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Breast Cancer Patients' Experiences within and outside the Safety Net

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Abstract

Background—Following reforms to the breast-cancer referral process for our city's health Safety Net (SN), we compared the experiences from first abnormality to definitive diagnosis of breast-cancer patients referred to Siteman Cancer Center from SN and non-Safety-Net (NSN) providers.

Materials and Methods—SN-referred patients with any-stage (0–IV) and NSN-referred patients with late-stage (IIB–IV) breast cancer were prospectively identified post-diagnosis during cancer-center consultations conducted between September 2008 and June 2010. Interviews were taped and transcribed verbatim; transcripts were independently coded by two raters using inductive methods to identify themes.

Results—Of 82 eligible patients, 57 completed interviews (33/47 SN [70%], 24/35 NSN [69%]). Eighteen (52%) SN-referred patients had late-stage disease at diagnosis, as did all NSN patients (by design). A higher proportion of late-stage SN patients (67%) than either early-stage SN (47%) or NSN (33%) patients reported feelings of fear and avoidance that deterred them from pursuing care for concerning breast findings. A higher proportion of SN late-stage patients than NSN patients reported behaviors concerning poor health knowledge/behavior (33% vs. 8%), but reported receipt of timely, consistent communication from healthcare providers once they received care (50% vs. 17%). Half of late-stage SN patients reported improper clinical or administrative conduct by healthcare workers that delayed referral and/or diagnosis.

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Conclusions—While SN patients reported receipt of compassionate care once connected with health services, they presented with higher-than-expected rates of late-stage disease. Psychological barriers, life stressors, and provider/clinic delays affected access to and navigation of the healthcare system and represent opportunities for intervention.

Keywords

breast cancer; delayed diagnosis; health disparities; late stage; qualitative methods; safety net; St. Louis

INTRODUCTION

In 2007, we noted a significant disparity in late-stage breast-cancer presentation by type of referral to the Alvin J. Siteman Cancer Center (SCC), a National Cancer Institute (NCI)-designated Comprehensive Cancer Center in St. Louis, Missouri. Among women privately referred to SCC, only 10–15% of new breast-cancer diagnoses were stage III or higher, whereas among women referred through local Safety-Net (SN) clinics for the uninsured and underinsured, 40% of breast-cancer patients presented with stage III or IV disease.¹ This discovery prompted initiation of systems-based reforms to increase rates of screening mammography among SN patients and to improve the efficiency of referrals for SN patients with abnormal breast findings.

In a mixed-methods pilot study, we interviewed breast-cancer patients prospectively referred to SCC through the SN clinics and through non-SN (NSN) providers to examine whether these system-level changes in the SN had improved the experience of SN-referred breast-cancer patients. We previously reported the extent to which personal and process factors often associated with late-stage diagnosis differed by source of referral – SN versus NSN – or, among SN-referred patients, by stage at diagnosis.² We found that despite improvements in mammography rates and streamlining of the referral process, SN patients continued to present with higher-than-expected rates of late-stage disease, with 52% of our SN sample having regional or distant breast cancer (Stages IIB–IV) at diagnosis.

In addition to the quantitative analysis of our survey data,² we also used qualitative research methods to examine whether the recently implemented SN-system reforms had improved the subjective experiences of breast-cancer patients coming through the SN system. The goal of qualitative research is to try and understand a given research problem or topic through the perspectives of individuals living in the local context, and the data collected are in the form of words, not numbers.³ Narratives are especially rich sources of data, providing descriptions of participants' values, opinions, behaviors, relationships, and social contexts. By analyzing the self-reported experiences of SN and NSN breast-cancer patients via a grounded-theory approach,⁴ we hoped to gain a better understanding of experiential factors that might be associated with the disproportionately high rates of late-stage breast cancer diagnosed among SN patients and to use this narrative data to help inductively develop a testable theory as to why these disparities have been observed. Here, we present the results of our qualitative analysis of participants' responses to open-ended interview questions from our pilot study.

