

Delays in Cancer Care Among Low-Income Minorities Despite Access

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Abstract

Introduction: Narrowing the racial/ethnic and socioeconomic disparities in breast and cervical cancer requires an in-depth understanding of motivation for adherence to cancer screening and follow-up care. To inform patient-centered interventions, this study aimed to identify reasons why low-income women adhered to or delayed breast or cervical cancer screening, follow-up and treatment despite access to cancer care-related services.

Methods: Semistructured qualitative interviews were conducted among women with access to cancer care-related services receiving care at an academic cancer center, federally qualified health centers, or free clinics in the Chicago metropolitan area. Transcripts were coded and analyzed for themes related to rationales for adherence.

Results: Among 138 participants, most were African American (46%) or Hispanic (36%), English speaking (70%), and between ages 41 and 65 years (64%). Primary drivers of nonadherence included lack of knowledge of resources, denial or fear, competing obligations, and embarrassment. Facilitators included abnormality identification, patient activation, provider-initiated actions, and motivation from family or friends.

Conclusions: Interventions targeting increased adherence to care among low-income and ethnic minority women should direct efforts to proactive, culturally and patient-informed education that enables patients to access resources and use the health care system, address misconceptions about cancer, ensure health care providers' communication of screening guidelines, and leverage the patient's social support network.

Introduction

LOW-INCOME POPULATIONS AND racial and ethnic minorities bear a disproportionate share of the cancer burden in the United States. Recent reduction in breast and cervical cancer mortality among women in the U.S. has been attributed in part to early detection;¹ however, ethnic minorities and poor women, irrespective of race, have not equally benefited from these gains. These groups have exhibited lower breast cancer screening utilization,²⁻⁶ lower likelihood of meeting risk-appropriate cervical cancer screening guidelines,⁷ and lower adherence to timely follow-up after an abnormal finding^{8,9} than nonminority or higher-income counterparts.

Several multilevel intervention approaches—from educational interventions to lay health advisor models—have emerged to address complex determinants of health. At the individual level, obstacles to care identified have included low education level,¹⁰ poor health literacy,¹¹ concerns about test efficacy,¹² and language and cultural beliefs related to cancer, distrust, and fear.¹³⁻¹⁵ Compounded with these con-

cerns, systems barriers such as difficulty accessing high-quality diagnostic services,¹⁶ variability in site of care,¹⁷ poor access to primary care physicians or specialists,¹⁸ and lack of insurance,^{19,20} can impact adherence to cancer-related care. Health care reform provisions target financial barriers to access to cancer care but will unlikely attenuate the full range of obstacles to care. To elucidate nonfinancial barriers, in-depth exploration of perspectives among low-income communities with access to cancer-related services merits considerable and timely attention.

Understanding women's perspectives is critical to developing appropriate patient-informed interventions, particularly as millions of women gain coverage for breast and cervical preventive health screenings through the Affordable Care Act. A small body of qualitative literature has examined breast or cervical cancer care among low-income women of color. Most focus on a single ethnicity,^{13,21-23} age group,²⁴ and time point along the care continuum, such as screening,^{21,23} follow-up,^{13,25} or survivorship,^{15,22,26} and factors directly linked to adherence are overall not consistently delineated.

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In this qualitative study, we explored reasons why predominantly low-income and minority women adhered to or delayed breast or cervical cancer screening, follow-up, and treatment despite access to cancer care-related services. In contrast with prior studies, our sample is multiethnic and represents a wider range of ages. Further, our analysis uniquely contributes to existing knowledge, first by examining perspectives across cancer detection, diagnosis, and treatment, second by focusing on low-income women who received free or covered cancer care services, and third by systematically identifying factors participants specifically attributed to delayed or incomplete care.

Materials and Methods

Study setting and participants

Study participants included women with a breast or cervical cancer-related abnormality or positive cancer diagnosis from three types of health care facilities in the Chicago metropolitan area: urban federally qualified health centers (FQHCs), an urban academic cancer center, or suburban free primary care clinics. We selected these sites because they cared for low-income, un- or under-insured, and racial/ethnic minority patients. Additionally, they provided access to free cancer screening and diagnostic services or served a high proportion of publically insured patients. Thus, patients had theoretically minimal financial barriers to entry. In Chicago, non-Hispanic black women are over 1.5 times as likely as non-Hispanic white women to die of breast cancer.²⁷

Study design

We enrolled participants from March 2008 through December 2010. Women were eligible if they were at least 18 years of age and had an abnormal cancer screening test (clinical breast exam, mammogram, or ultrasound for breast cancer or Pap test for cervical cancer) or a positive cancer diagnosis. They were excluded if cognitively impaired or institutionalized. We approached women for participation following a provider referral and obtained verbal informed consent including authorization to audio-record the interview. Trained research assistants collected sociodemographic data at baseline and conducted in-person semistructured interviews in the participant's preferred language (English or Spanish). At FQHCs and suburban free clinics, we interviewed participants up to three times: after an abnormal screening test and, if applicable, after a positive cancer diagnosis, and again during treatment. At the academic cancer center, all women were newly diagnosed and interviewed up to two times: after a positive cancer diagnosis and during treatment. Data were collected until data saturation of subthemes was reached. Each interview lasted approximately 45 minutes, and participants received \$25 upon interview completion. The University of Illinois at Chicago and Northwestern University Institutional Review Boards approved the study.

