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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-SN (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 after 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%] and 24/35 NSN [69%]). Eighteen SN-referred patients (52%) 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 patient reported behaviors concerning for poor health knowledge or behavior (33% versus 8%), but reported receipt of timely, consistent communication from health care providers once they received care (50% versus 17%). Half of late-stage SN patients reported improper clinical or administrative conduct by health care workers that delayed referral and/or diagnosis.

Conclusions: Although 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 or clinic delays affected access to and navigation of the health care system and represent opportunities for intervention.

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1. 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–designated Comprehensive Cancer Center in St. Louis, MO. 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 going through the SN system. Because 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, the qualitative data collected were 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.

2. Materials and methods

2.1. 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 with 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 2-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-min semistructured interview administered by a trained member of the research team via a computer-assisted telephone interview system. Women who were aged <18 years, 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. After written consent, each participant completed one interview before beginning treatment.

2.2. 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 regular contact with physicians and participated in screening before their breast cancer diagnosis, and how they would characterize their previous interactions with the health care system. Interviews were taped and transcribed verbatim. Clinical data including stage were obtained from patients' medical records.

2.3. 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 participants' comments 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

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