MATERIALS AND METHODS

Patients

We sought to examine whether the high rates of late-stage breast cancer previously observed among SN patients might be attributable to systematic differences between the SN- and NSN-referral processes or instead might reflect personal characteristics that made women more or less likely to present with early-stage or late-stage breast cancer. Accordingly, we designed our mixed-methods study to examine, describe, and compare the experiences of late-stage SN patients to those of both late-stage NSN patients and early-stage SN patients.

Approximately 30 SN patients are referred to Siteman's Breast Health Center annually, and we sought to recruit 25 SN patients and a similar number of NSN patients with late-stage cancer over a two-year period to evaluate SN and NSN processes and facilitate future planning as expeditiously as possible. Between September 2008 and June 2010, SN patients with any-stage (0–IV) breast cancer and NSN patients with late-stage (IIB–IV) disease only (by design) were identified consecutively during their initial consultations at SCC to participate in a 45–60-minute, semi-structured interview administered by a trained member of the research team via a computer-assisted telephone interview system. Women who were under 18 years old, with prior history of in situ or invasive breast cancers, with cognitive impairments (e.g., dementia), or who were unwilling or unable to give consent were excluded. Following written consent, each participant completed one interview prior to beginning treatment.

Data Collection

Open-ended interview questions were developed in collaboration with a clinical psychologist and modified from a questionnaire about delayed diagnosis in colorectal-cancer patients.⁵ We asked patients about how they first discovered they might have cancer (i.e., initial symptoms or exam findings), how soon they were aware of the potential seriousness of their breast abnormalities, how long it took them to seek medical care and/or pursue follow-up for their breast findings, the extent to which they had had regular contact with physicians and participated in screening prior to their breast-cancer diagnoses, and how they would characterize their previous interactions with the healthcare system. Interviews were taped and transcribed verbatim. Clinical data including stage were obtained from patients' medical records.

Data Analysis and Measures

To analyze the narrative data, two members of the research team independently reviewed and coded the transcripts and used thematic analysis techniques to highlight the key words, phrases, and concepts from the text that substantiated emergent themes.^{3,4,6,7} Consensus was reached for any coding discrepancies through discussion. We report examples of comments made by participants that we felt best reflected the inductively derived themes that emerged; text in brackets was inserted by the authors for further clarification.

Proportions of participants giving certain coded responses were calculated for descriptive purposes only and grouped by stage and referral source (early-stage [0–IIA] SN, late-stage

SN, and NSN). Tests of association (e.g., chi-square) were not performed and would have been inappropriate, as patient responses were made spontaneously to open-ended questions, and not every participant would have been expected to provide any particular type of response of her own accord. Furthermore, since our purpose was to generate theory to develop interventions and plan for further research rather than test hypotheses, we report only frequencies and proportions of patients giving certain responses without p-values.

Clinical and demographic data to compare participants and nonparticipants were analyzed using t-tests (for continuous variables, e.g., age) and chi-square tests (for categorical variables, e.g., race) using SAS 9.3 (SAS Institute Inc., Cary, North Carolina). Our study was approved by the institutional review board at Washington University School of Medicine.

RESULTS

Sample Characteristics

Of 82 patients identified, 57 completed interviews (33/47 [70%] SN patients, 24/35 [69%] NSN patients). Among NSN patients, 1 patient proved to be ineligible, 6 declined, 2 consented but were unable to be interviewed, and 2 were unable to be contacted. Among SN patients, 2 patients proved to be ineligible, 7 declined, 3 were unable to be contacted, and 2 consented but were unable to be interviewed. Nonparticipants were more likely than participants to be African-American (84% vs. 54%, $p=0.009$) but were similar to participants with regard to referral source (56% vs. 58% from the Safety Net, $p=0.906$), marital status (28% vs. 37% married, $p=0.538$), and disease stage (72% vs. 74% with late-stage disease, $p=0.896$).