Interview guide

The interview guide development was informed by the Social-Ecological Model,²⁸ whereby engagement in positive health behaviors is influenced by multiple bidirectional levels: individual, family, community, institutional, societal, and policy. We additionally integrated elements of the

Theory of Reasoned Action²⁹ to elucidate personal attitudes and subjective norms that play prominent roles in women's intent to pursue cancer screening, diagnostic resolution, and treatment. Interview questions thus assessed breast or cervical cancer care barriers across a range of dimensions, including: general health and screening behavior, barriers to timely follow-up, decision-making factors, access to health care, facilitating resources, cultural perceptions, transportation, neighborhood, and social support (Table 1).

Coding and analysis

Audio-recorded interviews were transcribed in the language in which the interview was conducted. Spanish

TABLE 1. EXAMPLE DOMAINS AND QUESTIONS FROM BREAST CANCER INTERVIEW GUIDE

Domain	Example interview questions
General screening behavior	<p>“When is the last time you had a breast exam and a mammogram?”</p> <p>“At that time, did you understand why you had an abnormal breast exam?”</p> <p>“Did you understand why you needed to go for another test, such as a biopsy or repeat mammogram?”</p>
Access to health care	<p>“Is it difficult for you to get the healthcare you need?”</p> <p>“What kinds of issues did you face in getting follow-up care or treatment?”</p> <p>“Are you able to afford visits to the clinic, medications, and treatment?”</p>
Culture	<p>“Do you think your culture could be an obstacle to your receiving the healthcare you need?”</p>
General barriers to follow-up	<p>“What are some of the barriers you have found to obtaining your breast exam, follow-up, or biopsy?”</p> <p>“Are there any side effects from the mammogram, breast exam, or further tests and treatments that make you less likely to follow-up with them?”</p>
Attitudes and perceived benefits	<p>“In your own words, why are breast exams and mammograms important?”</p> <p>“In your own words, why is following up for your cancer care important?”</p>
Decision-making factors	<p>“Why did you choose the time you did to have a breast cancer screen?”</p> <p>“What are some of the factors that helped you make this decision?”</p> <p>“If you delayed obtaining cancer-related care, what factors led to a delay in your decision?”</p>
Resources	<p>“What things or services have helped you to follow-up with your breast exam or mammogram?”</p>

transcripts were then translated into English and back-translated into Spanish for quality assurance. We generated initial codes by independently reviewing the same four transcripts. We then categorized related codes through a consistent team consensus method to synthesize a single, standardized codebook. Trained data analysts (T.L., N.N., A.P., and D.R.) used the codebook to conduct line-by-line coding of all transcripts with ATLAS.ti (Version 6.2) qualitative data analysis software. To ensure consensus among coding schemes, two teams of data analysts independently coded a subset of transcripts, and intercoder reliability was measured with Cohen's kappa of 0.8 or greater.³⁰

We systematically explored the data to identify consensus themes and then rank-ordered them by frequency. Since participants had coverage for cancer-related services, we focused on elucidating nonfinancial barriers to care. To delineate factors with direct impact on adherence, we classified codes as rationales for adherence or nonadherence only if the participant directly attributed the reported facilitator or barrier to a health care outcome (e.g., screening test completion, adherence to appointment, treatment initiation or continuance, etc.). Finally, we stratified the analysis by racial/ethnic group and clinic site, but because only few thematic differences emerged, we present the aggregate results and highlight notable distinctions when present.

Results

Participant characteristics

Participant characteristics are reported in Table 2. Among the 138 enrolled women, most were racial/ethnic minorities (84%), between the ages of 41 and 65 years (64%), and interviewed in English (70%). Forty-one percent enrolled at the academic cancer center, 36% at FQHCs, and 22% at free

clinics. Three-quarters of participants had an abnormal breast cancer screening test result, and half of all women had a positive cancer diagnosis either at baseline or during the study period.

Rationales to delay or forgo cancer-related care

The most frequently reported themes and subthemes for nonadherence are described below. Participants' race/ethnicity, clinic site, and type of cancer abnormality are described after each quotation. Table 3 provides additional exemplary quotations.

Limited knowledge about resources or processes. Confusion or limited knowledge regarding the process of seeking and utilizing preventive care services was the predominant barrier to timely completion of a breast or cervical cancer screening test. Most women expressed an understanding and desire for routine preventive care, but many lacked awareness of available resources for the uninsured. One woman said,

I retired, and then my health care went kaput and I just didn't know where to go or where to turn. ... I did try to get some more health insurance, and it was just too high; we couldn't afford it. (African American, cancer center, breast)

Several participants expressed confusion over processes of clinical care. For example, one woman described that her health care provider explained her abnormal Pap test and the necessity of follow-up testing, yet she still felt uncertain about the cancer detection and follow-up process: "It was like I understand it but I didn't understand it" (African American, FQHC, breast).

