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Provider-Patient Communication and Abnormal Mammogram Delays:
A Qualitative Study

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Abstract

BACKGROUND: Delays in communication and/or timely follow-up of abnormal mammogram results can lead to psychological distress and diagnostic delays. The majority of research on abnormal mammogram follow-up focuses on patient, rather than provider and healthcare system factors. Medically underserved and limited-English proficient women face structural and personal barriers that limit healthcare engagement. We explored the relationship between provider and healthcare system cultivation of patient engagement and timely follow-up to abnormal mammograms.

METHODS: We conducted 61 in-depth, semi-structured interviews with women from three health systems, across four race-ethnicities (African American, Asian, Latina, White) and three language groups (Cantonese, English, Spanish) who had an abnormal mammogram requiring biopsy documented in the San Francisco Mammography Registry (SFMR) in the previous year. We defined delay to follow-up as 30 days between index mammogram and biopsy. Women were asked to reflect on their experience and provide suggestions on improving communication and follow-up processes. A Grounded Theory approach was used to explore themes across transcripts.

RESULTS: Twenty-one women had a delay in follow-up. Unclear provider-patient communication due to (a) linguistic barriers, (b) complex terminology, or (c) mode of information presentation undermined women's understanding and was associated with delays. Women who reported feeling confused also reported feeling unable to ask clarifying questions. Interpreters or support from healthcare personnel (e.g. patient navigators) was associated with fewer delays.

CONCLUSION: Gaps in communication led to confusion and delays for women after an abnormal mammogram. System-based interpretation and navigational assistance can help to mitigate both confusion and delays.

Introduction

Every year in the United States, millions of women will undergo mammographic screening to detect breast cancer. The American Cancer Society (ACS) estimates there will be 266,120 new invasive diagnoses, 63,960 in situ diagnoses, and 41,400 breast cancer deaths in 2018 (American Cancer Society, 2018). The ACS's recommendation for regular mammogram screenings starting at 45 years of age (for average risk women) has been associated with early detection and reduction of cancer morbidity and mortality (Oeffinger et al., 2015). However, a limitation to breast cancer early detection is delayed follow up to an abnormal mammography screening. *Delays to timely follow-up* refers to delays in a patient's mammogram results, appointment/scheduling, follow-up mammogram, and biopsy. *Delays to resolution* refer to postponements in providers' and patients' understanding of the abnormal mammogram as cancer or benign. Delays in follow up and resolution to abnormal mammograms can cause both short and long term psychological distress (Brett et al., 2005; Molina et al., 2017; Molina et al., 2014; Tosteson et al., 2014).

The majority of research on abnormal mammogram follow-up delays focuses on patient personal and structural factors. For example, in a study surveying 970 women, risk factors that contributed to significant diagnosis resolution delays included: being African American, income less than $10,000, and perceived discrimination (Pérez-Stable et al., 2013). Differences in (a) breast cancer incidence, (b) abnormal mammogram results follow-up, and (c) time to diagnosis are more likely to be delayed among ethnic minority groups such as African Americans, Asians, and Latinas (Nguyen et al, 2017; Petersen et al., 2018; SEER, 2018; Warner et al., 2012). Particularly, African American and Hispanic women experience lower disease-specific survival rates, despite non-Hispanic white women having an increased risk of developing breast cancer (American Cancer Society, 2017a). Nonzee and colleagues investigated factors that contributed to low-income women's delays to breast cancer screening, follow-up and treatment despite access to care; they found this was due to "lack of knowledge of resources, denial or fear, competing obligations, and embarrassment" (Nonzee et al., 2015). Additionally, several studies have shown non-English speakers have difficulty communicating with providers and accessing care, which in turn can affect health outcomes (Fernandez et al., 2011; Karliner et al., 2012; Molina et al., 2014; Schwei et al., 2016; Terui, 2017). Based on the literature, there are limited studies that observe provider and healthcare system factors contributing to delays to abnormal mammogram follow up.

Although following through with next steps and medical care often falls on the responsibility of the patient, patients cannot fully engage with the healthcare system if there are health system barriers that limit comprehension and exacerbate delays. Throughout each step of the mammogram process, communication regarding diagnosis, upcoming appointments, treatment options, and next steps is necessary; however, unclear facility and provider communication can lead to lack of timely follow-up and delays in resolution (Karliner et al., 2005; Murphy et al., 2018; Nonzee et al., 2015). Using the 1998-2006 Breast Cancer Surveillance Consortium linked Medicare database, one study identified variation across facilities and found that facilities serving vulnerable populations with less education and more racial/ethnic minorities had lower rates of

biopsy and longer follow-up times (Goldman et al., 2013). A qualitative, single case study with 12 providers uncovered recurring themes/perspectives on the issue: (a) approaches to patient follow-up, (b) patient barriers to follow-up, and (c) improving follow-up through technology (Fair et al., 2017).