Participants' clinical characteristics grouped by referral source and stage (i.e., early-stage SN, late-stage SN, or NSN) are shown in Table 1. All 24 NSN patients were diagnosed with late-stage disease (by design). Among the 33 SN patients, 18 (52%) were diagnosed with late-stage disease and 15 (48%) were diagnosed with early-stage cancer.

During the coding process, four themes emerged from patients' responses to our open-ended questions: **personal assets**, **personal barriers**, **systemic assets**, and **systemic barriers**. Frequencies of coded responses grouped by stage and referral source are shown in Table 2.

Personal Assets

Having a primary care provider (PCP) was very important for expediting care for breast findings, regardless of referral source. Three-quarters (18/24) of NSN patients reported having a PCP compared with only 1/3 of early- (5/15) and 28% (5/18) of late-stage SN patients. Three NSN participants reported having easy access to PCPs through their affiliation with a local military base.

PCPs were especially important facilitators of care for patients with many life stressors. One NSN patient who was diagnosed with rheumatoid arthritis just prior to her breast-cancer diagnosis had difficulty coping with the physical strain of her disease as well as the financial straits in which she found herself following several prolonged hospitalizations:

I felt a lump, but I had rheumatoid arthritis [and] ... didn't want to dwell on [the lump].... I was getting all of those medical bills, and I didn't need no more. [44-year-old NSN patient, Stage IV]

But this patient eventually obtained a PCP who not only managed her chronic disease but also assessed the breast mass and made an appointment for the patient at SCC.

In contrast, an abrupt and prolonged change in one SN patient's finances impeded her access to routine primary care and, accordingly, to a timelier breast-cancer diagnosis:

I didn't see a doctor at all for probably fifteen or eighteen years because I went through a ... divorce and custody fight with [my] ... physician husband.... I shudder to think how ignorant I was. I didn't have ... friends who already knew how the health system could work for ladies who have low incomes. [51-year-old SN patient, Stage IIA]

This woman's daughter eventually found a SN physician willing to see her mother, and this PCP referred her to SCC after her physical exam and imaging proved concerning for breast cancer.

Personal Barriers

A greater proportion of late-stage (33%, 6/18) and early-stage (27%, 4/15) SN patients as compared to NSN patients (8%, 2/24) patients reported actions and/or beliefs consistent with **poor health knowledge and screening participation**:

I missed [my mammogram] last year. I was negligent and just didn't go back and reschedule it. [56-year-old SN patient, Stage IIIA]

[E]very ten years, you can [get a] follow up [mammogram].... I [had] a mammogram about eleven ... years ago and [it] didn't show anything. [53-year-old SN patient, Stage IIIC]

We specifically asked all participants "Would you say that you don't trust doctors?" to determine if **medical mistrust** was a factor in delay in diagnosis. Two late-stage SN patients, one early-stage SN patient, and no NSN patients reported distrust of the healthcare system based on previous experiences. While mistrust did not emerge as a prevalent characteristic in any one group, **feelings of fear and avoidance** were more commonly reported by late-stage SN patients (67%, 12/18) versus early-stage SN (47%, 7/15) and NSN patients (33%, 8/24). A number of these patients had symptoms that were longstanding and/or family histories of breast cancer:

My sister had had her breast removed.... And she said, "How is your breast? ... [Y]ou had a lump some time ago, didn't you?" And ... so I lifted up my bra to show it to her, and she ... and my other sister started crying, and that's what really got me. [53-year-old SN patient, Stage IIIB]

Sometimes, even women who were already connected to the healthcare system had difficulty following up abnormal findings because of fear and avoidance. A 52-year-old SN patient who had received annual mammograms for years could not bring herself to follow up her first abnormal mammogram. Although the imaging center "kept sending [me] letters,"

she delayed getting a diagnostic mammogram for six months until a certified letter finally convinced her of how important it was for her to get the follow-up exam.