Most evident among Hispanic women, cultural and language barriers contributed to difficulty navigating the health care system and understanding preventive care resources, especially for first-generation immigrants. One woman commented:

I didn't know the places where I could get a Pap smear test, a mammogram and all that. ... In Mexico I could, because you have your social security. But when I came here I thought, 'You don't know anybody here.' And then, there's the language ... (Hispanic, FQHC, breast)

Further, for some women, lack of a social network impeded acquisition of information. This theme was exemplified in the case of another Hispanic first-generation immigrant, who recognized the necessity of screening but detailed her difficulty identifying a clinic in her neighborhood: "I wanted to find a clinic close to where I was. But I couldn't ... I didn't have anybody to advise me" (Hispanic, FQHC, cervix). Without a social network beyond her immediate family that could connect her to a health care facility, she delayed completing her Pap test.

Denial or fear. Denial or fear of cancer arose as another major factor influencing decision making about pursuing or following-up on care. One 68 year-old woman with late stage breast cancer discovered a lump during a breast self-exam but delayed informing her doctor about the lump until after three visits. She explained, "I didn't want to know. It's like when I first felt the lump I was like, 'Oh no, I don't have anything like that,' ... and that's where I was in denial" (African American, cancer center, breast). Women with cancer also

TABLE 2. PARTICIPANT CHARACTERISTICS (N = 138)

Characteristic	n (%)
Race/ethnicity	
African American	63 (46)
Hispanic	50 (36)
White	22 (16)
Asian	3 (2)
Age (years)	
20–40	40 (29)
41–65	88 (64)
> 65	10 (7)
Preferred language	
English	92 (70)
Spanish	42 (30)
Clinic site	
Academic cancer center	57 (41)
Federally qualified health center	50 (36)
Free clinic	31 (22)
Abnormal screen type	
Breast	102 (74)
Cervical	36 (26)
Diagnosis	
Cancer	68 (49)
Noncancer	70 (51)

TABLE 3. MAJOR THEMES AND SUBTHEMES OF REASONS FOR ADHERENCE TO CANCER-RELATED CARE

<i>Major themes/subthemes</i>	<i>Exemplary quotations</i>
Limited knowledge about resources or processes Resources for the uninsured Processes of clinical care Cultural or language barriers Lack of social network	<p>“I don’t have insurance and I didn’t know anything about ... cheap health care.” (Hispanic, federally qualified health center [FQHC], cervix)</p> <p>“I was naïve to all that because when I was brought up, we didn’t have [mammograms]; I mean, I didn’t see my mother go in for nothing like that ... I have [cancer] because I was naïve.” (Hispanic, cancer center, breast)</p>
Denial or fear Denial/fear of cancer Misperception of disease	<p>“I kind of like didn’t want to make myself believe it so I was like ignore it so that definitely was an obstacle for me because I prolonged [my colposcopy].” (African American, FQHC, cervix)</p> <p>“Right now, I’m just beginning to hear that it is cancerous, because I didn’t even want to believe it ... so you know I wasn’t following up on a lot of my appointments.” (African American, cancer center, cervix)</p> <p>“My pain in my breasts. I was already very, I won’t say too late, well, yes it was too late ... because I was scared, in other words, I was scared to go to the doctor.” (Hispanic, cancer center, breast)</p>
Competing obligations Work Childcare Elderly caregiving	<p>“My friends said you need to go to the Doctor to see what it is, and I’m like oh okay, I ain’t missing work. ... Yes, I did delay [scheduling my screening appointment].” (African American, cancer center, breast)</p> <p>“And most the time I think it’s not about me, it’s about my kids so I get them to their appointment and then it’s like okay, well, now you’re extra late, so now you have to reschedule, then I reschedule again.” (African American, FQHC, cervix)</p> <p>“Well, my godmother is sick and she’s been in the hospital. So I’ve been with her most of the time. So I couldn’t ... I had to cancel an appointment” (Hispanic, FQHC, cervix)</p>
Embarrassment Cultural perceptions Provider gender discordance Discomfort with presence of intermediary	<p>“I was too ashamed to ask. I just kept [my symptoms] to myself ... I was very ashamed of going to the doctor so they could check me, because I wasn’t used to that.” (Hispanic, cancer center, breast)</p>

exhibited denial driven by a misperception of the disease. For example, a patient delayed her prescribed cervical cancer radiation therapy because she believed that the disease would disappear naturally:

Inadvertently, I prolonged it because I was kind of scared and disappointed. ... I kind of procrastinated on the treatment ... because I was thinking it might just you know “go away” or you know ‘oh, it’s not that bad,’ ... but you know, only thing it did was get worse. (African American, cancer center, cervix)

