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A Breast Navigator Program: Barriers, Enhancers, and Nursing Interventions

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The American Cancer Society (2010) estimated that 207,090 women and 1,970 men in the United States in 2010 were diagnosed with new cases of invasive breast cancer. From 1999–2006, female breast cancer incidence rates decreased 2% per year, largely attributed to reductions in the use of menopausal hormone therapy and a slight drop in mammography use that may delay diagnosis (American Cancer Society, 2010). However, excluding cancers of the skin, breast cancer is still the most common cancer among women. Incidence and death rates are lower among women of other racial and ethnic groups than among African American and Caucasian women (American Cancer Society, 2010). Despite effective adjuvant treatments for early-stage breast cancer, many women do not receive them (Bickell & Cohen, 2008).

Breast Cancer Treatment Disparities

Bickell (2002) constructed a model of underuse of breast cancer treatment and its causes. Treatment underuse is identified as the result of patient, physician, and system factors that exist, interact, and affect each other within a healthcare system and the patient's community. Physician and patient factors are comprised of knowledge, attitudes, beliefs, and behaviors. Specific patient factors include communication skills, income, health insurance, education, competing demands, transportation, language, literacy, and culture.

A component of the mortality differential may be caused by disparities in treatment (Bickell & Cohen, 2008). In a study of 100,311 women with breast cancer, McCarthy et al. (2006) identified that the disabled, as defined by the Social Security Disability Index and Medicare, were less likely to undergo standard therapy after breast-conserving surgery. Differences in treatment did not explain differences in breast cancer mortality

Purpose/Objectives: To identify barriers to and enhancers of completion of breast cancer treatment from the perspective of participants in a breast health navigator program.

Research Approach: Qualitative, using focus group methodology and telephone interview.

Setting: Two teaching hospital ambulatory cancer centers.

Participants: Women enrolled in the breast navigator program, including patients who completed (n = 13) and did not complete (n = 1) breast cancer treatment.

Methodologic Approach: Researchers used semistructured, open-ended questioning to guide the interviews and elicit identification of barriers to and enhancers of treatment. A flexible approach was used and the interviews were recorded. Content analysis was used to identify themes.

Main Research Variables: Perceived barriers and enhancers of breast cancer treatment.

Findings: The most common theme was the value of the education and information received from the navigator. Several participants saw this as the essence of the role. Assistance with managing symptoms, access to financial and community resources, and the team approach were completion enhancers.

Conclusions: Completion of breast cancer therapy and care can be improved by recognizing the value the nurse navigator role brings to the patient experience and enhancing that role.

Interpretation: The intentional presence of the oncology nurse and the nursing emphasis on culturally appropriate education and care can be seen as key competencies of the navigator. As the concept of the navigation process is expanded to other cancers, oncology nurses are particularly well positioned to advocate for the navigator role as a nursing domain.

rates. Inadequate or no health insurance had been found to be associated with shorter overall survival with breast cancer (Palmieri et al., 2009). Low socioeconomic status is a primary predictor of not undergoing screening (Dignan et al., 2005).

Ethnic differences in morbidity and mortality from breast cancer are likely the result of a complex array of factors (Shavers & Brown, 2002). Barriers include lack of continuity of care, lack of social support, mistrust, communication issues, culture, health beliefs, and differing economic, personal, and family health priorities (Ferrante, Chen, & Kim, 2008).

African American and Latino women have poorer outcomes after treatment for breast cancer (Katz et al., 2005; Kim, Ferrante, Won, & Hameed, 2008), and data suggest a racial disparity in treatment (Bickell & Cohen, 2008). Katz et al. (2005) conducted a population-based survey of 910 women diagnosed with breast cancer and demonstrated that non-English-speaking Latinas experienced somewhat lower receipt of adjuvant treatments. Kim et al. (2008), in a retrospective examination of 265 women, found that African American women had significant comorbidities that may affect treatment and also found a high rate of noncompliance with postoperative adjuvant treatment (15%) compared to non-African Americans (3%).

Masi, Blackman, and Peek (2007) completed a systematic review to identify interventions designed to enhance breast cancer screening, diagnosis, and treatment among racial and ethnic minority women. The authors noted that most interventions focused on expediting treatment initiation. Two controlled trials (Ell et al., 2002; Goodwin, Satish, Anderson, Nattinger, & Freeman, 2003) met the criteria for inclusion. Of interest, Goodwin et al. (2003) evaluated the effect of nurse case management on breast cancer treatment in racially diverse women receiving Medicare. Services included education, counseling, advocacy, and coordination of care. The authors found that being 75 years or older, a minority, unmarried, and living alone were associated with lower rates of appropriate treatment in the control versus the treatment group. Women with indicators of poor social support were most likely to benefit from case management.