Mode of communication is also important to consider for providers to reach patients in an effective and timely manner. There does not seem to be a consensus regarding the most effective mode of communicating results and follow-up to abnormal mammograms. Modes of communication include verbal communication (i.e., in-person communication, by telephone, and leaving voice message) and written communication (i.e., mail or electronic medical record). Pérez-Stable and colleagues found that patients who do not fully understand index mammogram results, or were notified by letter were more likely to have delayed follow up compared to direct provider communication or telephone calls (Pérez-Stable et al., 2013; Schapira et al., 2018). Facilities that used electronic medical records to notify patients of the need for further follow up were also more likely to be delayed (Schapira et al., 2018). Verbal communication is a more direct form of communication in which healthcare providers are able to interact with patients receiving their abnormal mammogram results and next steps. One study found that patients were more likely to have timely follow-up if they attended a facility that followed-up with patients through phone calls (Schapira et al., 2018). Provider communication methods may affect how patients engage with their healthcare and their abnormal mammogram follow up.

There can be a disconnect in clear communication for patients who do not fully understanding index mammogram results (Marcus, Drummond, & Dietz, 2012; Molina, Hohl, et al., 2014; Pérez-Stable et al., 2013). A study that surveyed 970 women to gauge patient comprehension of their mammogram results found that only 51% of the 304 women with abnormalities understood their mammogram results to be abnormal (Karliner et al., 2005). Patients also cannot engage if they do not comprehend the complexities of their health issue or the complex terminology used to describe it. Several studies have recognized the limitations medical language barriers can play in patients' understanding of medical communication and reports, and found that patients have difficulty understanding jargon, which can in turn affect shared decision making (Qenam et al., 2017; Simon et al., 2013). One study compared English functional health literacy and mammography receipt with Hispanic women and non-Hispanic U.S.-born White women and found that although an equal number of Hispanic and White women received their mammograms, functional health literacy and self-reported mammography in the last year differed among the two ethnic groups after adjusting for co-variates (Kadivar et al., 2016); this suggests the importance of addressing health literacy among all women during their mammogram experience.

Additionally, physicians reported difficulties communicating with patients due to language barriers (Karliner et al., 2011). Language discordance "occurs when patient and health care professional lack proficiency in the same language(s)" (Sears et al., 2013). Compared to professionally trained interpreters, untrained translators were found to be more likely to inaccurately translate medical information (Nápoles et al., 2015). When facility medical

interpreters are not available, often times clinicians attempt to translate medical information, ad hoc interpreters would translate, or patients would use their limited-English skills to communicate with clinicians, which can result in poor quality of information (Diamond et al., 2009; Diamond et al., 2012; Pérez-Stable & Karliner, 2013). Professionally trained medical interpreters are important in getting this message across languages (Flores, 2005; Karliner et al., 2006; Perez et al., 2016).

Karliner and colleagues found that clinicians reported communication difficulties affected how they engaged with patients, as well as limited the clinician's ability to empower patients regarding knowledge on diagnosis and treatment (Karliner et al., 2004). Patient empowerment is defined as "the ability of individual patients to acquire the negotiation and navigation skills…[and] to take responsibility for their own healthcare" (Williams, 2002). This type of direct involvement in one's own health can be achieved for some women; however, it does not account for medically underserved, vulnerable women facing personal and structural barriers that may prevent them from fully engaging with their health. These challenges in patient-provider communication, knowledge, and power can also affect the shared decision making process (Joseph-Williams et al., 2014). Fleming and colleagues argue that providers relying on patient engagement assume "patients [are] willing and able to engage in care and take actions to improve their health," placing the responsibility on the patient (2017).

Additional personnel, including patient navigators, may help resolve intrapersonal-level barriers, as well as system-level barriers (Tejeda et al., 2013). It is well documented that patient navigators are influential in alleviating delays in cancer care (Ali-Faisal et al., 2017; Freeman, 2013; Hoffman et al., 2012; Paskett et al, 2011; Ramirez et al., 2013). Harold P. Freeman describes patient navigation programs as a patient-centered approach to the health care service delivery model used to promote timely movement of an individual patient through the complexities of cancer care, and to eliminate barriers to timely care (Freeman, 2013). A qualitative study found African American female participants reported "staff can encourage medical advocacy through offering information in general in a clear, informative, and empathic style" (Molina et al., 2015). Supplemental healthcare personnel, such as patient navigators, may be influential in bridging the communication gap between providers and patients.

Our study is designed to highlight the value in exploring patient perspectives, and communication factors relevant during the process of delivering and receiving mammogram screening results. Specifically, in the following we explore how healthcare institutions and providers cultivate or undermine patient engagement and timely follow up for abnormal mammogram results.