Half (9/18) of late-stage SN patients reported **lack of or limited insurance** as a barrier to seeking medical care or maintaining already established primary-care relationships, as compared to 1/3 of early-stage SN (5/15) patients and 1/6 (4/24) of NSN patients:

I called and they said it would be \$325.00 cash because we had no insurance. Even though he had been my doctor now for two years, he still would not see me. [52-year-old SN patient, Stage IIIA]

I didn't have any money or insurance or transportation... I didn't think there was any program for me because I'm unemployed. I just felt that all I could do is ... lay on a heating [pad] and melt [the lump] through my nipple. [53-year-old SN patient, Stage IIIB cancer]

In addition, **having poor baseline health prior to being diagnosed with breast cancer**, which was reported by five (33%) late-stage SN patients and two (8%) NSN patients, caused some patients to have difficulty addressing their breast symptoms. In some cases, patients attributed new breast-cancer-related symptoms, such as weight loss, to their pre-existing conditions, causing them to minimize the significance of these new findings or ignore them completely:

Well, there was a loss of appetite ... and I had a little weight loss, but like I said, I have that colon thing, too. [40-year-old NSN patient, Stage IIIA]

Systemic Assets

Systemic assets were aspects of the healthcare system that helped facilitate patients' care. Half of late-stage SN patients (9/18), 1/3 (5/15) of early-stage SN patients, and 1/6 (4/24) of NSN patients reported receipt of **timely, consistent communication from physicians' offices**. In addition, late-stage SN patients (33%, 6/18) had the greatest proportion of patients' reporting **displays of empathy by administrative and clinical workers at clinics and hospitals** versus 7% (1/15) of early-stage SN and 21% (5/24) of NSN patients. Several patients described how clinic staff repeatedly contacted them, even when the patients found themselves too busy or too afraid to respond to these communications:

[A]ll summer, I [got] phone calls telling me to go ... so I went ... and they said it was cancer.... I went in the office ... crying and said, "I'm ready to just forget it." But the [healthcare worker] pushed me into coming up here [to Siteman]. [40-year-old NSN patient, Stage IIIA]

[She] kept kindly, politely pestering me to come in for that mammogram.... I wouldn't have finally ended up getting that mammogram if it wasn't for [her]. [51-year-old SN patient, Stage IIA]

Patients specifically praised healthcare workers who had not only provided assistance but had also displayed empathy when patients' efforts to see clinicians were thwarted:

[The doctor] was cold as ice.... I walked out of there with a lump in my throat. [The office worker] ... was fired up; she was upset.... [Another office worker]

called me and got everything straightened out.... These were great women. [53-year-old SN patient, Stage IIIB]

Patients also expressed appreciation for administrative staff that were persistent but withheld judgment:

She was never critical; she just kept saying, "We need you to ... come in for the mammogram." I probably got about six calls. [51-year-old SN patient, Stage IIA]

Systemic Barriers

But despite the efforts of individual administrative and clinical staff members, systemic barriers – centering on **improper clinical and administrative conduct** – led to significant delays in referral and diagnosis regardless of stage and referral source. Approximately half of SN patients (47% of early-stage SN [7/15], 50% of late-stage SN [9/18]) and 42% of NSN (11/24) patients described circumstances in which they sought medical attention for breast symptoms but were thwarted by administrative staff's not knowing how to assist or appropriately refer uninsured patients for follow-up and/or by physicians' not correctly recognizing and working up signs and symptoms concerning for breast cancer (see Table 2, Systemic Barriers, Clinic/MD admin/clinical conduct – improper judgment). When a 42-year-old SN patient with nipple discharge first went to a local clinic about her symptoms, the physician she saw told her "there was no problem with it." When the discharge continued after several months, the patient went back to the same clinic and saw a different PCP who immediately referred her for work-up. She was ultimately diagnosed with stage IIIB cancer.