Patient Navigation Programs

Patient navigation interventions were designed to reduce disparities in cancer treatment (Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008). The first patient navigator program was established at Harlem Hospital in 1990 (Freeman, Muth, & Kerner, 1995), and the model has continued to evolve and expand. Patient navigator programs represent a type of case management that is focused on a range of issues or healthcare needs (Lantz, Keeton, Romano, & Degroff, 2004). The model focuses on meeting the needs of a particular situation, such as providing information and support to those with breast cancer (Till, 2003). Farber, Deschamps, and Cameron (2002) investigated the navigator role and found that the term *navigator* was rarely used, but functions were identified: advocate, coordinator, and facilitator. Batta-

glia, Roloff, Posner, and Freund (2007) noted that services provided included case identification, detection of individual barriers to care, care plan implementations, and tracking through treatment completion.

Few studies have examined the effectiveness of navigator programs. Two randomized, controlled trials are evident. Ell, Vourlekis, Lee, and Xie (2007) demonstrated that navigation and counseling increased follow-up rates and diagnosis after abnormal mammogram in a sample of Latino women. Ferrante et al. (2008) randomized 105 women with suspicious mammograms to usual care or usual care plus navigation. Women in the navigation group demonstrated shorter time to diagnostic resolution, lower mean anxiety scores, and higher satisfaction scores than the control group.

As breast navigator programs continue to grow, their impact and effectiveness on clinical outcomes must be examined. An opportunity also exists to examine the role from the patient's perspective: What do patients identify as key enhancers and barriers to completion of therapy? The purpose of the current study was to identify barriers to and enhancers of completion of breast cancer treatment from the perspectives of participants in a breast health navigator program.

Methods

Setting and Participants

The current study employed a qualitative approach using focus group methodology and a telephone interview with subsequent random chart audits of program participants. The study took place at two nonprofit hospitals in the northeastern United States. The Breast Health Navigator Program at Rhode Island Hospital and Miriam Hospital was established in August 2005 and is funded by the Avon Foundation.

The role of the navigators is to provide patients with breast cancer assistance that is tailored to their needs in culturally appropriate ways. The primary objective is to increase the number of women with breast cancer who enter the program and complete treatment. Both sites are academic medical centers with active teaching programs and accreditation from the National Accreditation Program for Breast Centers, and both hospitals employ RNs as navigators.

Former participants in the navigator program were invited to participate in focus group sessions at both sites. The sessions were tailored to completers and non-completers. For the purposes of this study, completed subjects were defined as those who had finished IV chemotherapy or radiation therapy. As of August 2008, the database for the program, a Microsoft® Excel® file of all patients with breast cancer who had been seen by a nurse navigator at either site, revealed 187 enrolled participants (all were women): 78 were receiving active

therapy and were seen regularly by the navigators, 103 had completed the recommended treatment therapy and were no longer followed, and 6 had not completed recommended therapy and were no longer followed. Of the 109 participants who were no longer in the program, five were identified as non-English-speaking, all of whom had completed breast cancer therapy.

Procedures

The study was approved by the Lifespan Institutional Review Board. All of the potential completer subjects (N = 103) were sent an invitation letter describing the purpose and procedures and requesting their participation in a focus group to be conducted at their hospital site. Focus groups are increasingly used in nursing research and offer the advantage for larger numbers of participants than can be achieved with individual interviews. Disadvantages include less active participants being dominated by more vocal ones (Mansell, Bennett, Northway, Mead, & Moseley, 2004).

Subjects were informed that vouchers for transportation would be provided, translators would be available, and responses to questions would be tape-recorded. If interested in participating in the focus group, potential subjects were asked to return a phone call to the principal investigator or bilingual member of the research team if non-English-speaking. Potential subjects were asked for permission to receive a reminder phone call one day prior to the meeting. Based on the response (N = 13), a focus group session was held at each site 30 days after the invitational letter mailing. Participants attended only one session; seven attended at Rhode Island Hospital, and six attended at Miriam Hospital.