Methods

Participants

Participants were recruited through the San Francisco Mammography Registry (SFMR) database. Theoretical sampling was conducted (Charmaz, 2014; Glaser & Strauss, 1970); we accounted for race/ethnicity, clinical facility, whether the woman experienced a delayed or timely follow-up, and ensured we had several experiences for each. During this process, a convenient sample of 200 women were initially selected and stratified by facility—10 women with timely follow-up and 20 women with delayed follow-up for each race/ethnicity (Caucasian, Latina, African American, and Chinese). This number allowed for incorrect information or refusals and to reach recruitment goals. Women were stratified based on time to follow-up (less than 30 days from abnormal result to biopsy was considered timely, compared to delayed) with the goal of recruiting an equal amount of timely and delayed for each race/ethnicity.

The American College of Radiology Breast Imaging Reporting and Data System (BIRADS) categorizes breast cancer diagnoses in a standardized way; the system ranges from 0-incomplete, 1-negative, 2-benign findings, 3-probably benign, 4-suspicious abnormality, 5-highly suspicious of malignancy, and 6-known biopsy with proven malignancy (American Cancer Society, 2017b). Depending on the index mammogram result, patients are given a secondary mammogram, ultrasound, or biopsy to determine whether the abnormality is cancer or benign (diagnosis resolution).

There does not seem to be a clear consensus on what constitutes "timely follow-up" following an abnormal index mammogram. Many of these studies give varying definitions of what they considered timely abnormal mammogram follow up, ranging from 28 days to 9 months (McCarthy et al., 2016; Oppong et al., 2016; Pérez-Stable et al., 2013; Petersen et al., 2018; Selove et al., 2016). These studies cite the Mammogram Quality Assurance Act, National Quality Measures for Breast Centers value, Centers for Disease Control and Prevention (CDC) recommended performance standard, or use previous/their own definitions of timely follow up and resolution (Caplan, May, & Richardson, 2000; CDC, 2007; U.S. Food & Drug Administration [FDA], 2018). This unclear definition of timely follow-up could be contributing to differences among facility assessment and communication times. We categorized patients as having either short (timely) or long (delayed) follow-up, and defined women as *delayed* if follow-up occurred more than 30 days after the abnormal result. Although there is no clear guideline or standard for timely abnormal mammogram follow-up, the 30-day cut-off for a BIRADS 4/5 result defined in this study has both clinical relevance and face-validity based on the American College of Radiology (ACR) recommendations for rapid communication of these results due to the fact that they are the most likely results to represent a cancer and thus require a biopsy for follow-up.

Eligibility for this study includes women who (1) have had an abnormal mammogram (BIRADS 4 or 5) with a recommendation for biopsy in the prior one year, (2) have not declined to be for further research on the SFMR questionnaire, (3) speak English, Spanish, or Cantonese, (4)

are between the ages of 40 and 74, and (5) have no history of Ductal carcinoma in situ (DCIS) or invasive breast cancer prior to the index abnormal mammogram.

Once identified, eligible participants were sent an invitation letter through mail with an opt-out/in postcard. The letters were written in English, Chinese, and Spanish. Language data were not available for individual women through the SFMR; English-Spanish and English-Chinese letters were sent to participants who self-identified as Latina or Chinese, respectively. Two weeks later, women who did not opt out were called and invited to participate. A research assistant mailed letters and called women to confirm eligibility and schedule in-person interviews in a rolling fashion until the interviews from each ethnic group were completed. During the phone call, the research assistant confirmed the woman's eligibility to participate, her ethnicity, and preferred language of interview. Interviewer and patient language were matched for the in-person interviews.

Data Collection

Sixty-one in-depth semi-structured interviews were conducted with patients about their experience with the healthcare facility and its providers in handling their abnormal mammogram results. The interviews were conducted by the bilingual-bicultural research assistant at the research team's offices in the privacy of a closed-door office, or a preferred location designated by the participant. At the in-person interview, women were asked to sign a written consent form for participation in research, and they will also have the consent explained to them verbally in their preferred language. The interviews were conducted in the patients' preferred language (English, Spanish, or Cantonese). Questions and topics explored include: experiences with communication and coordination of care after an abnormal mammogram result, perceived system facilitators and barriers to timely follow-up, and specific recommendations for system improvements to facilitate timely follow-up. The interviews were audiotaped and transcribed verbatim. Each interview lasted approximately 40-60 minutes. The women were reimbursed for transportation or parking, and given $40 each to thank them for their time.