A 39-year-old breastfeeding NSN patient initially thought the changes in her breast were related to nursing and did not seek medical care until approximately 9 months after she first noticed the breast symptoms, at which time the physician dismissed her concerns:

I voiced my concerns including ... my new family history with my mom having ... breast cancer ... and said let's do a baseline [mammogram]. [A]nd the [doctor] was like, "No, there's nothing in the exam [Y]our symptoms ... were most likely caused by ... coffee ... combined with ... [your] periods."

Several weeks later, the patient developed additional symptoms, prompting her to call her primary-care clinic again and request a different physician; she was diagnosed with stage IIIA cancer.

A 29-year-old SN patient did not seek medical care until two or three months after first noticing a breast mass because she was busy caring for her mother who, ironically, had recently been diagnosed with breast cancer. She eventually sought care at a free clinic but proceeded to have a series of misdiagnoses and failed referrals as a result of her not having insurance and being too young to qualify for a local mammography program for low-income women.

The emergency room doctor gave me a prescription for a mammogram, and [the imaging center] would not honor that because ... they said they would have to do an ultrasound for someone my age. So when I called back ... and asked the ER

doctor to give me a prescription for an ultrasound, he said, “No, you can’t do that. You have to go to a family physician or someone who sees you regularly.” He wouldn’t give me an ultrasound prescription, but I had the mammogram prescription [and] they wouldn’t honor it.

Despite her family history and abnormal breast exam, four months elapsed before this young woman, ultimately diagnosed with stage IIIB disease, was seen by a cancer specialist.

Finally, some patients’ initial appointments regarding breast symptoms were delayed by clinic receptionists, who sometimes scheduled these patients weeks and even months beyond when symptoms demonstrating potentially advanced breast cancer should have been addressed. A 52-year-old SN patient, whose primary-care affiliation had been disrupted after moving, experienced multiple administrative delays while trying to address her self-detected breast mass:

I immediately went to the clinic ... and they said that it would be several weeks before I could see a doctor and they were entirely booked up.... She told me that I was going to have to pay for it, and I said, “... I’ll be glad to pay the bill, but I’ll have to pay [a little bit] at a time” ... [but] she turned me away from that clinic.... [At another clinic] one month later.... I got down there, and they refused to see me because they said I was outside of their [geographic] jurisdiction, and they ... reschedule[d] me over [at] another clinic where I did live ...so that took two more months.

This patient was ultimately diagnosed with stage IIIA cancer.

DISCUSSION

Investigations as to why late-stage disease is more common within certain groups often have focused on the association between delayed presentation and advanced stage, the assumption being that disparate rates of advanced disease could largely be explained by differing degrees of knowledge about, access to, and utilization of mammography as well as self- and physician-provided breast exams.^{8–11} But, as we observed in this study, disparities in late-stage presentation persist even as disparities in screening knowledge, access to care, and mammography receipt are diminishing. Today, rates of screening mammography among women age 50–74 are approximately equal at 80% among white, African-American, Asian-American, and Hispanic women.¹² Furthermore, the proliferation of initiatives providing free or low-cost screening has made mammography more accessible to women with limited or no insurance.^{12–14} In our study, more late-stage SN patients discovered their disease through mammography than NSN late-stage patients (22% vs. 8%, Table 1). Nevertheless, more SN patients with early- and late-stage disease reported actions and/or beliefs that reflected suboptimal levels of knowledge about breast cancer and screening. Thus, while facilitating access to screening mammography may be a less critical point of intervention with regard to improving breast-cancer outcomes than it once was among the medically underserved, there remain pockets of the population needing additional outreach and education.

