

Providers' Perspectives of Cancer Care for Rural Appalachian Women

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RURAL APPALACHIAN CANCER DEMONSTRATION PROGRAM

ABSTRACT

The purpose of this qualitative analysis was to determine rural primary care providers' perceptions on cancer care for women patients in their practice and to discover their perceptions of their role in the cancer care continuum. The study was conducted in three rural primary care practices in southwest Virginia and northeast Tennessee. All three practices were federally qualified community health centers (FQHCs) serving a lower income, rural population. The clinics were located from 33 miles to 70 miles from tertiary cancer referral centers. Interviews were conducted in May of 2004 and March of 2005. The number of group participants ranged from eight to 10, with a total of 26 participants. Of these, eight were men and 18 were women. There were 11 physicians, 14 nurse practitioners, and one licensed clinical psychologist. The number of women diagnosed with breast cancer per setting ranged from one to 50 with an average of 10.

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REVIEW OF LITERATURE

Primary care providers and their patients are concerned with screening for breast cancer (Dominick, Skinner, Bastian, Bosworth, Strigo, & Rimer, 2003; Ford, Minasian, McCaskill-Stevens, Pisano, Sullivan & Smith, 2003; Haas, Kaplan, Gregorich, Perez-Stable & DesJarlais, 2004; Smith, Gadd, Lawler, Macdonald, Grudberg, Chi, Carlson, Comengo & Souba 1996.) Low income women who are patients in FQHCs experience barriers to early breast cancer diagnosis including lack of knowledge, personal perception of good health, fear of mammography and lack of clinician recommendation (Ogedegbe, Cassells, Robinso, DuHamel, Tobin, Sox & Dietrich, 2005.) Rural women are screened for breast cancer through mammography less often than urban (Engelman, Ellerbeck, Perpich, Nazir, McCarter & Ahluwalia, 2004.) Rural Appalachian primary care providers report that barriers to recommended screening in their office practices include time constraints, conflicting guidelines and perceptions that patients do not value prevention (Shell & Tudiver, 2004).

Primary care providers' role in breast cancer care includes screening and diagnosis, referral, and post-treatment follow-up (Haggstrom, Phillips, Liang, Haas, Tye & Kerlikowske, 2004; Sherwood, Given, Scholnick & Given, 2004). Primary care providers value education about cancer screening, diagnosis and treatment (Anderson, Dziak, McBride, Camacho, Hege & Torti, 2004). O'Malley, Forrest and Mandelblatt (2002) found that coordination among providers and better patient-practitioner relationships improved inner-city, low-income women's adherence to cancer screening recommendations.

DATA COLLECTION AND ANALYSIS

A qualitative, inductive approach, with three focus groups was utilized to collect interview data. In an inductive, interpretive approach, hypotheses are not prespecified or tested. Rather, findings for this study emerged from understanding and interpreting the experiences of the providers. Data were generated from structured focus group sessions and investigator field-notes. Focus groups were used to enrich the description and facilitate comprehensive interpretation of the data. A structured group format in which each participant was asked each question captured certain dimensions of the data for all participants, and allowed them to respond to each other's comments and interject freely throughout the group sessions. Each participant was asked a "grand-tour" question: "Describe your experiences in your practice in providing care to women with breast cancer". Subsequent questions were generated as the discussion took shape and were guided by participant responses. For example, participants were asked to describe what barriers they had encountered, and what was working well.

Data collection and analysis proceeded simultaneously. Data from the three focus groups (N=8; N=8; N=10) consisted of primary care physicians and nurse practitioners and one doctorally prepared psychologist (LPC). Focus group interviews were audiotaped and lasted 2 to 2 1/2 hours each. Audiotapes were transcribed verbatim. Data were analyzed using the constant comparative method where portions of

text were compared to yield categories and themes. Reassessment and refinement of the categories and themes continued throughout data collection and analysis resulting in an explanation of the providers' experience of providing cancer care to rural Appalachian women with breast cancer. Emergent findings were reviewed with a group of health professionals (advanced practice nurses) to assist with establishing credibility and truth. Additionally findings will be reviewed with providers of cancer care who will judge the fit of the findings with the emerging coding scheme or explanation. This step will assist with finalizing the findings, and developing a cohesive explanation or model of provider experiences.

FINDINGS

Primary care providers in the study described their experiences of providing cancer care to rural women with breast cancer. For all providers, (physicians, nurse practitioners, LPC), their relationships with patients were paramount, providing support for patients to seek screening when they hadn't before, they were the impetus for providers to: problem-solve, coordinate, and piece together services needed by patients. Three themes emerged from the interview data: *Knowing the Patient*, *Walking Through Treatment with the Patient*, and *Losing the Patient to the System*.