An identical process was used for each session. Prior to starting the program, a light meal was provided. The researchers then obtained informed consent, also translated into Spanish for the Hispanic participant, and a translator was engaged. Subjects were told that participation was voluntary, they could withdraw at any time, and their decision to forgo participation or withdraw participation would not affect their current or future care. Participants were informed that responses would be tape-recorded, but individual respondents would not be identified by name, and that another member of the team would take notes during the session without identifying individual respondents. Study volunteers were encouraged to maintain strict confidentiality. The translator assisted the Spanish-speaking participant by reviewing the informed consent, clarifying focus group questions and the subject's responses as well as translating subjects' responses on behalf of the group.

Interviews were conducted by two members of the team with expertise in focus group design and facilitation. During each focus group, the primary researchers used open-ended questioning to elicit identification of

barriers to and enhancers of treatment. The questions were used to guide the group, but a flexible approach was used. Participation was encouraged, but individuals were not called directly to participate. Probing and redirection were used to keep the discussions on task and to maintain focus on the topic. Clarification and further expansion were used as needed. Participation at both group sessions was active and enthusiastic, and the facilitators believed the process was enhanced by relatively small group sizes.

Using the same procedure, the noncompleters (N = 6) were sent an invitation letter and asked to participate in a focus group. One English-speaking participant responded. A subsequent telephone interview was scheduled with the principal investigator and consent was obtained. Questions to determine barriers and potentially useful strategies as identified by the participant were addressed and recorded with paper and pencil. The participant was open to discussion and actively related reasons for discontinuing chemotherapy treatment against the advice of the medical team.

Data Analysis

Data obtained from the two tape-recorded focus groups were transcribed by the principal investigator and reviewed by the principal investigator and a researcher independently. Transcripts from the focus group were reviewed along with the notes taken during the session that emphasized nonverbal communication. Thematic analysis was used to identify theme and generalizations within and across cases (Ayres, Kavanaugh, & Knafl, 2003).

Lincoln and Guba (1985) identified four criteria for evaluating the trustworthiness of qualitative data: credibility, dependability, confirmability, and transferability. Credibility was ensured by providing feedback to participants at the end of the sessions to confirm preliminary data obtained and by sharing findings with the navigator nurses for their validation. Dependability was confirmed by the striking similarity between themes identified by the groups and the sole noncompleting participant. Confirmability was achieved by congruence of themes identified by two independent reviewers. Transferability will be established through dissemination of findings.

Findings

A response rate of 13% (n = 13) from the completers and 16% (n = 1) from the noncompleters yielded several themes that were consistent between the two focus groups and the participant interviewed by telephone. Seven women who completed treatment in the navigator program attended the first session and six attended the second. The majority of the women were middle-aged,

and all but one spoke English. Participants' demographic characteristics were representative of those in the overall group of navigator program participants (see Table 1). All participants agreed that each woman's experience was unique, but that the commonalities of their felt experience were overwhelming. Several themes of enhancers and opportunities for improvement emerged, and findings were remarkably consistent between the two groups (see Table 2).

Education and Information

All participants identified the critical role of information and education about the entire process. Women discussed the overwhelming nature of the treatment experience, which often made learning difficult. The navigator was seen as able to repeat, clarify, reinforce, and validate information the patient was receiving from multiple sources.

Support

Participants noted the emotional support provided by the care team, particularly the nurse navigator, and significant others was key to successful treatment completion. Support often was perceived as "just being there" and could be likened to the concept of intentional presence. The real or perceived emotional challenge of being alone during treatment was emphasized. Having someone to rely on, including other patients undergoing treatment, was seen as invaluable. One woman was so affected she wanted to give back and had become an "informal navigator." As a suggestion, several women felt that participants should be more formally offered the option of pairing up with another patient.

Symptom Management

Women expressed wide variability related to the depth and breadth of their symptoms but agreed that managing symptoms, whatever they were, was key to

successful coping. The navigator was seen as the source of helpful assessment and management suggestions. Many participants had worked during therapy and cited the need for more initial awareness and preparation for aftereffects prior to the initiation of therapy. Most also expressed an interest in learning more about what they saw as "alternate treatments" that could be accessed during chemotherapy, such as massage and Reiki therapy. Several participants at one site had received and benefited from those treatments, but others did not and were unaware that they were available.

Teamwork

Several women spoke of the importance of meeting the entire treatment team prior to starting therapy. This encounter was seen as clarifying roles, reinforcing support of caregivers, and instilling confidence that the collaborative team had a common understanding and acknowledgment of the plan of care. Those who did not have the opportunity to meet the treatment team in advance saw this as an area for improvement. Another suggestion was for more formal introduction of all the team members, including a brochure describing each discipline and role. For the nurse navigator, a clear list of services, hours of availability, and contact numbers was needed. The navigator was seen as playing a key role in obtaining and coordinating a vast array of medical and social services. The participants believed this aspect of the role and the collaboration with social workers should be emphasized in the role clarification.