Given the greater propensity of young women – who are less likely to be engaged in regular mammographic screening – to present with locally advanced, biologically aggressive breast cancers,¹⁵ it is particularly important for these women's breast symptoms to be investigated promptly when they arise. Some organizations that provide free or low-cost mammography only cover women above the age of 35.¹³ Thus, young uninsured and underinsured women are particularly vulnerable to delayed follow-up of abnormal breast findings. The extent to which administrative assistants of PCPs for the medically underserved may be responsible for the delay in appropriate access to care cannot be ignored. These individuals serve as gatekeepers to timely medical access and must be educated about breast cancer and its potential manifestations in young women and directed to expedite scheduling of appointments for patients with concerning breast symptoms. Primary care clinics and cancer centers could partner in programs to educate administrative and medical assistants at these clinics regarding the signs and symptoms of breast cancer. In addition, these staff members should be routinely screened for compassion fatigue and strongly encouraged to view empathy and compassion as an important component of their interaction with patients, especially those patients who might have cancer. Our patients' narratives revealed that many SN patients had positive healthcare experiences once they were actually seen in the clinic, but often their greatest hurdle was obtaining an appointment.

But even if older women are being screened appropriately and younger women are getting expedited follow-up for abnormal breast findings, a patient's own delay in seeking care may still be an important contributor to disparities in breast-cancer stage at presentation. Some women in our study reported delays in follow-up of abnormalities that had been detected by physician exam or breast imaging secondary to feelings of fear and avoidance. Reasons for delay after screening mammography are multifold and complex. Many studies have demonstrated a strong relationship between increased risk of delayed presentation after abnormal breast findings and each of minimizing one's own disease risk, emotional distress, distrust of medical professionals, and fears about the costs and consequences of breast-cancer treatment.^{8,9,16–22} Given these potential personal barriers, some of which were mentioned by patients in our sample, additional work must be done to assist breast-cancer patients in general, and SN patients in particular, as they transition from screening to treatment. One way of addressing this issue could be through the establishment of “No Fear” media campaigns that are developed in collaboration with cancer centers, community health organizations, survivor support groups, and primary care providers to publicize the curability of breast cancer, the importance of pursuing follow-up of abnormal mammograms, and the necessity of undergoing treatment once breast cancer has been diagnosed. Efforts to launch a “No Fear” campaign in the St. Louis region are already underway and have been informed in large part by research on breast-cancer disparities conducted by Siteman Cancer Center investigators.

Our study had some limitations. First, as this was a pilot study conducted in one city that included patients seen first within the city's SN system or seen first in the private sector, our sample size was small. Both SN and NSN patients were ultimately referred to the same NCI-designated comprehensive cancer center located in St. Louis. These patients might differ from other patients in the St. Louis metropolitan area who are first seen in other medical care settings and subsequently referred elsewhere for breast-cancer treatment. Second,

selection bias may make our results less generalizable. Only 70% of eligible patients were included in the study; nonparticipants may have differed significantly from participants with regard to social and financial assets or other unmeasured variables.²³ Reflecting a documented trend in medical research, nonparticipants were more likely than participants to be African-American.^{24,25} But, as we previously reported,² in multivariate regression models, race was not found to be independently associated with either late-stage disease or delayed presentation among our participants. Thus, it is not clear whether including more African-Americans in our study would have changed our findings. Participants and nonparticipants were similar with regards to marital status, referral source, and rates of late-stage disease, thus we are not overly concerned about selection bias along these dimensions.

In addition, we acknowledge the possibility of recall bias and the potential for underreporting personal and systemic assets while exaggerating personal and systemic barriers that participants might have seen as contributing to their being diagnosed with late-stage cancer, as some patients might have been inclined to blame others for what had happened to them. But the finding that more SN late-stage patients reported positive, timely communication with healthcare providers than their NSN counterparts in part reassured us that our patients were not systematically inclined to blame “the system” for their late-stage diagnoses. Moreover, it assured us that the interventions we put into place to redress some of the systemic problems detected among SN clinics in 2007¹ were, in fact, working to improve the overall experience and expedite the follow-up of SN patients with abnormal breast findings.