Data Analysis

The interview transcriptions were deidentified for confidentiality and did not contain the names of the participating women. Transcripts were translated into English. The transcripts were formatted appropriately and uploaded into ATLAS.ti v.7, a computer-assisted qualitative data analysis software, for coding (*ATLAS.ti*, 2013).

A qualitative analysis using a Grounded Theory approach was used to openly explore common themes across transcripts. Coding was conducted by a graduate student research assistant trained by one of the investigators. Analysis of data involved reading through the transcripts and coding them using an inductively and deductively derived codebook. Inductive codes were new ideas or concepts mentioned in the transcripts (e.g. understanding of tags), and deductive codes were concepts that the study was designed to answer (e.g. communication between providers and

patients, and patient recommendations). Throughout the coding process, team members met to discuss codes and emergent themes. Once all codes were entered into ATLAS.ti, we conducted "queries" and "co-occurrences" to evaluate the associations between specific codes and identified patterns in the data (*ATLAS.ti*, 2013). We coded and created analytically appropriate code groups, ran queries, and drafted theoretical memos reporting patterns and themes that emerged from the data. These patterns became the themes reported in our findings.

Results

Descriptive characteristics of study participants are presented in **Table 1**. Most of our interviewees received their care in the safety-net setting (n=30). Of the 61 women interviewed, 40 were classified as having timely follow-up (13 Spanish-speakers, 24 English, 3 Cantonese) and 21 as delayed follow-up (4 Spanish-speakers, 15 English, 2 Cantonese). Interviews were conducted in women's preferred languages, which include: 39 in English, 16 in Spanish, 6 in Cantonese. The race/ethnicities of the 61 interviewed female participants include: 14 African American, 13 Chinese, 19 Latina, and 15 Caucasian women. The patients had their mammograms conducted in one of four urban clinical facilities. **Table 2** reports participant follow up status facility and preferred language. Follow-up status by facility include: Safety-net (22 timely, 8 delayed), Academic (14 timely, 10 delayed), and Community facility (4 timely, 3 delayed).

Table 1. Descriptive Characteristics of Study Participants (N=61)

	N (%)
Facility	
Safety-net	30 (49)
Academic	24 (39)
Community	7 (12)
Language	
English	39 (64)
Spanish	16 (26)
Cantonese	6 (10)
Race/Ethnicity	
Latina	19 (31)
White	15 (25)
African American	14 (23)
Chinese	13 (21)
Total N	61 (100)

Table 2. Study Participants' Preferred Language by Facility, and Timely or Delayed Follow-up Status (N=61)

Facility	Timely N (%)	Delayed N (%)
Safety-net		
English	6 (60)	4 (40)
Spanish	13 (81)	3 (19)
Cantonese	3 (75)	1 (25)
Academic		
English	14 (64)	8 (36)
Spanish	0 (0)	1 (100)
Cantonese	0 (0)	1 (100)
Community		
English	4 (57)	3 (43)
Spanish	0 (0)	0 (0)
Cantonese	0 (0)	0 (0)

Characteristics and supplemental support at each facility varied. The Safety-net Facility had an established patient navigation program while the other two facilities did not. Healthcare institutions and providers play a crucial role in determining how the mammogram experience will unfold for patients. Unclear provider-patient communication at any point in the mammogram process can undermine patient engagement and result in delays. This is especially the case for medically underserved patients. Our study highlights various factors that play key roles in effective facility and provider communication with patients: (a) mode of communication, (b) explanation of medical processes and terminology, and (c) use of translational services. These system factors can also make a difference in whether patients experience delays or psychological distress at any point in their mammogram process—particularly those who receive abnormal mammogram results.

In the following, we present findings from interviews with patients from one of three healthcare facilities (Academic Facility, Community Facility, and Safety-net Facility), and highlight instances of their abnormal mammogram experience that were either hindered or cultivated. All women's names are pseudonyms used to protect the woman's identity. After each quote, demographics and characteristics of each patient are listed as such: (Patient Identification, Interview Language, Ethnicity, Follow-up Status, Facility).

Mode of Communication

Patient-provider communication can vary by mode in which information is presented. Mode of communication between healthcare providers and patients can range from written, verbal,

direct or indirect interactions. Results delivered via letter/mail and electronic medical record are indirect, since there is no way for patients to engage, ask questions, or go back and forth. On the other hand, verbal and direct communication creates opportunities for more personable interactions and can cultivate engagement.