Competing obligations. Some participants cited the precedence of competing obligations as a rationale for non-adherence. Work conflicts and associated lost wages frequently contributed to canceled or rescheduled appointments. Child-care coordination and direct scheduling conflicts were also frequently discussed. One participant who missed her cervical follow-up appointment and presented in the emergency room disclosed, “I didn’t go, because the truth is that it takes too long. Sometimes there’s no one to watch my kids” (Hispanic, FQHC, breast). Furthermore, commitment to elderly caregiving conflicted with follow-up care. A woman with metastatic breast cancer who initially delayed her diagnostic mammogram to care for her dying father, described her situation:

He died of cancer, lung cancer ... and then I stayed there for like maybe three months and then I came back, you know. This time I went into mammography. It was really like delayed. I

wasn’t able to make the appointment like twice because of the concern of when my father was dying. I was one of the people who took care of him. (African American, cancer center, breast)

Embarrassment. Although the theme of embarrassment was minimally represented overall, nearly one-fifth of Hispanics reported feeling embarrassed about completing or discussing a breast or cervical exam. Several women directly attributed their reservations to their cultural perceptions of preventive care. One woman stated, “Regretfully, as Mexicans we are very shy when it comes to getting a breast exam or a Pap smear. We just feel very embarrassed” (Hispanic, free clinic, breast). Another woman noted that husbands could perceive screening tests as transgressions of physical privacy:

We [Hispanics] are more prone to [cervical cancer] because in our country we are very lazy to have a Pap smear test ... because they may feel embarrassed. They are ashamed [doctors] may see them. That the husband may ask, “How’s that person gonna see you?” (Hispanic, FQHC, breast)

Provider gender discordance also generated embarrassment; women expressed preference for female physicians during screening exams. As one Hispanic participant described,

I didn’t feel very comfortable because he’s a man... I don’t know if it’s Latin women ... I was quite nervous and uncomfortable about the doctor doing a full exam on me, a smear test. And thank God he gave me the option whether I wanted [a female doctor] to check me. (Hispanic, FQHC, breast)

Furthermore, some women expressed discomfort with the presence of an intermediary, such as a medical interpreter. Instead of communicating more openly with her provider, one woman described hesitating to ask questions during her Pap test:

I sometimes kind of feel ... embarrassed to ask something, because the translator is there.... It's the doctor, me, and the other person that's for me ... one of the things that sometimes makes me feel embarrassed to ask about certain things. (Hispanic, FQHC, cervix)

Rationales to adhere to cancer-related care

The most frequently reported themes and subthemes for adherence to cancer-related care are described below. Table 4 provides additional exemplary quotations.

Identification of an abnormality or abnormal screening test. The most frequently cited reason for seeking confirmatory testing for breast or cervical cancer was the discovery of an abnormal finding. Some findings were patient-identified, such as a symptom associated with breast or cervical cancer or a physical condition that prompted women to seek follow-up. On other occasions, findings were provider-identified,

such as a clinical abnormality discovered upon routine physical exam.

Patient activation. Approximately one-third of participants took measures beyond routine preventive or follow-up cancer care. Instead of a reactive response to symptoms and clinic or provider reminders, they proactively managed appointments, follow-up, and navigation of health care system barriers. The most common example of this behavior was completing appointments without reminders. In describing why she presented for Pap tests annually, one woman said, "No one reminds me. Um, me and my doctor we set a plan on or agree to how often I need to come and get it done and I just make the appointment. And when it's that time I just come and take it and get it done" (African American, FQHC, cervix). Since many women struggled financially, some also reported actively seeking free cancer screening tests. Reflecting on the period of time when she was uninsured, one woman reported, "I went ahead to every health fair that I could think of and took every exam free exam" (Hispanic, FQHC, cervix).

The most assertive proactive behavior involved patients directly requesting immediate action or test results from

