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Lessons Learned in Developing a Support Intervention for African American Women With Breast Cancer

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Purpose/Objectives: To describe the process of planning a theory-based support group project for African American women with breast cancer

Data Sources: A needs assessment and recruitment strategies consistent with the Oncology Nursing Society's *Multicultural Outcomes: Guidelines for Cultural Competence* were used to adapt a support group intervention for newly diagnosed African American women in urban central Texas.

Data Synthesis: The reviewed literature and local cancer survivor leaders indicated the need for education and support of newly diagnosed women. Although researchers worked for several years with lay leaders to gain legitimacy and trust, not enough participants were recruited to test an intervention specifically for African American women.

Conclusions: Recruiting support group research participants from a relatively small minority population is problematic even when collaborating with population leaders.

Implications for Nursing: Nurses may encounter barriers to conducting research in minority populations. Starting early to build credibility with that population, being flexible with eligibility criteria, beginning with pre-experimental studies, and paying participants may be required.

he Oncology Nursing Society's (ONS's, 1999) Multicultural Outcomes: Guidelines for Cultural Competence, developed to address nursing practice, education, and research, targets many aspects of diversity, including ethnic minority and socioeconomic status. These guidelines directed a project to develop, implement, and test a theory-based support group intervention for African American women newly diagnosed with breast cancer. This article discusses the reasons for the proposal of this component of a larger project, the actions taken during the development phase, and the lessons learned along the way.

The African American Breast Cancer Support Group Project was the secondary aim of a five-year Self-Transcendence in Breast Cancer Support Groups Project. The primary aim of the study was to test the impact of theoretically based activities during an eight-week support group intervention for women of any ethnic background recently diagnosed with breast cancer. The facilitation of self-transcendence views and behaviors in weekly, 90-minute, closed support group sessions was expected to positively affect self-transcendence and physical and emotional well-being outcomes by the end of the intervention and six months later. Intervention session activities included problem solving, values clarification, and training in relaxation techniques, constructive thinking, assertive communication skills, and emotional management. In total, 161 women were assigned by order of recruitment

Key Points...

- ➤ Evidence exists of differential treatment and decreased survival in African American women with breast cancer.
- ➤ Breast cancer advocacy in the African American community includes empowering survivors to advocate for themselves and other women.
- ➤ Although traditional cancer support groups are resources for education and support that may lead to empowerment, few minority patients participate in such support groups.
- ➤ Nontraditional interventions may be needed to empower African American women with a stronger sense of self-agency to effectively advocate for treatment information and appropriate care.

to intervention or community cancer support groups of 8–10 women each.

The secondary aim of the Self-Transcendence in Breast Cancer Support Groups Project was planned with support from local African American breast cancer activists. Race and ethnicity data from two earlier pilot support group studies (Coward, 1998, 2003) revealed that African American women were underrepresented in that research. Although increased efforts in minority recruitment and retention resulted in higher minority representation in the Coward (2003) study, a different approach was chosen for the current study to reach newly diagnosed African American women.

Literature Review

Education and Support Needs of African American Women With Newly Diagnosed Breast Cancer

The cultural competency guidelines outlined by ONS (1999) directed the researchers to base their work on previous research findings and current healthcare problems in the target

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population. A review of the research literature and communication with breast cancer survivor advocates in central Texas were initiated before the proposal was funded. The findings indicated that although African American women had not participated in previous pilot projects, education and support regarding breast cancer and breast cancer treatment were needed.

In the late 1990s, despite increasing breast cancer incidence rates, mortality rates had declined for the first time in several decades. Breast cancer mortality rates decreased for Hispanic and Caucasian women; however, they remained stable for older and African American women (Greenlee, Murray, Bolden, & Wingo, 2000). A number of contributing factors were implicated for the decrease in mortality rates and the differences in these rates by age and race. Long (1993) attributed African American women's breast cancer mortality to (a) low socioeconomic status, (b) advanced stage of disease at diagnosis, (c) delays in diagnosis and treatment, (d) biologic and constitutional characteristics, and (e) treatment differences. More recently, Dignam (2000) reported findings from several studies indicating that when the stage of disease at diagnosis and subsequent treatment were comparable, outcomes for African American and Caucasian women were similar.