Hindered

Indirect modes of communication were challenging for patients in our study. Several examples of limiting interactions among patients and providers include those over the phone, especially when a one-way voicemail is received by the patient. For example, Michelle received an unclear voicemail on her telephone from a nurse stated:

> *"To be honest it seemed like, somebody who was inexperienced in leaving that kind of voicemail because it was sort of vague and I don't know, I was very unsure what it meant…It didn't have a lot of information about what was or wasn't found. It was just sort of vague about something was up and you should call this number. I sort of wished at that point that I had spoken with somebody so that I could kind of get more clarity or maybe even the doctor had left a message because my doctor is really good at…just being clearer."*
> (174, English-speaking, White, Timely, Academic Facility)

The Academic Facility left Bonnie a voicemail about her abnormal mammogram result. After listening to it, she reported feeling confused and "frantic." Bonnie did not know what to do after receiving the results, nor was the message specific about why/how her mammogram was abnormal. The message included an incorrect follow-up phone number and no name of a specific person to contact.

> *"They left a message and they weren't very informative, unfortunately. I wasn't very impressed with the way they presented the information…my mammogram was abnormal but they couldn't give me any information. That was frustrating too, why it wasn't normal."*
> (189, English-speaking, White, Delayed, Academic Facility)

If the phone message was clearer, or if she was given the results in person, she would have been able to ask clarifying questions. Similarly, Diana was called over the phone regarding her index mammogram results.

> *"[The phone call] went fine but once I hung up, I was like, "Oh my gosh." I started Googling everything…it was traumatic to me…"*

She went back for her second mammogram less than a week later:
> *"They never called me back saying anything was wrong but they were telling me to come back within a year and check again to make sure everything is okay. I still haven't made that appointment yet…because I'm just nervous and I haven't gotten around to it."*
> (40, English-speaking, African American, Timely, Safety-net Facility)

Diana's experience demonstrates the anxiety caused when the patient, on two separate occasions, was not able to ask questions. As another patient, Paula, noted:

"[It] doesn't have to be face to face conversation about it, but a genuine conversation with [providers]…Not just saying you need to make an appointment to come in… Just explaining exactly what was abnormal, why was this specifically, and what are the good reasons, or what the potential findings are would be of something like that…what we're going to do to define those in the process of having a biopsy."
(188, English-speaking, White, Timely, Academic Facility)

Josefina received her care from the Safety-net Facility and reported her frustration with trying to make appointments over the phone, especially since she speaks Spanish:

"To schedule an appointment is very complicated. I almost always go in person because I don't understand them…But I had to insist a lot, they didn't deal with it right away, one person would transfer me to another, the other to another one, and that's how it was…that makes me very angry…I was so frustrated."
(26, Spanish-speaking, Latina, Timely, Safety-net Facility)

When asked about reading electronic medical records, a Cantonese-speaking woman reported, *"I don't even know how to use [a computer]…I don't know how to surf the internet, even with an iPad…I'm not in the mood to learn it."*
(271, Cantonese-speaking, Chinese, Timely, Safety-net Facility)
Natalia reported feeling distressed as a result of receiving her results via letter.

"[The facility sent] a letter…it said that [the biopsy and the mammogram] were abnormal…I felt bad because both results were bad…that's when I told my friends. She hugged me and we cried. I wanted to be strong but I couldn't."
(96, Spanish-speaking, Latina, Timely, Safety-net Facility)

For many of these instances indirect or unclear mode of communication hindered engagement and women experienced psychological distress.

Cultivated

It was the first time Barbara had a biopsy. "I didn't really know what to expect, and I didn't know what to compare it to," she told us. However, she was given a brochure as a visual representation of the procedure, and then discussed the process with her provider.

"They did a good job of both explaining it, then they gave me this kind of brochure thing that essentially said the same thing she said, but that way, you don't always remember stuff you're told…[To] see the drawing and you have something to expect, helps."
(161, English-speaking, White, Timely, Community Facility)

Joanne reported having a good relationship with her primary care provider, which is reflected in the communication they had over the phone and in person.

"I really like my primary care doctor…I appreciate the way that she takes time, that she talked to me, that she really encourages me in my own self health care…She said, 'It's probably nothing but I just want to be sure. I just want to be able to rule it out.' I remember those words…[My appointment] was made. My doctor…always makes sure that

appointments are made for me and someone calls me and reminds me…[During the
appointment] my doctor talked to me a lot about [the biopsy]. Just reassured me."
(115, English-speaking, African American, Timely, Academic Facility)

 Faith was first notified of her results via phone call but immediately scheduled to meet
with two providers in person regarding next steps.

"[The facility] called me and they made an appointment for me to come back. I actually
had to go talk to the doctor [and anesthesiologist] first because they'd determined that I
needed the [biopsy] …They wanted to know how my mindset was…They were trying to put
me at ease… trying to relieve my anxiety."
(38, English-speaking, African American, Timely, Safety-net Facility)

Patients reported follow up communication, direct and personal interactions with
providers, or supplemental personnel as helpful in understanding next steps, giving patients the
opportunity to ask clarifying questions, or feeling supported.

