 2006) may facilitate appointment adherence and sustained screening rates.

In 2019, Anderson, Hillemeier, Camacho et al. (2023) developed and tested a new framework measuring mammogram facility resources, policies and practices: the Breast-Imaging Operations, Practices and Systems Inventory (BIOPSI). The BIOPSI instrument was designed to assess key health facility practices and policies, as well as resources believed to influence breast cancer screening uptake and patient outcomes through early cancer detection. With this instrument, the investigators aimed to classify and compare screening uptake from a range of screening facilities, as well as identify organizational features or qualities that could be targeted for improvement to increase screening rates. They administered the BIOPSI instrument to 377 mammography centers in the Appalachian region and determined their catchment areas to identify facilities' uptake of screening mammograms. In the present study, we sought to enrich the interpretation of the BIOPSI survey data through qualitative interviews to support clarifications and refinements in strategies for supporting facility performance.

Objective

The objective of this study was to explore facilitators and barriers to breast cancer screening in the Appalachian region. To inform policy solutions to address access-related issues, we sought to understand strategies taken by providers and staff at breast cancer screening facilities to overcome the barriers.

Methods

Study Design

We employed a qualitative study design to understand key informant interview perspectives on facilitators and barriers to access to breast cancer screening for patients residing in the Appalachian region.

Sampling

We located facility administrators, radiologists, nurses, and radiologic technologists employed by breast screening facilities in the BIOPSI study region, inclusive of independent facilities and health systems in the Appalachian regions of Pennsylvania, Kentucky, and West Virginia. In terms of informants' professional roles, we sought to interview a balanced mix of providers (e.g., radiologists) and staff (e.g., technologists).

We initiated the recruitment process via initial contact to health facility office managers and nurse managers who could serve as coordinators for organizing individual or group interviews at each facility. In that initial email communication, we explained the purpose and procedures of the interviews, and requested that the coordinators invite their colleagues to participate. We

conducted follow-up outreach via phone on an as-needed basis with coordinators to identify additional informants from their facilities and schedule interviews. We selected informants to interview on a rolling basis until we reached consensus on the adequacy of the level of new information being reported during interviews.

Data Collection

We conducted semi-structured interviews. We offered key informants (hereafter referred to as "informants") from each facility the option of participating in individual or group interviews according to their preference and availability. As depicted in our interview guide (see Supplemental Material: Appendix I), interviews covered topics such as services provided at informants' facilities, barriers to achieving or sustaining high breast cancer screening rates and other organizational challenges; facilitators to high screening rates and other successful organizational strategies; and the impact of the COVID-19 pandemic on facilities' policies and practices.

We utilized Zoom's built-in audio recording software to record interviews for transcription. We took extensive field notes and developed memoranda during data collection. The primary investigator also practiced reflexivity, a process whereby researchers acknowledge their position as investigators who bring their own experiences, and biases, to the research (Dodgson, 2019). She acknowledges that her identity as a woman residing outside of the Appalachian region and without clinical training may have influenced the extent to which and direction of probing questions asked during interviews of informants, many of whom resided in Appalachia and/or were practicing clinicians. We utilized an independent, HIPAA-compliant transcription service (Mulberry Studio, 2023) to transcribe the interview data prior to coding.

We offered informants Amazon gift cards worth $100, regardless of whether they participated in an individual or a group interview. We mailed compensation to each informant's place of work/breast health facility.

Analytic Approach

Four members of the research team (CBS, BR, GB[i], and GB[ii]) utilized an inductive approach to identify emergent themes from the data. This process began with three analysts (BR, GB[a], and GB[b]) individually open coding, without a pre-determined coding scheme (Strauss & Corbin, 1990), the same three transcripts in order to preserve context. The open-coding process involved applying tags, or codes, to transcript excerpts reflecting key ideas or messages conveyed to generate an initial code list. Coders resolved discrepancies in coding applications by consensus.

Each analyst open-coded more than 10% (O'Connor & Joffe, 2020) of the total sample (i.e., three interviews). Once we achieved agreement on coding applications based on that subset of interviews, we expanded the code list and generated a draft codebook, which included the code name, a definition, applicable sub-codes, and example excerpts. The entire team then met to discuss applications of open codes in each of the three initial transcripts.

To establish inter-coder reliability, each coder subsequently coded the remaining transcripts such that two analysts coded each transcript, again resolving discrepancies in coding applications by consensus. We refined the codebook iteratively by modifying, merging, and splicing codes as needed to develop a final version.