TABLE 4. MAJOR THEMES AND SUBTHEMES OF REASONS FOR DELAYED OR MISSED CANCER-RELATED CARE

<i>Major themes/subthemes</i>	<i>Exemplary quotations</i>
Identification of abnormality or abnormal test	"I just started having pains on my breast; my left one and I went to the Doctor, and she sent me for further tests." (Hispanic, cancer center, breast)
Patient-identified abnormality	"When the itch that burnt started it was right away, you know, I made an appointment and when they gave it to me I came." (Hispanic, FQHC, breast)
Provider-identified abnormality	"Because I knew something wasn't right with my breast because it was bleeding and it was bigger." (African American, cancer center, breast)
	"My primary care physician recommended that I come in for a biopsy." (African American, cancer center, breast)
Patient activation	"I went ahead and I called the MRI place and I literally insisted on having the report read to me." (Hispanic, FQHC, breast)
Completing appointments without reminders	"So in other words if there was a problem I just contacted somebody else." (White, cancer center, breast)
Seeking free cancer screening tests	
Requesting immediate action or test results	
Health care provider as facilitator	"My doctor keeps me on check. Don't leave it up to me I'll forget all about it." (African American, FQHC, breast)
Verbal reminders	"My doctor said when you pass 40 you should have one every year." (African American, cancer center, breast)
Provider proactive measures	"She [primary care physician] found out that I had the lump she referred me right away, and I started going through the treatments." (African American, cancer center, breast)
Motivation from family or friends	"My daughter was influencing me to go find out what's wrong. In her words, she didn't say pap smear, but mom you need to go to the doctor, you need to get to the doctor, you need to get to the doctor." (African American, cancer center, cervix).
Direct motivation (verbal encouragement)	"People told me I should go...and why did I put it off too long, my daughter, a couple other friends." (White, cancer center, breast)
Indirect motivation (modeling behavior, inspiration from children)	"I've had friends who have suffered with breast cancer. And I've watched them go through what they went through. And I don't want to go through that." (White, free clinic, breast)
	"[My baby] keeps me having a light at the end of the tunnel and to get up and try again another day." (African American, cancer center, breast)

providers or the clinic. For example, one woman recounts self-advocating for a diagnostic test that ultimately resolved positive.

I called the doctor Monday and told him, 'Remember last week I asked you for a mammogram and you said I didn't need it? I think I do need one because there is a visible lump there and it's tender when I palpate it.' (African American, FQHC, breast)

Participants with cancer also proactively avoided delays in scheduling specialist consultations, follow-up tests, and treatment appointments. After waiting 2 months, one woman insisted that the clinic proceed with her mastectomy, stating, "I just feel like if I didn't push somehow I could have fallen through the cracks" (Asian, cancer center, breast).

Health care provider facilitation. Provider-facilitated actions also frequently prompted patients to seek screening or follow-up on abnormal breast or cervical screening results. Verbal reminders served as cues to action and facilitated patient education about screening guidelines. Women also attributed adherence to more hands-on provider proactive measures, such as rapidly facilitating referrals or informing patients of results by phone to help them to avoid unnecessary copays. A woman who completed her mastectomy within 3 weeks of her screening mammogram attributed her timely treatment to her provider, stating, "My referral by my primary care physician was right away; she was like rushing me in" (African American, cancer center, breast). Similarly, a participant with breast cancer described her physician as her "hero," because despite a negative magnetic resonance imaging test, he relentlessly advocated for her biopsy.

He never abandoned me. ... If he did not follow me up you know I could have been, you know, like just dropped dead for not knowing that it's really breast cancer.... But because of him, because of his insistence that he let me go into needle biopsy, ... they found out that I have cancerous cell[s]. (African American, cancer center, breast)

Motivation from family or friends. Finally, many women identified motivation from family or friends to adopt positive healthy behaviors as a reason for adhering to cancer-related care. For instance, one woman attributed her early breast cancer detection to direct motivation from her husband: "I wasn't going to get it and he pressed me a little bit.... I listened to him on that and I'm glad I did because they were able to catch it in such an early stage that I'm almost guaranteed to be cancer free" (White, cancer center, breast). Physically suffering from treatment side effects and mentally demoralized, another participant contemplated prematurely discontinuing her chemotherapy, but completed it with her mother's encouragement: "She was like you want to at least try. Nothing beats a failure except a try and she just kept telling me that. And she was like, 'You're giving up. That's not you'" (African American, FQHC, breast).

Women also conveyed the impact of indirect motivation, for example, discussing how their friends' or mothers' experiences with breast cancer influenced their decisions to pursue routine mammograms. In addition, inspired by their children, women sought care to serve as role models. As expressed by one woman, "I have daughters. I mean, if I'm

irresponsible about my health and my breast health then how...what does that say to them?" (White, free clinic, breast). Other women were motivated by the desire to experience milestones in their children's lives. One cancer survivor said, "The biggest factor is my six-year-old son, and I wanted to be around to...see him grow and develop and mature and...everything a parent wants...to be around for the children,...so it was imperative on me that I did everything to make that happen" (African American, cancer center, breast).

Discussion

This qualitative study, conducted among predominantly low-income minorities, explored reasons women adhered to or delayed breast and cervical cancer-related care. Though women had access to care, our results showed that common rationales for nonadherence included limited knowledge about preventive or cancer care resources, denial or fear, conflicting obligations, and particularly among Hispanic women, embarrassment. Reasons for adherence included abnormality identification, patient activation, provider-initiated actions, and motivation from family or friends. Unlike some qualitative studies,^{13,15,21,31} ours purposefully identified only reasons women directly attributed to adherence, thereby highlighting factors most proximal along the pathway to care decisions.