Medical Care

Several women commented that doctors often talked beyond patients' ability to understand and the group unanimously agreed with a comment about doctors being too cerebral. In both hospitals, the navigator did not accompany the patient in the examination room with the physician. Encouraging navigator presence during the medical appointment was seen as an opportunity to improve communication and understanding. The Hispanic participant stated that more non-English-speaking providers were needed. Although she noted that interpreters were available, she did not believe that simply having an interpreter was "always enough."

Survivorship

Almost unanimously, the participants described the void they felt at treatment completion. After months of intensive therapy and interaction with multiple team members, the issues were focused on leaving a supportive environment, fears of recurrence, and questions about long-term follow-up.

The one participant who had not completed recommended therapy was interviewed by telephone. She clearly articulated that she came to the treatment team

Table 1. Demographic Characteristics

Characteristic	n
Age (years)	
40–49	6
50–59	6
60–69	1
70–79	1
Ethnicity	
African American	1
Caucasian	12
Hispanic	1
Language spoken	
English	13
Spanish	1
N = 14	

with a preconceived vision of what therapy she would be willing to consent to. She stated she was initially hesitant, but after meeting with the physician and nurse navigator, she agreed to two treatment sessions. She then discontinued treatment without regret, saying, "At the end of the day, it was my decision, my body and my health."

The noncompleting patient mirrored the focus groups, stating that education and information were critically important. She independently researched breast cancer but appreciated the opportunity to ask questions and seek clarification. Echoing the support component, she said, "I met with the navigator and her assistant . . . they would just sit with me and talk with me. . . . I thought my family or boyfriend would ask to come with me. Everyone else had at least one person with them and I had no one."

A different topic arose in the course of this single interview that had not been raised in either focus group. The noncompleter expressed tremendous satisfaction with public awareness and education events. Attending large events, often with well-known speakers, made her feel part of a larger group of women who knew "exactly what I was talking about and had been through. At the end of the day, you do it for yourself." She had no suggestions for what might have been improved to help patients make decisions, improve the treatment process, or complete treatment.

A subsequent random chart audit of records from about 30% of the total participant database (N = 101) was conducted to identify the documented nursing actions used during care in the breast navigator program. The examination of 32 records revealed the nursing interventions of education and emotional support as being predominant and occurring in 30 of 32 records. The majority of these

Table 2. Perceived Enhancers and Barriers to Breast Cancer Treatment

Theme	Perceived Enhancers	Perceived Barriers
Education and information as key	<p>"You are often told important information but simply cannot process it."</p> <p>"Helps anticipate what is coming . . . when you don't know, it's very scary."</p> <p>"You need to know what to expect in the journey."</p> <p>"It's all about knowing what is happening."</p> <p>"I was deathly sick. I really felt like I would rather die than continue that way. The navigator nurse helped me to eat and to remember that each day after the treatment will get a little better."</p>	<p>"Not knowing what to expect is the worst thing."</p> <p>"You need to know the process or you don't know what to ask."</p> <p>"They really don't tell you the full scope of side effects that really hit you, usually about the fourth chemo."</p>
Symptom management	<p>"Life goes on. You still need to do all the other things that you do in your life . . . to be able to talk with someone about how to manage the aftereffects of treatment can really help."</p> <p>"I knew I could ask the navigator anything, call her at any time."</p> <p>"I never felt alone. I knew I could call if I was having a bad day."</p> <p>"Sitting with me, just being there, made such a difference."</p>	<p>"I was, and remain, petrified. Seeing the red poison come down the line made me cry every time. Very scary."</p> <p>"Navigators are not always available when you need them."</p>
Support	<p>"I don't think I would have gotten through this without my faith."</p> <p>"It really helped me to see other people ring the bell and [know] that I would ring it someday."</p> <p>"Talking with other people helped me to know I am not the only one."</p> <p>"Everyone is different, so you really need to individualize."</p>	<p>"The negative things, people who you thought were friends who avoid you, really hurt."</p> <p>"I really wanted to give back, so I tried to help anywhere I could but would like to have been asked how I could help."</p>
Treatment to meet individual needs	<p>"The navigator knew me, my individual needs, and supported me through the process."</p>	<p>"Women are stronger, have far more obligations outside of themselves, but are often afraid to ask for help."</p>
Importance of teamwork	<p>"Meeting with the team was really important; it helped me to understand the whole process."</p>	<p>—</p>
Resource assistance	<p>"The navigator helped me to get a medicine that my insurance didn't cover. . . . She did what had to be done to get it."</p> <p>"These issues are really overwhelming on top of everything else."</p>	<p>"Doctors are too cerebral."</p> <p>"I want to talk to my own doctor, not a medical student. I know they need to learn, but this is my life I am fighting for."</p>
Coordination of care	<p>"I used every service available, because I was aware of them."</p>	<p>—</p>
Role definition	<p>—</p>	<p>"Patients should be told about the navigator program, what the nurse does, and how it all works for us."</p>
Survivorship	<p>—</p>	<p>"After all you go through, the chemo, the radiation, all the treatments, when it is over, they say, 'Come back in three months.' You really feel alone . . . and ask, 'Who do I go to if . . . ?'"</p>