Once the team agreed on the codebook, two team members coded each of the remaining transcripts using a qualitative research software program (Dedoose) (SocioCultural Research Consultants LLC, 2020). Analyst pairs met independently to discuss discrepancies and agree (Glaser & Strauss, 1967) on code applications. The whole team met weekly to discuss overarching

coding issues and to track progress. Codebook refinement involved analysts noting new codes and presenting them to the group for consideration before determining which codes may be germane to the rest of the transcripts, and thus warrant inclusion in the iterated codebook. CBS and CL facilitated and oversaw the coding process.

Once the team coded all transcripts, we conducted a thematic analysis. We considered various interview features, including each key informant's professional role as well as the site of their breast screening facility. We grouped codes into first-order categories rooted in the words of our key informants reflecting the codes applied to the data, which enabled the identification of second-order emergent themes.

We received Institutional Review Board (IRB) approval to conduct the interviews by the Boston University Medical Campus IRB (H-38487). We report data in compliance with the recommendations put forth by the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

Results

Interview Details

We conducted 23 qualitative, semi-structured interviews with a total of 28 informants, including breast screening facility clinical providers and staff, from the BIOPSI study region health facility clinical providers and staff, between September 2022 and March 2023. There were more informants than interviews because we held two of the interviews with multiple informants. We conducted interviews via Zoom (Zoom, 2023) with each lasting approximately 30 to 60 minutes.

Informant Characteristics

We interviewed 11 informants whose main sites were based in PA; 8 whose sites were based in KY, 3 whose sites were in VA, and 1 whose site was in WV. We interviewed 7 radiologic mammographers/technologists; 10 non-clinical informants with coordinating, managerial, directorial, or supervisory roles in radiology or imaging; 9 clinical radiologists; and 9 nurses, one of whom served as a nurse navigator. We describe these and additional informant characteristics in Table 1.

Thematic Development

Figure 1 depicts the first-order categories and second-order emergent themes. Themes included how limiting features of breast screening facilities influenced access to screening care; the way patient-level barriers presented challenges to access to breast screening; and that external and regulatory forces presented obstacles to access to care. In addition, the unique geographical and non-geographical attributes of the Appalachian region shaped access and adherence to mammography screening recommendations. To address the access-related issues, breast imaging centers employed unique, patient-centered strategies. In the following sub-sections labeled Themes 1-5, we describe each theme, expounding on any sub-topics within each in ***italics***. Within each sub-topic, we include exemplary quotes offered by key informants (KI).

Theme 1. Limiting Features of Breast Screening Facilities Influenced Access to Breast Screening Care

A majority of informants described facility-level shortcomings that impeded access to timely and effective breast screening care for patients. The most commonly noted facility-level challenges noted were a lack of specific services or breast screening equipment; limited capabilities for patient outreach and marketing; ineffective coordination with outside (i.e., primary and specialty care) practices and facilities, and the decision-making capabilities of facility leadership. Among these, a general lack of resources represented many of the barriers that informants discussed. Informants reported that high staff turnover, low-grade technology, and a lack of financial resources for marketing/advertising/outreach, as well as the impact of COVID-19, plagued many facilities. Collectively, these barriers contributed to suboptimal delivery of effective breast screening services.

Staffing Issues

The vast majority of informants viewed staffing as a resource that directly impacted screening rates. Low staffing levels limited the number of daily screening timeslots and created a backlog of screening appointments. Additionally, informants described insufficient staffing as likely deterring screening, as informants speculated that patients may forego screening if they cannot schedule a timely appointment or be able to walk in. One radiologist offered:

> *It's difficult to staff…some of our community facilities, the wait time is incredibly high… there's barely any staff there. And so for them to be able to schedule something, it's a month or so out, or maybe even two months out…The further along you schedule people out, the more difficult it is, and potentially the less likely it is for some of our patients to want to do [get screened].* (KI 20 - Radiologist, PA)

Facilities found it difficult to recruit and retain new employees, especially in rural areas. Indeed, multiple informants noted that physicians and other health care providers and staff were reluctant to move to remote areas. One radiologist and another informant said, respectively:

> *We are a pretty high-volume center, with limited staffing resources. You know, in a rural area, it's hard to recruit people, both radiologists and techs and nurses, which is a nationwide problem now, but especially in rural area…* (KI 18 - Radiologist, PA).