The finding that limited knowledge of cancer care was a major obstacle supports the need for educational interventions addressing multiple individual-level domains: what (knowledge), how (processes), and where (resources). Innovative breast and cervical cancer education programs, such as culturally relevant multimedia interventions that explain biomedical concepts or community-based focus discussion groups that dispel cancer misperceptions, have shown efficacy in improving cancer knowledge,³² screening utilization³³ and perceived benefits, self-efficacy, and screening intentions.³⁴ Such educational approaches may assist in diminishing the personal-level barriers our study participants reported, such as cancer knowledge, misconceptions, denial, and fear. Less anticipated, however, was that many women understood the benefits of preventive screening and expressed motivation to comply but identified lack of awareness about clinical processes and financial resources as barriers. Thus, educational interventions—particularly among low-income populations—may need to extend beyond traditional parameters to involve active guidance on processes of preventive care, including instruction on how to identify and use available resources. This multifaceted approach has been often exhibited in lay health advisor and patient navigator interventions.³⁵

In addition to individual-level factors, external influences on health behavior surfaced across many themes. For example, several women expressed provider recommendations and motivation from family and friends facilitated their adherence to cancer-related care. These findings corroborate previous studies demonstrating the effectiveness of provider recommendations^{18,24,36} and social networks^{31,37,38} in catalyzing cancer screening uptake and follow-up. While the impact of social networks on cancer care remains mixed in the literature, Allen et al. found perceived approval of family and friends and the perception that screening was normative

among one's age group were positively associated with recent mammogram use.³⁹ Allen's study comprised mostly white, insured, educated, and married women, however, and could not delineate network members (family, friends, co-workers, peer advisors) who most significantly influenced screening. By contrast, our study comprised mostly African American, Hispanic, low-income, and uninsured women and suggests family and friends in particular act as prime motivators through direct encouragement, modeling of positive health behaviors and attitudes, and fulfillment of a caretaker role. Among Hispanic women, the impact of these ties may be explained by cultural values grounded in familism⁴⁰ and inclusion of family in treatment decision-making.⁴¹ Given participants' emphasis on social networks, lay health advisors, in addition to connecting women to care, should consider either more closely aligning themselves within or engaging key opinion leaders in a woman's social network.

Hispanic cultural values also threaded through multiple themes. For instance, many Hispanic participants expressed embarrassment about cancer screening and diagnostic tests, a theme consistently presented in other qualitative studies.^{13,42–46} Women emphasized modest conduct, discretion, preference for female providers, and discomfort with the presence of intermediaries during provider consultation. Furthermore, some Hispanic participants discussed husbands' unsupportive attitude towards breast and cervical cancer screening tests. Educating Latino partners and leveraging cultural gender roles may facilitate women's engagement in the screening process.^{47,48} Finally, Hispanic women noted an absence of a family member to passively model or directly consult about cancer-related care, which supports interventions targeting improvements in cancer knowledge transfer across generations.

Several study limitations should be acknowledged. First, our sample may be biased toward more compliant patients who followed up on care, given the use of in-person recruitment at clinics following provider referral. As such, barriers are likely to have been underreported. Second, findings from our sample may not be generalizable to all low-income minority populations or rural communities that may uniquely experience greater access barriers, but offer relevant insight into barriers that may persist among women gaining coverage to preventive health services through health care reform. Third, concerns about cancer screening or follow-up and treatment may disproportionately represent women from health centers or academic centers, respectively; however, the study sites similarly served predominantly uninsured or publically insured and minority patients. Fourth, participants were enrolled when interventions targeting improvements in diagnostic evaluation and cancer treatment adherence were simultaneously being implemented, which may have affected perception of care. These settings, however, likely reflect realistic exposure to care coordination initiatives at average health care facilities, which in addition to our large sample size, increases generalizability of results.

These findings directly translate into practice. Given the majority of women attributed follow-up to either a self- or provider-identified abnormality, interventions at the individual level should educate and enable women to proactively self-manage their health and identify and act upon cancer symptoms. At the system level, clinical reminders as well as provider or practice incentives to encourage communication

about screening guidelines in lay language may improve abnormality identification. Finally, community health workers address both individual- and system-level factors by providing culturally grounded education about cancer care processes, resources, and health care system navigation; addressing cultural constructs underlying embarrassment and fear; establishing a trusted longitudinal relationship that transcends the role of an interpreter; increasing confidence to engage in self-care; and leveraging support from the patient's social network. For resource-constrained health centers, these strategies may require systems redesigns whereby trained nonclinical professionals play an integrated role in cancer care teams, addressing time-intensive psychosocial barriers that extend beyond clinical disease management. Further research exploring underlying pathways to care, patient preferences, direct and indirect financial barriers, potential age and generational differences, and cultural barriers are merited.

Conclusions

In conclusion, despite access to breast and cervical cancer screening and diagnostic services, low-income women faced barriers driven by gaps in resource knowledge, perceptions of cancer, embarrassment, and prioritization of competing obligations. Coverage of preventive care services may increase access, but additional patient-centered strategies are still likely needed to enable screening follow-up and treatment. As vulnerable populations gaining access to preventive health screenings for women may initially experience complexities of seeking care, further exploration of reasons why underserved women with theoretical access to cancer-related care choose to adhere to or forgo it, and how to develop interventions to mitigate challenges remains critical.