CONCLUSION

Despite increased local, statewide, and nationwide mammographic utilization,^{2,12–14} additional community outreach and breast health education is still needed, particularly among women with life stressors – such as poor health due to other chronic conditions, inadequate insurance, low income, and restricted primary care access – that are prevalent among SN patients and other medically underserved populations. Not only do women need to be better informed as to what signs and symptoms should prompt them to seek medical attention and where they can go to address medical problems even if they do not have insurance, but there also needs to be increased education directed at PCPs and their staff. Given the many personal and systemic barriers reported by both SN and NSN patients, the clinical acuity of PCPs and their staff is of the utmost importance in getting patients to definitive breast-cancer treatment in a timely fashion.

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Table 1

Characteristics of safety-net (SN) and non-safety-net (NSN) patients ($N = 57$)

	SN early	SN late	NSN	P value
Age, mean (SD)	53.0 (9.9)	52.2 (9.2)	53.4 (11.4)	0.753
	$n = 15$ (%)	$n = 18$ (%)	$n = 24$ (%)	
Race				<0.001
African-American	26 (78.8%)	15 (83.3%)	5 (20.8%)	
Native American/Alaskan Native	1 (3.0%)	0 (0.0%)	0 (0.0%)	
Caucasian	6 (18.2%)	3 (16.7%)	19 (79.2%)	
AJCC ^a Stage				0.001
0/in situ	4 (12.1%)	N/A	0 (0.0%)	
I	1 (4.2%)	N/A	0 (0.0%)	
IIA	10 (41.7%)	N/A	0 (0.0%)	
IIB	N/A	7 (21.2%)	7 (29.2%)	
IIIA	N/A	5 (15.2%)	8 (33.3%)	
IIIB	N/A	3 (9.1%)	2 (8.3%)	
IIIC	N/A	3 (9.1%)	2 (8.3%)	
IV	N/A	0 (0.0%)	5 (20.8%)	
How patient first discovered she might have breast cancer				0.025
Mammogram	8 (53.3%)	4 (22.2%)	2 (8.3%)	
Physical sign or symptoms	7 (46.7%)	13 (72.2%)	21 (87.5%)	
Incidental finding by MD	0 (0.0%)	1 (5.6%)	0 (0.0%)	
Mass/lump detected by partner	0 (0.0%)	0 (0.0%)	1 (4.2%)	

^a AJCC – American Joint Committee on Cancer

Table 2

Interview Codes: Early-stage safety-net (SN Early), late-stage safety-net (SN Late), and non-safety-net (NSN) patients ($N = 57$)

Categories	Codes	SN Early $n = 15$ (%)	SN Late $n = 18$ (%)	NSN $n = 24$ (%)
Personal Assets	Attitudes:			
	Positive attitude towards health care in general	1 (6.7%)	1 (5.6%)	2 (8.3%)
	Previous good experience with health care	0 (0.0%)	1 (5.6%)	0 (0.0%)
	Understood likely seriousness of condition early on	7 (46.7%)	10 (55.6%)	9 (37.5%)
	Familial/friend support - present	3 (20.0%)	6 (33.3%)	7 (29.2%)
	Financial resources - adequate	0 (0.0%)	0 (0.0%)	1 (4.2%)
	Job stability	0 (0.0%)	1 (5.6%)	1 (4.2%)
	Level of health/screening knowledge and behavior - good (gets mammograms, self-breast exam, compliant)	9 (60.0%)	12 (66.7%)	13 (54.2%)
	Management of initial signs/symptoms	10 (66.7%)	9 (50.0%)	16 (66.7%)
	Overall health status	1 (6.7%)	2 (11.1%)	0 (0.0%)
Personal Barriers	Regular primary care provider &/or clinic	5 (33.3%)	5 (27.8%)	18 (75.0%)
	Stressors	0 (0.0%)	1 (5.6%)	0 (0.0%)
	Attitudes:			
	Fear	4 (26.7%)	5 (27.8%)	3 (12.5%)
	Avoidance	3 (20.0%)	7 (38.9%)	5 (20.8%)
	Did not suspect/did not want to believe symptoms were serious	7 (46.7%)	7 (38.9%)	14 (58.3%)
	Did not trust MDs ^a /health-care system	1 (6.7%)	2 (11.1%)	0 (0.0%)
	Care for other family members - distracting, not sufficiently supported	0 (0.0%)	2 (11.1%)	1 (4.2%)
	Childcare - inadequate/uncertain	0 (0.0%)	2 (11.1%)	1 (4.2%)
	Familial/friend support - low/absent	1 (6.7%)	1 (5.6%)	0 (0.0%)
	Financial resources – poor	3 (20.0%)	9 (50.0%)	4 (16.7%)
	Job insecurity	2 (13.3%)	3 (16.7%)	2 (8.3%)
	Level of health/screening knowledge and behavior - poor (no mammograms, no self-breast exam, noncompliant)	4 (26.7%)	6 (33.3%)	2 (8.3%)
	Management of initial signs/symptoms - Did not seek medical care	8 (53.3%)	11 (61.1%)	10 (41.7%)
	Overall health status – poor	0 (0.0%)	5 (27.8%)	2 (8.3%)
	Payor status - Un/underinsured	5 (33.3%)	9 (50.0%)	4 (16.7%)
	Regular primary care provider &/or clinic - no	3 (20.0%)	3 (16.7%)	3 (12.5%)