> *I'm [at this facility] because it's home. This is where I grew up. It's the hospital I grew up in...on the flip side, there is no way to get other people here ... to try to recruit another radiologist who's not from here to come here is a huge task – a task that really, no amount of money will get someone to come, especially [because] our specialty is in such high demand, that anyone can get a job anywhere. There are very few people looking to move to rural [PLACE] two hours away from anything.* (KI 16 - Radiologist, PA)

Suboptimal Screening Technology and Equipment

A lack of updated screening technology and equipment also limited facilities' ability to provide effective services. Informants frequently expressed concern about a lack of modern screening devices leading to patients seeking services at other facilities, potentially outside of their local community. One informant said:

> *We're not performing 3D [mammography]...I feel that more people would use our facility if we were providing 3D because, in my opinion, 3D is the standard of care these days.* (KI 5 - Manager of Imaging, PA)

One nurse navigator described her facility as "behind" in procuring up-to-date screening technology, to the point that it was costing the facility patients. Alluding to providers an staff not wanting to highlight the technology's arrival so as not to draw attention to its previous absence, she said:

> *We're losing some people … because we don't have tomosynthesis yet and we were late getting digital mammography. We were behind the eight ball there, too. And I think, by the time we got it, I thought, 'Oh, [providers and staff] will advertise. They'll say that we got digital.' They never did.* (KI 1 - Nurse Navigator, PA)

To increase accessibility to mammograms, informants suggested using mobile mammography units or opening more screening clinics closer to patients. Other suggestions included increasing and upgrading facilities' mammography machines. While informants expressed a desire to provide the latest radiologic technology to their own patients, they underscored that, due to the size and rurality of their facilities, technology was often only available to those who were able to drive to access it. One informant described this:

> *...we are a small rural facility and we have one mammo machine and it's very old. It still works. It works well. But, with any radiology equipment, technology is [outdated] after a few years. And we would really love to upgrade and offer our patients the same equipment that they can have if they drive 30 minutes to a bigger city…(*KI 14 - Radiology Manager, KY)

Facility Finances

In addition to facilities' small size and rurality, informants perceived a lack of overall financial stability as a primary reason why facilities were unable to provide adequate staffing and/or cutting-edge technology. One radiologist noted:

> *…if the hospital could afford more equipment, we could do more studies every day. And then our backlog … we'd have a normal wait time ... If we had more techs, we could do mammograms into the evenings, and on the weekends, to open up time, on the equipment that we have. But...we're limited financially, from the hospital side, for equipment and staffing.* (KI 16 - Radiologist, PA)

In terms of equipment, many informants identified mobile screening units as a "wish list" item to be purchased, were it possible. One radiologist described how a lack of financial and human resources precluded this possibility, limiting screening access to rural-living populations, saying:

> *I'd buy a mobile mammography unit and staff it, and have the funds to staff it, and send it to … the rural areas. I know there's a big Amish population up north near [PLACE]. I'd do a bunch of outreach with that.* (KI 22 - Radiologist, PA)

Impact of COVID-19

Many informants described the mandate to pause screening mammograms at the beginning of the pandemic. Most imaging centers had shifted to offering diagnostic mammograms and reducing opportunities for preventive breast health care. One radiologist noted that a facility completely "…shut down for about a month and a half…" (KI 22 – Radiologist, PA), recalling learning of fear among patients and family members with a family history of breast cancer. Other informants recounted staff furloughs resulting in reduction of working hours, resulting in fewer available appointments (KI 7 – Clinical Manager, Breast Care Center, KY). Informants also noted unique screening events, such as a "walk-in Wednesday program" offering patients the chance to obtain a screening mammogram without a prior appointment; unfortunately, that event, and similar others, closed during the COVID pandemic and were never reinstated (KI 21 – Radiologist, PA). Finally, one informant characterized the height of the pandemic in that region as "a pretty bad winter," and underscored that screening mammograms did not return to their pre-pandemic volumes for about a year afterward (KI 18 – Radiologist Section Chief, PA).

Theme 2. Patient-Level Barriers Presented Challenges to Screening Access

Informants described various barriers that individual patients faced in accessing breast screening. They discussed patients having limited transportation options as an obstacle when traveling long distances to seek care, as is common in many parts of Appalachia. Informants also perceived patient beliefs and personal priorities as patient-level barriers to screening.

Personal Priorities

Informants frequently described their patients as "poor," "proud," and "private," and who often prioritized work over preventive health care, avoiding or delayed medical visits until any existing symptoms worsened or new conditions emerged. One technologist reported, "These people were just raised poor and to focus on work and things like that, instead of their health…" (KI 3 - Radiologic Technologist, KY). Another informant held a similar belief about patients, saying:

> *We live in a real rural area. It's country folk… And, a lot of ladies, if they don't see a problem, they don't come for a mammogram. Unless they are having a real problem, they won't have an exam to have anything checked out. So as far as what we do, is just trying to follow up, and trying to call them, get them on schedule, send them reminders... That's all we can do. We can't make someone come in.* (KI 11 - Mammography Supervisor/Lead Technologist, VA)

Other informants talked about other characteristics among Appalachian patients, suggesting that features of their upbringing contributed to modesty and a reluctance to expose themselves during appointments. One informant said:

> *...we're in the heart of Appalachia. And so there's just this bubble, I guess sometimes I like to say. It's a very proud people, a very private people. That's how they've been raised. And that's how we've always been. And so these are people who don't even like to have conversations about medical issues that they may be having that doesn't require them to remove clothing, with their provider.* (KI 17 - Director of Radiology, KY)

Informants also described other deterrents for patients in getting screened, including the inevitability of death and having cancer. One nurse described the attitude of some patients who believe ignorance is bliss, saying:

> *We have a lot of 'better off not knowing.' We hear a lot of, 'Well, something's going to kill me.' Hear that a lot, especially with our older population. And so it's hard to convince them, [and say], 'Well that's true. But it doesn't have to be breast cancer. We can avert that one if you just work with us.'* (KI 17 - Nurse and Director of Radiology, KY)

Personal Feelings about Health Care as a Result of the COVID-19 Pandemic

Several informants suggested that patients felt differently about their willingness to get screened for breast cancer as the pandemic wore on. At the beginning, many screening facilities closed. Once they reopened, some patients were reluctant to come in for various reasons. One informant described how people were reluctant to wear masks—which facilities required staff and patients to do in order to reduce the risk of exposure and transmission – causing patients to avoid visiting a health care facility to get screened. This hesitance was also tied to political leanings. One informant said:

> *I noticed that the patients are very sick of masks…But that's also geographical, too. This area is more anti-mask than if you went to [PLACE], based on political leanings. But that's something you notice here, is people are very tired of masks.* (KI 16 - Radiologist, PA)

Informants also reported that patients incorrectly and inappropriately connected confusing or inaccurate information with COVID-19 vaccinations and other health-related information. For example, one informant discussed a misinterpretation of the relationship between COVID-19 vaccinations and enlarged lymph nodes with breast cancer, saying:

> *…there was a lot of media about how we can find increased lymph nodes … after immunization. That did cause some confusion … And then, people were getting conflicting messages about whether they could come for their mammogram, whether they should, how they should space it, and how they should schedule it. And I still have a few patients … when they were told they needed a biopsy, or that they actually had a cancer, they were like, 'Do you think this is from the COVID vaccine?'* (KI 19 - Radiologist, PA)

Theme 3. External and Regulatory Obstacles Presented Challenges to Screening

Our data revealed that external issues, such as lack of access to transportation, as well as regulatory ones, such as differing screening guidelines, complicated matters related to access to breast health screening.

Inadequate Transportation

Several informants reported that due to the lack of nearby screening facilities and under-resourced facilities in rural areas, patients must either drive long distances, which were often particularly difficult for the elderly or sick, or wait for someone else to drive them to their appointment. This infrastructure issue presented a problem for patients residing in areas without public transportation options. One informant related:

> *We have zero public transportation…we have no Ubers. We have no taxis. We have no…other ride share things. We have zero, none. There are no public buses. So everybody has to depend on somebody else…* (KI 17 - Nurse and Director of Radiology, KY)

Another informant bolstered this idea:

> *We service approximately a ten-county area, which is a little less than 400,000 lives. And…we're the largest provider in that ten-county region. So some of them, some of the patients would have to travel an hour for a screening mammogram...a lot of the patients are elderly and can't drive across three counties to get their screening mammogram; they have to wait till they have a ride from family members, and a lot of family members work.* (KI 6 - Radiological Services Manager, KY)

Health Education

Informants often perceived patient education and health literacy as patient-level barriers to screening care. However, health literacy also emerged as a regulatory barrier to care. Informants often viewed educating the public as a responsibility and public service of the local health system. When asked what could be done at their facility to improve screening, a radiologist replied that patient education requires provider education, saying:

> *I wish I had more time … to go to every single family practice doctor's office, and talk to the doctors, educate the doctors [on updated breast screening recommendations]. And then they could educate the patients. ...The world of medicine is not like that right now. There's certainly no free time allocated for things like that.* (KI 19 - Radiologist, PA)

Multiple informants noted that conflicting guidelines provided by external agencies impeded their ability to educate the patient population about cancer-related health and best screening practices. Informants often saw these competing guidelines as a shortcoming of their facility, and providers' ability to offer sound, consistent screening recommendations to patients. This inconsistency and ensuing confusion was viewed as detrimental to effective patient education

and health literacy. One radiologist offered a poignant example of how differing guidelines confused not only patients, but also physicians:

> *…some [physicians], were telling their patients to come every two years, and not starting them until 50 ... I had a colleague once, a family practitioner, I was like, 'Just curious why you go along with the USPTF Guidelines instead of the ACR Guidelines.' And his response was, 'Oh, are there different guidelines?'... So if your doctor is telling you to come every two years as a patient, you're probably not going to be compliant with coming every year, which is a big deal.* (KI 19 - Radiologist, PA)