Stage of disease at diagnosis and treatment may differ in African American women for several reasons. Even though an increasing number of African American women use mammography screening, they may not obtain appropriate treatment if diagnosed with breast cancer. Ashing-Giwa and Ganz (1997) reported that many African American women with breast cancer were not informed about treatment options or encouraged to participate in treatment decision making. In addition, women with low incomes may have access to free or low-cost mammograms, but higher-cost breast cancer treatment is unavailable to them. For example, Mandelblatt et al. (2002) found that African American fee-for-service Medicare recipients treated in 1994 were 48% more likely than Caucasian Medicare recipients to not receive radiation therapy after having breast conservation surgery for localized breast cancer.

Spiritual beliefs may influence screening behavior and treatment choice and are a primary source of support and coping for African American women with breast cancer (Ashing-Giwa & Ganz, 1997; Barroso et al., 2000; Bourjolly & Hirschman, 2001; Lackey, Gates, & Brown, 2001). Women with strong spiritual convictions may believe that a higher power has more control over the development of breast cancer and the treatment outcome than the individual's behavior or type of treatment. For example, Barroso et al. reported that African American women were more likely than Caucasian women to believe in chance or depend on powerful others for their health. In that study, scores for African American women on a powerful others health locus-of-control subscale were associated with lower perceived cancer susceptibility and seriousness of cancer and with doubting the value of early diagnosis.

Cancer Support Groups as Educational Resources

Breast cancer support groups provide an opportunity for women to share their cancer experiences, exchange information about treatment options, and learn to advocate for themselves. Interactions with their peers in a supportive setting also may help newly diagnosed women resolve issues related to relationships with professionals and in their family and social networks (Cope, 1995; Coward, 1998, 2003). Studies have shown that the healing process may be affected by the knowledge women

gain and the opportunities for emotional expression they realize from cancer psychosocial supportive services (Coward & Reed, 1996; Fobair, 1997a, 1997b; Johnson, 2000; Reynolds et al., 2000). Unfortunately, minority patients with cancer are less likely than patients from a majority group to attend cancer support groups (Barg & Gullatte, 2001; Taylor, Falke, Shoptaw, & Lichtman, 1986).

Findings from a recent study of personal issues and the concerns of female African American breast cancer survivors illuminate why they may not join available cancer support groups (Wilmoth & Sanders, 2001). Eighteen focus group participants, although voicing concerns similar to those of Caucasian women, identified different issues related to those concerns. Participants believed that the differences between Caucasian women's life experiences and their own made it difficult for either group to understand the impact of breast cancer on the others' lives. Although many African American women kept their diagnoses private and did not seek information and support, they actively participated in increasing breast cancer awareness in the African American community through outreach projects. Participants also found that few African American women attended cancer support groups, and they perceived the need for a support group designed specifically for African American women. Similar findings were reported in Barg and Gullatte's (2001) study of African American breast cancer survivors.

In summary, research indicates that African American women with newly diagnosed breast cancer do not receive the same treatment as other women and do not survive as long as women of other ethnic or racial groups even when diagnosed at the same stage of the disease. Cancer support groups were documented as a source of education about treatment options and empowerment for active partnership in treatment decisions. However, both nationally and locally, African American women were underrepresented as participants in cancer support groups. Therefore, the secondary aim of the Self-Transcendence in Breast Cancer Support Groups Project was to develop a support group intervention that was acceptable to African American women and explore its effect in a sample of 40 women.

The African American Breast Cancer Support Group Project

Project Objectives

The objectives of the African American Breast Cancer Support Group Project were to (a) assess the educational and support needs of local African American women with newly diagnosed breast cancer, (b) implement changes in the format of the current support group intervention that would make the intervention acceptable to African American women, and (c) conduct an exploratory study to compare scores on measures of self-transcendence and physical and emotional well-being in African American women who participate (n = 20) or do not participate (n = 20) in the support group intervention.