Medical Processes and Terminology

Clinicians sometimes overlook translating medical jargon and complex medical processes
into lay terms that can be universally understood. We highlight several women's perceptions of
providers explaining medical processes and terminology, and how this can affect their
comprehension of diagnoses, next steps, or treatment.

Hindered

Women reported the use of medical jargon and a failure to explain procedures in an
accessible manner as a challenge. For example, Mona was not given any information beyond the
diagnosis, but reported wanting more information.

"Basically, the only thing that they specified was that it wasn't cancerous. They never
explained to me why it happened, why it grew, whether there was a possibility for it to
grow back in the same place or if anything was extracted; I never knew. I didn't even
know who to ask about those things."
(94, Spanish-speaking, Latina, Delayed, Safety-net Facility)

May reported not understanding medical terminology,

"Doctors have big words and you don't understand…Just break it down to me…A lot of
doctors' terms is not something I would just know…I think we as a patient need to be
responsible and clarify whatever you don't know because at the end of the day it's about
you."
(43, English-speaking, African American, Timely, Safety-net Facility)

Several patients expressed confusion regarding the breast tissue marker, or tag, that was
inserted after the biopsy. The breast tissue marker was placed at the biopsy site for subsequent

breast examinations and future reference for the provider. For example, Tanya was not sure what they were placing inside her.

> *"I got the biopsy, and then they put something in there, so that they know for the next mammogram that the lump has been checked out."*
> (15, English-speaking, Latina, Timely, Academic Facility)

She later reported wishing the providers had given more information about the tag, and that the process was more clearly explained to her. Similarly, after Esperanza had her results revealed to her, the providers wanted to give her a breast tissue marker.

> *"Then when the [nurse], the one translating, asked me if I gave authorization to leave that little thing in—Actually from the nerves, I didn't even hear whether it was to mark something or whether it was an experiment."*
> (26, Spanish-speaking, Latina, Timely, Safety-net Facility)

Although many of these women were not considered delayed by our definition, these experiences undermined their understanding of the procedures they were undergoing. As Martha noted,

> *"They just told me they were going to implant the microchip and it was for this purpose. That was the only thing they told me. They didn't tell me the side effects. So I would like them to be more honest and more open, so the patient can decide. 'I am going to do it knowing the risks, but I am aware of what I am going to do.'"*
> (25, Spanish-speaking, Latina, Timely, Safety-net Facility)

Lastly, Daniela had a biopsy in the past. When she went for her most recent mammogram and there was an abnormal finding, the provider told Daniela that she needed to choose between a biopsy or wait until her next routine mammogram for another follow up. She reported feeling scared making this important decision on her own.

> *"I panicked. Another biopsy…There is the option that if it does not grow it can be there, but it was like—not knowing what to do. I did not know what to do. I needed someone to tell me, 'You have to do this because it is the best option for you.'"*
> (09, Spanish-speaking, Latina, Delayed, Academic Facility)

Ultimately, she decided to not have the biopsy, and to wait until the next screening for follow up. These examples highlight the importance of systematic guidance for patients throughout complex medical processes.

Cultivated

Instances in which medical terminology and processes were clearly explained resulted in less delays and less reported distress. Healthcare personnel played an important role in such communications. For example, one patient, Jane reported:

"The pathologist…kind of tells [other providers] in their language what's going on. Then, translated it to me in layman's terms. Then, they…tell us right away if there's cancer or anything like that…It hasn't been so far…they're on top of it."
(106, English-speaking, African American, Timely, Academic Facility)

Lupe reported her satisfaction with her patient navigator, who helped explain and support her throughout the mammogram process:

"During that time the person who was my navigator, the one in charge of explaining the process to me and giving me support, encouraging me…in the midst of all the worry and the sadness that you feel, at the same time you also feel joy from knowing that there are people who care about what's happening to you. Even if you don't know them, seeing that they're moving and trying makes you feel more confident about making decisions. In this case, mine was to get [a biopsy] done sooner…She was on top of everything."
(46, Spanish-speaking, Latina, Timely, Safety-net Facility)

Lupe reported appreciating the navigator not only for the explanations, but for the help she received making informed decisions about surgery. The navigator expedited this process for Lupe, which helped her feel comfortable about having the biopsy, which resulted in a timely follow-up.

When asked about recommendations for other women going through the same medical process, several Chinese women mentioned having an advocate figure that would help patients through these complex medical processes. For example, Xin reported:

"Well hopefully they could have an advocate, you know, somebody. I don't know, doctors don't provide that…Just to make sure the communication is clear and in their primary language and questions are answered."
(232, English-speaking, Chinese, Timely, Academic Facility)

Fei highlighted her positive experience with a nurse who also served as her translator,

"Although the doctors speak English, they have translators for you, especially the nurse. She can explain things well and she's a caring person. She knows how to say diplomatically, which is really comforting…She makes you relaxed by telling you there's nothing to worry about…The way one talks to you does make a difference."