Misinformation Stemming from Conflicting Guidelines Around Screening

Informants identified another barrier as misinformation surrounding, and misunderstanding of, screening mammogram recommendations. Informants described patient confusion due to inconsistent breast cancer screening guidelines. One radiologist referenced disagreement between two organizations providing guidelines around breast cancer screening: the Society of Breast Imaging (SBI) and the American College of Obstetrics and Gynecology (ACOG). According to the informant, members of both groups recommended annual screening beginning at age 40, while noting that the ACS changed its recommendation from initiating screenings at age 40 to 45, and the USPSTF suggested biannual screening starting at age 50. The informant reported negative consequences of this inconsistency, saying of the USPSTF guidelines:

> *So [SBI and ACOG] recommend…'start at 40'…the American Cancer Society used to agree with that. But then a couple of years ago, they started waffling a little bit, maybe [making it] a little bit more confusing for patients…They say, 'Have the conversation at 40. Definitely start by 45'…Then, to compound that, you had the USPSTF…who recommends starting biannual screening at 50. So not annual screening…And you know, I have seen patients die because of those recommendations…* (KI 22 - Radiologist, PA)

Another informant discussed the way different guidelines suggesting differing ages at which to start and end screening mammogram uptake can lead to infrequent screening , and can lead to a reduced quality of life, especially for older adults:

> *I know a bunch of 80-year-olds who are vivacious, active. If they stop getting their mammograms at age 72, we know cancers in older people tends to grow slow—maybe takes 10 years before you get a big mass, or have metastatic, or whatever disease. But still, it ends their quality of life.* (KI 12 - Radiologist, VA)

Theme 4. Facilities Used Innovative Approaches to Overcome Barriers to Screening Access

While informants acknowledged both facility-level (Theme 1) and patient-level (Theme 2) barriers to screening mammograms, providers and staff used various means to accommodate patient needs, enabling access to these services. Specifically, informants noted that providing effective communication and outreach, removing financial barriers, extending appointment hours,

and coordinating patient care with other facilities served as the primary mechanisms for overcoming barriers to screenings and follow up. Moreover, many of these facilities were located in small communities, where informants understood that personal connections through friendly and comforting staff was paramount.

Strong Health Care Personnel-Patient Communication and Rapport-Building

Informants frequently described using effective communication as a tool to remind patients of annual screenings, upcoming appointments, and information on guidelines and recommendations. Means of communication included purposeful outreach, such as phone calls, letters, and asking providers to remind patients of annual screenings. One informant said:

> *...We try to reach out in every way that we can, to make them aware and get them in...We do… follow-up letters. And then, if they don't respond to that…our mammo tech…will call the patient and say, 'Hey, I sent a letter out. And we haven't heard from you. So we're just following up to see if you would like to schedule your mammogram'.* (KI 14 - Radiology Manager, KY)

In addition to follow-up, other means of facilitating provider-patient communication included providers and staff speaking with patients directly about their care. One informant described the importance of the long-standing, trusting relationships between patients and their physicians who had been in the community for a long time, as opposed to with nursing and other staff at informants' sites in encouraging screenings. One nurse said:

> *...the second biggest issue that I see, is that I can call the patient all day, and talk to them about the importance. Nursing staff, x-ray staff, all the ancillary staff can have that conversation with the patient. But some patients are not on board until they sit down with their provider, who they trust, and who they love in most cases, and would never see another provider no matter what, says to them, 'You need to go have this done.'* (KI 17 - Nurse and Director of Radiology, KY)

Informants noted multiple times that the personal connection was important in building rapport and "trust" with patients of small communities. Having friendly and comforting staff, treating patients with respect, maintaining staff longevity, and making accommodations to decrease patient fears were emphasized as the relational aspects that held the most value. Team collaboration and shared decision-making and (screening and treatment planning) goal alignment were also important relationship builders. One technologist exemplified this:

> *… Everyone I work with, we all work great together…When everyone can work together for the one purpose, of taking care of these women, and finding breast cancer, and treating it moving forward, to live longer lives. That's what we're here for.* (KI 8 - Lead Breast Ultrasound Technologist, KY)

Employment of Fear Mitigation Techniques

Informants developed trust with patients by drawing upon proven strategies to reduce fear among patients with a higher-than-average risk for breast cancer or who were awaiting a possible diagnosis. These efforts included accommodating scheduling needs through same-day appointments and providing fast turnaround times for results. One informant expanded on this, saying:

> *…We try to get everybody in as quickly as we can if they're for additional views. We work people in when they're scared. If we call them back, and they're crying on the phone, we'll bring them right back in that same day. So, our patients know we care about them…*(KI 10 - Lead Breast Care Center Technologist, Radiology)