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References

1. Cancer Facts and Figures. Atlanta, GA: American Cancer Society, 2014.
2. Strzelczyk JJ, Dignan MB. Disparities in adherence to recommended followup on screening mammography: Interaction of sociodemographic factors. *Ethn Dis* 2002;12: 77–86.
3. DeSantis C, Siegel R, Bandi P, Jemal A. Breast cancer statistics, 2011. *CA Cancer J Clin* 2011;61:409–418.
4. Purc-Stephenson RJ, Gorey KM. Lower adherence to screening mammography guidelines among ethnic minority

- women in America: A meta-analytic review. *Prev Med* 2008;46:479–488.
5. Wells KJ, Roetzheim RG. Health disparities in receipt of screening mammography in Latinas: A critical review of recent literature. *Cancer Control* 2007;14:369–379.
 6. Dailey AB, Brumback BA, Livingston MD, Jones BA, Curbow BA, Xu X. Area-level socioeconomic position and repeat mammography screening use: Results from the 2005 National Health Interview Survey. *Cancer Epidemiol Biomarkers Prev* 2011;20:2331–2344.
 7. Paskett ED, McLaughlin JM, Reiter PL, et al. Psychosocial predictors of adherence to risk-appropriate cervical cancer screening guidelines: A cross sectional study of women in Ohio Appalachia participating in the Community Awareness Resources and Education (CARE) project. *Prev Med* 2010;50:74–80.
 8. Jones BA, Dailey A, Calvocoressi L, et al. Inadequate follow-up of abnormal screening mammograms: Findings from the race differences in screening mammography process study (United States). *Cancer Causes Control* 2005;16:809–821.
 9. Adams SA, Smith ER, Hardin J, Prabhu-Das I, Fulton J, Hebert JR. Racial differences in follow-up of abnormal mammography findings among economically disadvantaged women. *Cancer* 2009;115:5788–5797.
 10. Yabroff KR, Breen N, Vernon SW, Meissner HI, Freedman AN, Ballard-Barbash R. What factors are associated with diagnostic follow-up after abnormal mammograms? Findings from a U.S. National Survey. *Cancer Epidemiol Biomarkers Prev* 2004;13:723–732.
 11. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal Pap smear: A prospective study. *J Gen Intern Med* 2006;21:829–834.
 12. Watson-Johnson LC, DeGross A, Steele CB, et al. Mammography adherence: A qualitative study. *J Womens Health (Larchmt)* 2011;20:1887–1894.
 13. Percac-Lima S, Aldrich LS, Gamba GB, Bearse AM, Atlas SJ. Barriers to follow-up of an abnormal Pap smear in Latina women referred for colposcopy. *J Gen Intern Med* 2010;25:1198–1204.
 14. Yang TC, Matthews SA, Hillemeier MM. Effect of health care system distrust on breast and cervical cancer screening in Philadelphia, Pennsylvania. *Am J Public Health* 2011;101:1297–1305.
 15. Ashing-Giwa KT, Padilla G, Tejero J, et al. Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psychooncology* 2004;13:408–428.
 16. Rauscher GH, Allgood KL, Whitman S, Conant E. Disparities in screening mammography services by race/ethnicity and health insurance. *J Womens Health (Larchmt)* 2012;21:154–160.
 17. Battaglia TA, Santana MC, Bak S, et al. Predictors of timely follow-up after abnormal cancer screening among women seeking care at urban community health centers. *Cancer* 2010;116:913–921.
 18. Schueler KM, Chu PW, Smith-Bindman R. Factors associated with mammography utilization: A systematic quantitative review of the literature. *J Womens Health (Larchmt)* 2008;17:1477–1498.
 19. Rodriguez MA, Ward LM, Perez-Stable EJ. Breast and cervical cancer screening: Impact of health insurance status, ethnicity, and nativity of Latinas. *Ann Fam Med* 2005;3:235–241.
 20. Erickson BK, Zhang B, Straughn JM, Jr. Screening Behaviors and Cultural Barriers in Women with Newly Diagnosed Cervical Cancer. *J Low Genit Tract Dis* 2013;17:425–429.
 21. Tejada S, Thompson B, Coronado GD, Martin DP. Barriers and facilitators related to mammography use among lower educated Mexican women in the USA. *Soc Sci Med* 2009;68:832–839.
 22. Ashing-Giwa KT, Padilla GV, Bohórquez DE, Tejero JS, Garcia M. Understanding the breast cancer experience of Latina women. *J Psychosoc Oncol* 2006;24:19–52.
 23. Mishra SI, Deforge B, Barnet B, Ntiri S, Grant L. Social determinants of breast cancer screening in urban primary care practices: A community-engaged formative study. *Womens Health Issues* 2012;22:e429–e38.
 24. Ogedegbe G, Cassells AN, Robinson CM, et al. Perceptions of barriers and facilitators of cancer early detection among low-income minority women in community health centers. *J Natl Med Assoc* 2005;97:162–170.
 25. Allen JD, Shelton RC, Harden E, Goldman RE. Follow-up of abnormal screening mammograms among low-income ethnically diverse women: Findings from a qualitative study. *Patient Educ Couns* 2008;72:283–292.
 26. Ashing-Giwa KT, Kagawa-Singer M, Padilla GV, et al. The impact of cervical cancer and dysplasia: A qualitative, multiethnic study. *Psychooncology* 2004;13:709–728.
 27. Whitman S, Orsi J, Hurlbert M. The racial disparity in breast cancer mortality in the 25 largest cities in the United States. *Cancer epidemiology* 2012;36:e147–151.
 28. Brofenbrenner U. Toward an experimental ecology of human development. *Am Psychol* 1977;32:515–531.
 29. Fishbein M, Ajzen I. Belief, attitude, intention, and behavior: An introduction to theory and research. Reading, MA: Addison-Wesley, 1975.
 30. Hruschka D, Schwartz D, John D, Picone-Decaro E, Jenkins RA, Carey JW. Reliability in coding open-ended data: Lessons learned from HIV behavioral research. *Field Methods* 2004;16:307–331.
 31. Allen JD, Stoddard AM, Sorensen G. Do social network characteristics predict mammography screening practices? *Health Educ Behav* 2008;35:763–776.
 32. Valdez A, Banerjee K, Ackerson L, Fernandez M. A multimedia breast cancer education intervention for low-income Latinas. *J Community Health* 2002;27:33–51.
 33. Calderon JL, Bazargan M, Sangasubana N, Hays RD, Hardigan P, Baker RS. A comparison of two educational methods on immigrant Latinas breast cancer knowledge and screening behaviors. *J Health Care Poor Underserved* 2010;21:76–90.
 34. Deavenport A, Modeste N, Marshak HH, Neish C. Closing the gap in mammogram screening: An experimental intervention among low-income Hispanic women in community health clinics. *Health Educ Behav* 2011;38:452–461.
 35. Freund KM, Battaglia TA, Calhoun E, et al. National Cancer Institute Patient Navigation Research Program: Methods, protocol, and measures. *Cancer* 2008;113:3391–3399.
 36. Hawley ST, Earp JA, O'Malley M, Ricketts TC. The role of physician recommendation in women's mammography use: Is it a 2-stage process? *Med Care* 2000;38:392–403.
 37. Suarez L, Lloyd L, Weiss N, Rainbolt T, Pulley L. Effect of social networks on cancer-screening behavior of older Mexican-American women. *J Natl Cancer Inst* 1994;86:775–779.
 38. Kang SH, Bloom JR, Romano PS. Cancer screening among African-American women: Their use of tests and social support. *Am J Public Health* 1994;84:101–103.