Knowing the Patient

Providers described four dimensions of having personal knowledge of their patients with breast cancer that had bearing on patient screening and treatment. Patients viewed them as trusted experts, and they in turn viewed their patients as "experts" in their own lives. The providers in this study didn't tell their patients what to do; rather, they got to know the women and many details of their lives. This detailed knowledge of the particulars of patients' lives provided insight into what kept them coming for care, what got them to screening, and also provided specifics regarding barriers to screening and care. For example, a woman who had never had a mammogram (though understanding fully the importance of the test, given her age and family history), would decide to have it because the provider suggested it.

Providers expressed that telling their patients to have the test did not make a difference or have an impact on screening behavior. But, because providers had relationships with the women in their practices, knew the details of their lives, and could make a suggestion specific to their personal circumstances, they influenced screening behaviors in positive ways. They believed women responded to their suggestions not so much because they were medical experts (though they clearly felt the women viewed them in this way, and depended on their expert knowledge), but more so because there was a human-to-human caring connection. Medical expertness and caring human were equally valued by their women patients, according to the providers. Women were motivated to screening and self care because their providers cared about them, not just cared for them. In this way, the trusted relationships they had developed offered a type of leverage toward self-care—women cared for themselves because their providers cared for them personally.

Walking Through Treatment with the Patient

Primary care providers described that patients commonly came to them after a visit to the specialist or oncologist at the cancer center, to elicit their opinion on recommended treatments and therapies before initiating the prescribed treatment. Patients relied on the PCPs to manage symptoms, interpret information, and to help them make sense of the experience of breast cancer, and how it affected them personally. The women relied on their relationships with their PCPs as trusted experts and wanted their view on recommended therapy before they were willing to start. In essence, they went home to the doctor or nurse practitioner that they knew to ask “what do you think of this (treatment or therapy)?” For some PCP’s this was uncomfortable, for reasons ranging from lack of knowledge of current treatment, to lack of communication from the oncologist regarding exactly what that person had communicated to the patient, to inability to discern specialist handwriting on patient records from the oncology center. For other PCPs, the internet was a source of state of the science treatment, and they relied on it often to stay current, and to be able to answer patient questions. They expressed that often patients brought current treatment information to them, as patients and providers alike had access to a great deal of electronic information. Sometimes, they struggled to keep up with their patients’ knowledge about treatment, or tried to help them sort out which information to pay attention to.

Losing the Patient to the System

For some PCPs, referring patients to oncology specialist care resulted in patients being “out there” –they were not sure what was happening with their care, and felt “out of the loop”. This group of providers described discontinuities in care related to “who’s in charge”, or not knowing clearly which responsibilities for patient management belonged to the PCP, and which would be handled by the oncologist. This lack of clarity started, for some, at diagnosis. Sometimes PCPs were unclear about who would give information to the patient regarding her diagnosis, stating that in certain instances, the oncologist wanted only to handle treatment, and “not any of that other stuff” such as giving diagnostic bad news, offering support, or handling patients’ emotional needs as a part of care. They described their experiences of some specialist care as being very segmented, while their approach to practice and to their patients was holistic and inclusive. It wasn’t that they minded giving information about diagnosis and even treatment (provided they felt appropriately informed), what they reacted to was the effect that this fragmentation had on their patients. The women often had to wait several days--between diagnostic testing, learning of their diagnosis and upcoming therapy--if the oncologist took the position that he or she dealt with only the treatment portion of the illness. PCPs viewed this as being looked down upon by their specialist colleagues, and as a devaluing by specialists of both the patient’s experience at the critical time of diagnosis, and of the PCP as one who dealt with more “low tech” areas of patient care.

PCPs described a set of barriers that, in their view, contributed to the discontinuities experienced by some of their patients with breast cancer. Financial barriers were noted frequently, since rural women often had to schedule screening or

treatment during the week, necessitating they miss a day of work. The expense of travel to referral centers was also noted as a barrier by some, as was financial burden of certain treatments or drugs not fully covered by insurance. Overall, the PCPs in this study noted that their uninsured patients fared far better in terms of treatment than those who were underinsured.

Plans for Dissemination

The results of this study will be submitted for consideration for presentation at the National Organization of Nurse Practitioner Faculties by October 14, 2005. A manuscript will be submitted to the *Journal of Rural Health* or other appropriate journal.

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