Indeed, some informants understood that the fear or hesitance around obtaining screening mammograms stemmed from a fear of pain of the procedure. According to one informant who said, "you have some people who are afraid of a mammogram. They are afraid that it's going to hurt" (KI 1 - Lead Breast Care Center Technologist, Radiology), working through that fear is a barrier that providers and patients can work through together. Another informant praised her colleagues for prioritizing bedside manner in mitigating patient fears around screening mammograms:

> *I'm pretty proud of the little facility we have here…We don't treat patients like they are cattle coming in and out. I mean they're—you know, they're brought in. If they have a problem, our radiologists give them the results before they leave, so they're not, you know, going home scared if it's a cyst…We work people in when they're scared, you know, if they—We call them back, and they're crying on the phone, you know, we'll—if we have to, we'll bring them right back in that same day…we are very caring towards our patients. And they know that. I think they can sense that.* (KI 10 - Lead Breast Care Center Technologist, Radiology)

Adjusting Imaging Center Practices Around Patient Needs

Accommodating patients' scheduling needs sometimes involved extending facility hours to overcome financial and transportation-related barriers. Informants described how facilities extended their hours while promoting the importance of screening, particularly during October for Breast Cancer Awareness Month. Imaging centers also leveraged local community events to raise awareness of breast cancer screening and promote opportunities for screening via extended facility hours. One imaging center manager said:

> *...we participate in a lot of community events, there's a career day at the high school that we go to. And one of our techs will go down and give the information to the students about becoming a mammography tech...There's also an event at the high school with volleyball…And we pass out little pink volleyballs with our hospital name on it...we run ads in the newspapers…and we also offer mammograms later in the evening, on the second and fourth Tuesday of the month…for the women who are working or…can't get here during the day.* (KI 9 - Manager of Imaging, VA)

Informants also described how facilities covered some of the costs that patients often incur related to breast screening, such as those related to overnight stays, travel, or child care. One informant exemplified this:

> *We certainly have some staff that help with anything that they can do to help patients in regards to maybe cards for gas, or we also have a family house at [INSTITUTION] that offers a discounted rate that would be less than a hotel room for patients to stay.* (KI 23 - Medical Director, Breast Health Center, WV)

Another informant discussed informants' need for childcare, noting one facility's willingness to accommodate a patient by allowing her son to accompany her to her medical appointment:

> *[One patient said], 'I need to come in for my mammogram. But I don't have a place for my little son. He's not in school yet. Can he come along?' And I said, 'Yes, certainly.' So he came along, and I sat with him in the little waiting area. And she had her 10-minute mammogram. And she was done, and out the door. So we try to accommodate that way.* (KI 1 - Breast Health Nurse Navigator, Mammogram, PA)

Electronic Health Records

To encourage patients to make or keep their screening appointments, some informants described policies and practices their facilities implemented, such as reminder phone calls, community outreach events, and communication through an electronic health record (EHR) system. EHR systems were noted as being useful for rural-living patients because they often accessed their medical information using their cell phones rather than personal computers. One informant recounted this benefit and how it facilitated immediate access to patients' health information:

> *It actually does fairly well to those that have access to the internet. Because they can come in, and get their screens, and get their labs, reports, and everything is sent to their phone. Where, if they have the application on their phone, they can view their reports, just as soon as they are updated.* (KI 3 - Radiological Services Manager, KY)

Tailoring Patient Care to Reduce Risk of COVID-19 Exposure

Finally, many facilities employed strategies to keep patients safe during the height of COVID-19. In the spirit of patient-centered care and in response to the pandemic, most facilities were forced to adapt their procedures to reduce the risk of COVID-19 transmission. In addition to mandating mask-wearing, staff at one facility relocated patient registration from the waiting room to the private mammogram area. One nurse explained one of their re-engineered processes by saying:

> *[prior to COVID] when a patient came in, they would register out front. And [staff] would give them a clipboard with our question ...As soon as COVID hit, I said, 'Oh, we're not sharing clipboards and pens.' So we took it upon ourselves to…our tech actually goes over the questions with the patient, and fills out all the paperwork. So, the patient is not dealing with clipboards and pens…we found, too, that our techs can get a little bit better information … I think that's worked out well.* (KI 1 - Breast Health Nurse Navigator, Mammogram, PA)

Another imaging center administrator described how her facility eliminated its dressing room and allowed women to change in the mammography screening room, encouraging patients to undress and don their mammogram gowns in the same room where they received the procedure, which patients enjoyed:

> *we just quit using that dressing room altogether. And then we started taking the patients directly into the room and having them undress there…we still haven't gone back to using that waiting area because the majority of patients loved just coming straight back into the room and getting undressed right there and not even having to leave again.* (KI 7 - Clinical Manager, Breast Care Center, KY)

Theme 5. Characteristics of the Appalachian Region Shaped Screening Access

All informants provided insight into the unique characteristics of the Appalachian region where facilities were based and where patients often resided, as well as their impact on breast cancer screening uptake. From informants' perspectives, features of rural Appalachia in particular made it difficult for many patients to access screening mammograms.