Categories	Codes	SN Early n = 15 (%)	SN Late n = 18 (%)	NSN n = 24 (%)
	Stressors - present/significant	3 (20.0%)	4 (22.2%)	3 (12.5%)
Systemic Assets	Accessibility of clinic/MD: easy to set up appointment	7 (46.7%)	6 (33.3%)	11 (45.8%)
	Clinic/MD administrative conduct - good			
	timely, consistent communication with patient	5 (33.3%)	9 (50.0%)	4 (16.7%)
	multiple attempts to contact unresponsive patient	2 (13.3%)	3 (16.7%)	1 (4.2%)
	Clinic/MD clinical conduct - good			
	timely diagnosis	3 (20.0%)	8 (44.4%)	9 (37.5%)
	timely referral	3 (20.0%)	7 (38.9%)	12 (50.0%)
	regular screening – MD initiated	2 (13.3%)	4 (22.2%)	0 (0.0%)
	MD/HCW ^b personal conduct - empathy/conveyed sense of seriousness and need for medical follow up	1 (6.7%)	6 (33.3%)	5 (20.8%)
	Payor status effect: facilitated access to insurance	0 (0.0%)	2 (11.1%)	0 (0.0%)
Systemic Barriers	Accessibility of clinic/MD: difficulty/delay in setting appointment time	4 (26.7%)	6 (33.3%)	5 (20.8%)
	closed without replacement	0 (0.0%)	1 (5.6%)	0 (0.0%)
	Clinic/MD administrative conduct - error			
	lost paperwork	0 (0.0%)	1 (5.6%)	0 (0.0%)
	delayed communication with patient	1 (6.7%)	1 (5.6%)	1 (4.2%)
	Clinic/MD admin/clinical conduct – improper judgment			
	misdiagnosis	1 (6.7%)	3 (16.7%)	4 (16.7%)
	delayed diagnosis	5 (33.3%)	2 (11.1%)	2 (8.3%)
	delayed referral	1 (6.7%)	2 (11.1%)	3 (12.5%)
	no MD-initiated regular screening	0 (0.0%)	1 (5.6%)	0 (0.0%)
	incorrect referral based on clinical characteristics (e.g., age, symptoms)	0 (0.0%)	1 (5.6%)	1 (4.2%)
	MD/HCW personal conduct - apathy/lack of sensitivity	1 (6.7%)	3 (16.7%)	2 (8.3%)
	Payor status effect: led to delayed or no care	1 (6.7%)	2 (11.1%)	0 (0.0%)

^a MD – physician

^b HCW – health-care worker