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What Women Want: Patient Recommendations for Improving Access to Breast and Cervical Cancer Screening and Follow-up

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ABSTRACT

Background: The patient voice remains underrepresented in clinical and public health interventions. To inform interventions that strive to improve access to breast and cervical cancer screening and follow-up among low-income populations, we explored recommendations from low-income women pursuing health care in the safety net.
Methods: Semi-structured interviews were conducted among women receiving follow-up care for an abnormal breast or cervical cancer screening result or a positive cancer diagnosis in federally qualified health centers, free clinics, or an academic cancer center in the Chicago metropolitan area.
Findings: Of the 138 women interviewed in the parent study, 52 women provided recommendations for improving access to screening and follow-up care. Most were between 41 and 65 years old (62%) and African American (60%) or White (25%). Recommendations included strengthening community-based health education with more urgent messaging, strategic partnerships, and active learning experiences to increase patient engagement, which women regarded as a key driver of access. Women also suggested increasing access by way of changes to health care delivery systems and policy, including more direct patient–provider and patient–clinic communications, addressing delays caused by high patient volume, combining preventive services, expanding insurance coverage, and adjusting screening guidelines.
Conclusions: This exploratory study demonstrates important insights from the patient lens that may help to increase the acceptability and efficacy of community and clinical interventions aimed at improving access to breast and cervical cancer screening and follow-up. Further research is needed to identify appropriate integration of patient input into interventions, practice, and policy change.

Low-income and ethnic minority women are less likely to adhere to recommended breast and cervical cancer screening and follow-up care than nonminority and higher income counterparts (Elit et al., 2013; Goldman, Walker, Hubbard, & Kerlikowske, 2013; Swan et al., 2010). The need to address these cancer health disparities is pressing, given research linking higher cancer mortality rates with nonadherence to screening and timely follow-up (Hoerger et al., 2011). A large body of research has documented that low-income and minority women experience a multitude of barriers to receiving breast and cervical cancer screening and follow-up care (Ashing-Giwa et al., 2010; O'Malley & Mandelblatt, 2003).

Interventions that aim to improve patient engagement in health care have been largely based on policymakers' recommendations (Coulter & Ellins, 2007). Although many studies have documented provider-level or systems-level evaluations and perspectives along the continuum of breast and cervical

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cancer-related care (Sabatino et al., 2008; Viadro, Farris, & Will, 2004), fewer focused studies have directly solicited patients' recommendations to address patient-reported barriers (Ashing-Giwa et al., 2013; Heisey et al., 2011; Mishra, DeForge, Barnet, Ntiri, & Grant, 2012). More formative research is needed to gather direct patient input for developing interventions for cancer screening and follow-up. Integrating patient input in the design of interventions encourages the benefits that could come from utilizing principles of community-based participatory research (Israel, Schulz, Parker, & Becker, 1998), whereby stakeholders—in this case, patients—contribute their knowledge and experience of a given phenomenon toward action to improve the health of community members.

Therefore, the purpose of this exploratory study was to help bridge the gap in patient-driven perspectives by gathering patients' recommendations for improving access to breast and cervical cancer screening and follow-up care. We interviewed low-income women receiving follow-up care in the health care safety net for an abnormal screening result or diagnosis for breast or cervical cancer. This study adds to the literature by linking women's barriers to care with their own recommendations. Bridging the patient voice from this study with those of providers and policymakers may lead to the development of interventions that improve women's access to care and facilitate positive breast and cervical cancer-related care outcomes.

Methods

Setting and Participants

A purposive sample of women was recruited between March 2008 and December 2010 to participate in a qualitative study that investigated barriers and facilitators to breast and cervical cancer-related care among women receiving follow-up for an abnormality or positive cancer diagnosis from three clinic types in the Chicago metropolitan area: urban federally qualified health centers, suburban free primary care clinics, or an urban academic cancer center. We selected these sites because their patient populations mainly comprised low-income, uninsured or underinsured, and ethnic minority patients. Further, these clinic sites provided charity care, served publically insured patients, or provided women with access to free screening and diagnostic services through the Illinois Breast and Cervical Cancer Program, regardless of insurance status. After a provider referral, trained research assistants approached women at the health clinic to recruit and enroll them into the study. Women were eligible if they received an abnormal breast or cervical cancer screening result or a positive cancer diagnosis. Women who were cognitively impaired, institutionalized, or under the age of 18 were ineligible for the study.

Data Collection

After obtaining written informed consent, bilingual research assistants collected demographic data and then conducted semi-structured, in-person interviews in English or Spanish. Interview questions were guided by the Chronic Care Model and elements of the Socio-ecological Model (Bronfenbrenner, 1977; Wagner, 1998); they assessed access to health care, follow-up, resources, social support, rationale for seeking care, and patient recommendations. Patients recommendations to improve women's access to breast or cervical cancer screening and follow-up were specifically solicited with this question, asked of all participants, at the end of the interview: "How do you think we can improve women's access to breast examinations and mammograms [or Pap tests and cancer care] and follow-up for them? Is there some obstacle that we could work on?" All interviews were audio-recorded and lasted approximately 45 minutes. This study was approved by the Northwestern University and University of Illinois at Chicago Institutional Review Boards.

Analysis

Interviews were transcribed, and Spanish interviews were then translated into English and back-translated into Spanish for quality assurance. Only data from patients who provided recommendations to improve women's access to breast or cervical cancer screening and follow-up were included in the analyses presented in this report; patients were excluded if they reported that they did not have any recommendations or chose not to provide a recommendation. A team of four data analysts coded interviews following the inductive methodological approach of Hruschka and associates (2004) using ATLAS.ti 6.2 qualitative data analysis software. Team members independently reviewed the same four transcripts to generate initial codes, which were compared and reconciled through a consistent team consensus method to synthesize a standardized codebook of codes and code categories. To ensure consensus among coding schemes throughout the analysis, 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 (Hruschka et al., 2004). After transcript coding, the research team systematically explored the data to identify consensus themes and subthemes among patients' recommendations. Themes and subthemes were rank ordered by frequency, and thematic relationships were explored.

Results

Sample Characteristics

Of 138 women who participated in the parent study, 52 women (38%) provided recommendations when queried for suggestions for improving access to breast and cervical cancer screening and follow-up. As shown in Table 1, most (62%) of the 52 women in our sample were between 41 and 65 years old, African American (60%) or White (25%), and English speaking (88%). All 52 respondents had an abnormal breast or cervical cancer screening result, and about one half had a positive diagnosis for breast or cervical cancer.

After the multi-stage coding process, we grouped predominant themes into two categories: (1) Community-level recommendations and (2) institution- and policy-level recommendations. Table 2 provides a summary of the aggregated patient recommendations that we herein describe in detail.

Community-Level Recommendations: Education and Dissemination

Heighten health messages

Overall, women regarded patient engagement as a facilitator of access, but the majority of participants expressed concern that breast and cervical cancer-related prevention and care is a neglected priority among women. Participants voiced that accentuating the quality-of-life and "life-or-death" implications associated with adherence to care should be a crucial element of