Geographic Vulnerability to Natural Disasters

One particular natural disaster disrupted patient care when the facility employing some informants lacked the infrastructure to cope. These informants described how a then-recent major flood in their region exposed the vulnerability of their region, leaving many without homes and access to medical care. One informant described how one of the facilities affected by the flood required staff to discontinue screening temporarily due to flood-induced damage to the facility's only mammography machine. She said:

> *our home clinic here, we had about four feet of water within our building…our mammography machine had to be replaced. That was July 28th. September 26th, we started doing mammography again here* (KI 13 - Director of Radiology, KY)

In addition to being flood-prone, features of the Appalachian region in which breast cancer screening facilities and their patients resided presented multiple barriers for both facilities and patients in this study. As one informant elaborated, expanding access to breast screening providers would be needed to increase screening rates:

> *I think to increase screening rates here, you would have to go to the patients, or have more options for places they could get their screening mammogram, versus where I'm talking about is an hour and a half away, might come to me for a screen, because it's their only—you know, I'm the closest one. And to get people to come that distance is hard. So I think that's either opening more clinics, or having some sort of mobile program, I think is—would help in a rural area like this.* (KI 16 - Radiologist, PA)

The same participant echoed the idea that, among patients with access to a personal vehicle, limited access to providers often demanded that patients drive long distances and/or take time off work to visit the doctor. She said:

> *It's inconvenient here. You know, our hospital is in one town. But the next town is 40 miles away. It's hard to get people to go to the doctor if it's in the town they live in, let alone drive 40 miles to take a day off of work to go get a mammogram.* (KI 16 - Radiologist, PA)

Discussion

In this paper, we present findings from qualitative, semi-structured interviews with providers and staff from Appalachia-based breast cancer screening facilities. The results from the present study were intended to extend and contextualize the findings from the BIOPSI survey and inform breast cancer imaging center policies and practices in Appalachia.

According to informants, breast screening patients in Appalachia – and in rural Appalachia, where many breast screening facilities are located, in particular – faced barriers to screening mammograms due to a lack of transportation, money to pay for office visits, and individual priorities, which reflected a personal need to work over accessing preventive health care (Theme 2), as well as poor health literacy (Theme 3). In spite of high staff turnover and low volume of staff at many facilities—as well as the long-term impact of COVID-19 on facilities' screening rates(Themes 1)—when patients did attend office visits, they were able to access patient-centered care. Reasons for thismay include the long-standing relationships with health care providers and staff, who have been employed for many years and have thus developed rapport and trusting relationships with patients (Theme 4). Those personnel implemented policies and practices, many of which were instated as preventive protocols in response to COVID-19, to improve engagement with patients and, return, access to screening mammograms. Informants seemed to relish the fact that patients appreciated many of the newly-instated policies and practices, encouraging staff to continue them beyond the pandemic's peak. Still, findings illustrate that, from informants' perspectives, characteristics of the Appalachian region and its residents shaped access to screening mammograms for a majority of patients (Theme 5).

With respect to Theme 5, various features of Appalachia presented multiple barriers for patients and health care personnel, only some of which facility staff were able to help address. While facility providers and staff were unable to address immutable patient-level barriers, such as inadequate transportation and personal priorities limiting screening mammogram uptake, they were able to address others. Informants identified prevailing misinformation among patients and attempted to offer sound and consistent guidance in order to address confusion stemming from the inconsistent messages around screening. Informants also employed other strategies, such as permitting same-day appointments, to reduce reluctance to obtaining mammograms due to fear of results or hesitance to attend office visits. Due to low facility resources, personnel were often

unable to address staffing issues as well as facilities' equipment with suboptimal screening technology and equipment. On the other hand, they were often able to educatepatients about the importance of screening mammograms, in spite of reporting less frequent success clarifying misconceptions around COVID-19 and the vaccine. Overall, informants reported that strong health care personnel-patient communication and rapport-building helped address patient reluctance and fear, and provide needed health education.

Informants also believed that meeting patient desires by way of implementing new policies and practices was of utmost importance to patients. For example, eliminating the dressing room and thus preserving patients' modesty served patients as well as providers and staff better in that they were able to see patients more quickly than when patients undressed in the dressing room first. This new practice represented one way that providers and staff tailored patient care to reduce the risk of exposure to COVID-19. Finally, the benefits of having EHR often helped address transportation-related barriers facing patients that precluded their ability to access breast health results in person, since patients could use their cell phones to review screening results.