(217, Cantonese-speaking, Chinese, Timely, Safety-net Facility)

Patients reported feeling supported when they had engaging interactions with knowledgeable healthcare staff, including patient navigators, interpreters, and nurses.

Facilitation of Translational Services

Linguistic barriers pose fundamental communication challenges for patients. Discussions of important health information between patients and providers are critical to understanding diagnoses and next steps. Translation services, or lack thereof, within each facility contributes to varying experiences for women during their mammogram process.

Hindered

After two mammograms, Carmen's provider asked her if she wanted either a biopsy or an ultrasound; however, these options were communicated in English and Carmen was Spanish-speaking. No interpreter was present during this interaction.

> *"I didn't talk to anyone or the doctor because there wasn't an interpreter…you want to have what's going on explained to you in Spanish. Because if they talk in English among them…you have no idea what's going on…I think that if they had explained it to me in Spanish…perhaps I would've accepted. But in English they told me, 'Do you want the biopsy?' So I said, 'I don't know.' I mean for me it seemed easier to say than, 'Oh it's better if you do the ultrasound because it doesn't hurt, right?' …I left very angry and said, 'I didn't understand a thing!' So I don't know, I just have to wait."*
> (65, Spanish-speaking, Latina, Delayed, Safety-net Facility)

Carmen expressed feeling unable to make a decision about her treatment options without an interpreter present. She mentioned that she did not understand what they said thus, she did not receive the biopsy.

Similarly, another Spanish-speaking patient, Rosa, was asked about her overall experience and she responded that the process should have been faster. When further asked about communication during her most recent appointment, she responded,

> *"I thought, 'If I ask for an interpreter, it's going to take longer and I want to go.' So I said, 'No, it's fine.'"*
> (42, Spanish-speaking, Latina, Delayed, Safety-net Facility).

Time was important to Rosa, and her perception of the time it would have taken to call an interpreter prevented her from fully engaging with providers. Ultimately, she was considered delayed. If the facility or provider had had an interpreter present during the interaction, this situation might have been different.

Another Spanish-speaking patient, Nina, reported seeing other patients struggle with paperwork.

> *"Sometimes you get out of your appointment and you see a person who can't even fill out their paperwork, or anything…and they get stuck [on a question] and don't move on…Because there's no one who speaks Spanish there."*
> (73, Spanish-speaking, Latina, Timely, Safety-net Facility)

Not having an interpreter or someone present in the waiting room to assist low literacy and low English Proficient patients filling out paperwork hinders these patients' ability to fully engage with the health system. Linguistic communication issues within healthcare facilities posed serious challenges for LEP and non-English speaking patients.

Cultivated

Bella had received an abnormal mammogram and reported feeling worried and scared regarding her biopsy. A Spanish-speaking social worker was present through the process. She assisted with paperwork, set up appointments, and was present before the biopsy procedure. Bella reported,

> *"[The social worker] was like my guardian angel and never left me. Every time I had a doubt, I would tell her…I looked for comfort in the social worker…but she transmitted a lot of confidence to me."*
> (25, Spanish-speaking, Latina, Timely, Safety-net Facility)

Juanita described a similar experience,

> *"And the lady who was there that spoke Spanish was holding my had the whole time, telling me everything was fine. 'There's nothing serious happening. Don't worry about it. This is going to be fast.'…[For the results] they called me…The doctor called me to say I shouldn't worry, because everything was fine. That they would send me a follow up appointment, and that if I wanted to come to have things explained in person, I could….[The doctor] called me in English, but the girl who spoke Spanish was right there…[After receiving the result] I felt better. I felt happier."*
> (48, Spanish-speaking, Latina, Timely, Safety-net Facility)

Donna recalled receiving a letter regarding her follow up. She called the facility and said,

> *"I asked [the staff] if there was anyone speaking in Cantonese…they had an interpreter. The nurse would speak to the interpreter first, then the interpreter would translate for me in Cantonese…When I had my breast checked each time, though the doctors did not understand Chinese, and I did not understand English either, I did not have to worry. They were so nice…I did not have to worry either, because they had a Chinese interpreter for me."*
> (246, Cantonese-speaking, Chinese, Timely, Safety-net Facility)

Provider linguistic ability was also noted as a strength. As Valentina stated,

> *"[My doctor] does understand a lot of Spanish…when it came to the mammogram, it wasn't very difficult for her to communicate and explain to me what it was. She explained it to me properly in Spanish."*
> (88, Spanish-speaking, Latina, Timely, Safety-net Facility)