interventions were documented as part of teaching and counseling in visits timed at 30–60 minutes. The functions of prescription assistance and appointment scheduling were noted activities, found documented as tasks timed at visits less than 30 minutes.

Summary

Using the patient's perspective, this research attempted to validate the effectiveness of navigator programs by identifying barriers to and enhancers of completion of breast cancer treatment. A limitation was the small number of noncompleters and the single interview conducted. All of the interviewed participants identified the navigator role as valuable in their breast cancer experience. The nurse navigator was seen as the source of information, emotional and physical support, and a constant presence that allowed them to persevere through the months of treatment. From this research, as the navigation concept expands to other disease groups, clinicians can learn some of the core competencies required from the patients' perspective. For cancer administrators and clinicians, further research can validate patient perspectives and help identify the impact of the role on clinical outcomes. Because the services provided by the navigation role are typically not able to be quantified for reimbursement by third-party payers, healthcare systems must absorb the costs of this role. As healthcare dollar expenditure undergoes closer scrutiny, demonstration of impact on either clinical outcomes or patient satisfaction will become more critical.

Interpretation

Nurse administrators and direct caregivers can learn much from the patient feedback. Common recurring themes offer opportunities for improvement in the delivery of breast cancer care and support services, including the navigator role. At the core of each patient's journey was the need for accurate education and information presented by culturally competent caregivers in a supportive environment. This feedback validates one of the essential competencies of oncology nursing: recognition of the value of individualized patient education. Almost equal in importance was the impact of support—the ongoing intentional presence that the nurse navigator brings to the patient in life crisis. As a skilled interviewer, listener, coordinator, and counselor, the nurse navigator can be the one person who can guide and support the patient from diagnosis to survivorship.

In an interview conducted by Yard (2009), Michael Goldstein, MD, cochair of the American Society of Clinical Oncology's Workforce Advisory Group, stated, "I think oncology practices and delivery of oncology care is going to be more of a team effort . . . the team will include

the oncologist, the nurse or [physician's assistant], the chemo administration nurse, plus various other people . . . it's really going to be the team approach" (p. 25). Several patients expressed the value of team approaches but hoped for clearer definition of all roles, including the navigator. Clear role delineations introducing and integrating the collaborative team and the navigator role, particularly early in the treatment experience, is important to patients. Knowing the team and feeling confident that all are focused on the same goal allow the patient access to information and support at the critical juncture of early treatment decision time.

Clearly articulated for nurses is also the imperative for a more coordinated approach to the patient's follow-up care after active treatment concludes. Developments of survivorship treatment summaries, often as a part of a coordinated survivorship program, are becoming more standard in cancer care settings. Settings vary in their implementation of the summary presentation to the patient and the programs in general, but consideration should be given to the value of the navigator role in this process. Having a clearly integrated role from beginning to end in the care process and being seen by the patient as a source of information and support are both attributes that make the navigator a candidate for coordinating the survivorship information given to the patient.

Identification with other patients with breast cancer, a concept not widely recognized by clinicians, validates earlier work done with a survivorship support group at one of the research sites. Female survivors were eager to have identified a "buddy" to share the treatment experience with. Nurse navigators can play a critical role in developing partnerships between patients during the treatment process and opportunities to meet in larger educational and public health awareness events.

Particularly when caring for patients with cancer, caregiver knowledge of cultural differences in languages, rituals, approach to therapy, meaning of aggressive and supportive therapy, and end-of-life decisions is critical. Cancer settings must strive for integration of culturally diverse caregivers and support staff to match patient demographic mix. As one patient stated, translators are important but cannot replace the trust in seeing a caregiver who is from the same cultural background.

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