Findings from this study extend and bolster those from extant literature. In this study, we found similar barriers to those identified in prior research. In a qualitative study of 27 in-depth interviews with women in Appalachian Kentucky (Cohen et al., 2016), informants descrybed similar barriers to breast screening to those identified by health care professionals in our study. These include how pain and embarrassment, fears about cancer, and poor provider communication may preclude timely and appropriate adherence to mammograms as well as follow-up care. Indeed, the study highlights some barriers that our study also identifies as common among Appalachian women (Cohen et al., 2016).

Another concept that arose in our study was that related to patients' health literacy. Gunn and coauthors (2021) found that primary care providers were reluctant to engage patients with low health literacy in shared decision-making for multiple reasons, including time constraints of the visit and a fear of causing information overload. Study informants felt that education prior to the PCP visit might support the shared decision-making success (Gunn et al., 2021). Our study bolsters those findings by suggesting that providers and staff at some facilities in Appalachia attempted to overcome patient health literacy barriers by implementing fear mitigation techniques and rapport-building with patients.

Given the plethora of challenges in providing and/or obtaining screening mammograms for both facilities and patients, some health systems have undertaken still other approaches to increasing uptake. Some health systems have opted to integrate approaches to increase breast as well as cervical and colorectal screenings. Subramanian et al. (2022) described how existing programs integrated evidence-based interventions like patient reminders with other activities, such as approaches to optimize medical records for patients. Nelson-Brantley et al. (2021) identified strategies and barriers, adaptations, and determinants of cancer screening among 8 rural primary care practices based in the Midwestern US after joining an accountable care organization (ACO). Results from focus groups with those practices' health care providers and staff showed that, after participating in the ACO, practices adopted various strategies, successfully increasing screening rates by utilizing EHRs and engaging nurses in screenings. Results from the present study may hold promise for screening uptake among patients in rural Appalachia, representing an area for future research.

Similar to other exploratory studies of this nature, our study has some limitations. First, our study sample consisted of breast cancer imaging center administrators, staff, and physicians from across the Appalachian region. However, it was not population-based, suggesting that the findings may not be generalizable or transferrable to all breast cancer screening facilities in the study region. However, the fact that our findings are consistent with those from other studies in

Appalachian areas suggests that the themes we have identified likely pertain to other health care settings in the region, deeming our study one with likely applicability and relevance to other facilities in the same geographic location.

Second, our data may be limited by asymmetry of information, as we did not interview everyone at each of the imaging centers where we conducted interviews. This may have hindered our ability to understand the full picture of breast cancer screening at each facility. However, we did make multiple attempts to interview additional informants at each imaging center where unique practices or policies were uncovered in initial interviews. Those attempts to gain additional information were typically successful.

Last, recall bias may limit this research. Informants often offered differential levels of knowledge about particular topics based on their unique areas of expertise or experience. For example, some informants had been practicing for decades in nursing roles at some facilities, while others were newly employed radiologists. However, key informant interview data often reflect different perspectives based on these and similar informant characteristics, (UCLA Center for Health Policy Research, n. d.) and therefore likely do not threaten the robustness of this research.

Finally, we recommend specific policy recommendations related to two of our five themes. In terms of Theme 3 (External and regulatory obstacles presented challenges to breast cancer screening), municipalities should invest in public transportation for breast health patients. Health systems should ensure education of providers on updates to breast health screening practices, which would thereby keep patients informed of the same information when providers serve as a trusted source of information. Relatedly, organizations issuing guidance on breast health should agree on screening recommendations to avoid confusion, unnecessary anxiety, or missed opportunities for primary or secondary preventive medical attention stemming from conflicting recommendations.

With respect to Theme 4 (Facilities used innovative approaches to overcome barriers to screening access), we suggest that facilities bolster their existing approaches. First, they should maintain quick turnaround times after patient visits to ease patient anxiety and reduce transportation burden. This requires adequate staffing, which relies partially on adequate funding. As such, they should continue to engage with the community to raise or maintain funds. Finally, facilities should continue to offer social support services to patients who need them. While both recommendations require adequate financing to enable or facilitate their implementation, these efforts would enable access for many rural-living breast health patients.

Conclusion

While mammography centers track and report their screening rates in US Food and Drug Administration (FDA) facility audits, few have investigated how key features of their organizations' policies and practices relate to screening rates and outcomes. Through the interviews in this study, we achieved a deeper understanding of the way organizational structures, such as patient-centered strategies to address barriers to access to breast cancer detection services, may shape access to breast and other cancer detection services. Findings from this research may also be used to inform future resource allocations to reach breast cancer screening performance goals and reduce disparities in adverse breast health outcomes among women in Appalachia and beyond.

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