As these examples suggest, having an interpreter, social worker, patient navigator, or provider fluent in the patient's language matters for low-English proficient patients. As Camila noted,

> *"How good would it be if when they were dealing with a [Spanish-speaking] person so that there could have better communication…so you could feel more sure about everything that's going on, because you just don't understand…"*
> (98, Spanish-speaking, Latina, Timely, Safety-net Facility)

Discussion

Among a variety of women's experiences across different facilities, variations exist in follow-up and diagnosis following abnormal mammogram results. The central themes uncovered were the processes in which healthcare facility and provider level communication cultivated or hindered follow up based on (a) how information was presented, (b) explanations of complex medical processes and terminology, and (c) translational services to patients. We found that facilities with patient support mechanisms using supplemental and bilingual personnel (i.e., patient navigators, bi-lingual clinicians and nurses, professional interpreters, social workers, etc.) were more likely to communicate (a) in a timely manner and (b) in ways patients could comprehend functionally and linguistically. However, the process in which each facility facilitates, conducts, and utilizes these translational and support services needs to be further explored.

Women reported that the mode of communication affected their engagement and ability to interact with the facility and provider regarding their abnormal mammogram results. Similar to our findings, a study conducting focus groups with low-income inner-city minority women found that women were dissatisfied with results communication, experienced difficulty comprehending the notification letter, preferred direct verbal communication of results, desired supplemental print material, desired an action plan/hotline to ask questions, and were interested in understanding likelihood of additional follow up (Marcus et al., 2012). Having multiple iterations of direct, verbal communication using a variety of platforms may help reach and remind women of the need for follow-up after they receive their abnormal results. Additionally, system-level interventions, such as electronic triggers can flag and identify patients with delayed abnormal mammogram follow up (Murphy et al., 2018).

Translational services and the facilitation of interpreters also played an influential role in whether providers could communicate with patients in their preferred language. Terui argues language barriers present unique challenges to theoretical and practical implications in healthcare delivery, and points out that not all patients experience linguistic challenges in the same way (2017). She also describes how language barriers contribute to health disparities by highlighting both direct and indirect pathways to health disparities, such as stressors and access to healthcare, respectively. These pathways were supported by our findings since many participants reported feeling scared or frustrated when they did not understand providers or the results due to language barriers; in turn limiting their engagement during the mammogram process and possibly delayed next steps. A qualitative study on breast cancer care and patient-provider communication found Spanish speakers preferred Spanish-speaking providers and were appreciative of language support resources (Simon et al., 2013). Several of our participants reported feeling happier and confident knowing someone spoke the same language during medical encounters. Having access to interpreters was seen to improve health outcomes (Karliner, Pérez-Stable, & Gregorich, 2017).

For time-sensitive mammography results, patient-provider communication with full understanding is necessary to make important decisions regarding next steps. The screening process is complicated and requires coordination between patients, providers, and institutions

(Abdiwahab et al., 2016). Several studies suggest that patient navigation has been successful in gaining appropriate follow-up and shortening time after abnormal mammograms (Dudley et al., 2012; Freeman, 2013; Markossian, Darnell, & Calhoun, 2012; Percac-Lima et al., 2015). Furthermore, studies have shown that patient navigators assist patients receiving abnormal mammogram results by providing support, and supporting the communication between patients and providers (Ferrante, Chen, & Kim, 2008; Gabitova & Burke, 2014).

Many studies have considered patient navigation programs as a way to address mammogram process barriers, especially for vulnerable women (Ell et al., 2007; Gabitova & Burke, 2014; Markossian et al., 2012). There are efforts to engage patients in an appropriate way, while specifically alleviating the disparities faced by vulnerable populations. This can be achieved through engagement with patients directly about their health experiences in order to improve patient experience (Molina et al., 2017; Ziebland et al., 2013). Using complex medical terminology and instruction can limit the engagement patients have with providers. Our participants reported the value in discussing their mammogram results with supplemental personnel; and they were able to contextualize and translate complex medical terminology, and were more likely to have timely follow-up to abnormal results. Widely adopting patient navigation programs in addition to supplemental personnel on a health system level may alleviate delays to follow up and patient distress during this uncertain time.

Conclusion

Unclear facility and provider communication was reported more often by women who experienced delay in follow-up and resulted in reported psychological distress, delayed resolution, or lack of follow-through with next steps. Patients in healthcare systems with supplementary personnel (i.e., patient navigators, healthcare providers, or social workers) available to provide direct, in-language navigational assistance reported understanding and following through on next steps. Participants recommended direct and clear communication (e.g. lay language) with medical personnel regarding their results. Translation of complex medical terminology and processes in patients' preferred language through supplemental personnel may alleviate disparities in patient understanding of abnormal mammogram results, which may impact delays in resolution.

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