39. Allen JD, Stoddard AM, Sorensen G. Do social network characteristics predict mammography screening practices? *Health Educ Behav* 2008;35:763–776.
40. Sabogal F, Marin G, Otero-Sabogal R, Marin BV, Perez-Stable EJ. Hispanic familism and acculturation: What changes and what doesn't. *Hispanic J Behav Sc* 1987;9:397–412.
41. Maly RC, Umezawa Y, Ratliff CT, Leake B. Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. *Cancer* 2006;106:957–965.
42. Austin LT, Ahmad F, McNally MJ, Stewart DE. Breast and cervical cancer screening in Hispanic women: A literature review using the health belief model. *Womens Health Issues* 2002;12:122–128.
43. Bakemeier RF, Krebs LU, Murphy JR, Shen Z, Ryals T. Attitudes of Colorado health professionals toward breast and cervical cancer screening in Hispanic women. *J Natl Cancer Inst Monogr* 1995:95–100.
44. Byrd TL, Chavez R, Wilson KM. Barriers and facilitators of cervical cancer screening among Hispanic women. *Ethn Dis* 2007;17:129–134.
45. Bobo JK, Dean D, Stovall C, Mendez M, Caplan L. Factors that may discourage annual mammography among low-income women with access to free mammograms: A study using multi-ethnic, multiracial focus groups. *Psychol Rep* 1999;85:405–416.
46. Engelman KK, Cizik AM, Ellerbeck EF, Rempusheski VF. Perceptions of the screening mammography experience by Hispanic and non-Hispanic White women. *Womens Health Issues* 2012;22:e395–e401.
47. Trevino M, Jandorf L, Bursac Z, Erwin DO. Cancer screening behaviors among Latina women: The role of the Latino male. *J Community Health* 2012;37:694–700.
48. Thiel de Bocanegra H, Trinh-Shevrin C, Herrera AP, Gany F. Mexican immigrant male knowledge and support toward breast and cervical cancer screening. *J Immigr Minor Health* 2009;11:326–333.

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