Although the participants in the primary aim of the Self-Transcendence in Breast Cancer Support Groups Project were randomized sequentially, randomization was not planned for the more exploratory secondary aim. While acknowledging that randomization procedures strengthen the internal validity of the findings, participants must be comfortable with recruitment procedures. Obtaining access and building trust in the African American community were expected to be difficult;

therefore, participants were given as much control as possible during implementation of the third objective.

Assessment of Local Education and Support Needs

Networking with women in the African American community began in 1997 during the proposal application process. The principal investigator (PI) met with a representative from the local Sisters Network advisory group to obtain her support for the project and develop the objectives for the secondary aim. Sisters Network, a national African American breast cancer survivors' organization, was founded in 1994 by Karen Jackson. The local chapter meets monthly for the purpose of empowering survivors with the will and knowledge to help themselves and other women in the fight against breast cancer.

In 1999, the PI attended two Sisters Network meetings to describe and begin to build trust in the project and herself. Members appeared interested in a project that could empower newly diagnosed women by helping them locate information and support, as well as encourage self-transcendence views and behaviors. At a third meeting in May 1999, the project leaders and group members brainstormed about the support needs of newly diagnosed women. The women discussed how the organization currently assisted newly diagnosed women. A flip chart was used to list additional needs that were identified: develop a "buddy" system for newly diagnosed women, incorporate journaling and sharing of stories, have outside speakers present educational topics, and hold the sessions in a formal setting. Other needs identified were for member orientation before a group started, check-in time at the beginning of each session, and the inclusion of friend and family caregivers and were slated for discussion at the next Sisters Network meeting.

The day after the third meeting, the project manager sent a letter to the president of the local Sisters Network summarizing the discussion and affirming that the PI was committed to working with the members to develop a support group for newly diagnosed women. When project leaders heard nothing from the group for several months, they initiated lunch in November 1999 with a leader of the group. Reaffirming that a support group for newly diagnosed women was needed, the Sisters Network leader offered to notify the women about a potluck to be held in February 2000 to discuss the project and ask attendees to complete the study questionnaires. At that event, women also would choose in which of the two study groups they wanted to participate. Changes to be made to the intervention protocol would be decided with participants at that time. February 2000 came and went as subsequent phone calls and e-mails to the Sisters Network leader went unanswered.

Frustrated, project leaders concentrated on the primary aim of the project, which encompassed newly diagnosed women of all ethnicities. They also began outreach directly to minority, low-income women attending a city breast clinic. Although clinic patients were receptive to information and support while waiting for appointments or receiving chemotherapy, a clinic staff member was unsuccessful in starting a lunchtime support group. Only one or two women remained after their clinic appointments each week, which was not enough to sustain a support group.

Implementing Changes to the Format of the Intervention

In May 2001, when all 161 women had been recruited for the primary aim of the project and most had completed data collection, the project leaders met with a new president of the local chapter of Sisters Network. The original format of the theory-based closed group of women diagnosed with breast cancer in the past six months was to meet weekly for eight weeks. Because the current Sisters Network leaders believed attending sessions weekly for eight weeks would be difficult for many women, the support group would be offered for six sessions meeting every two weeks instead. Names of potential African American facilitators for the support group were discussed, and the PI pursued hiring them. Because many women could not attend meetings during the summer, the first African American support group was set to begin in September 2001. During the summer and fall, the project was discussed and contact information was distributed at Sisters Network meetings, a minority health fair, community breast health coalition meetings, and local ONS chapter programs. However, no newly diagnosed women responded or were referred for the project during that time.

In October 2001, the PI was approached by the local Sisters Network president to help write a proposal to the Susan G. Komen Breast Cancer Foundation for funding a monthly breast health and breast cancer education program. The proposal was granted funding. In spring 2002, the PI met with the Sisters Network president and vice president to assist with program planning and use that venue to recruit for the African American Breast Cancer Support Group Project.

Ten monthly educational programs were conducted from May 2002–May 2003. Topics included cancer screening, breast health and cancer detection, lymphedema management, lifestyle management (e.g., nutrition for good health, use of pharmaceuticals, women's activism), and hospice care. The project PI (an oncology clinical nurse specialist) attended 8 of the 10 programs to discuss her project and distribute flyers. She also presented the cancer screening and lymphedema programs. Between 5 and 11 women attended each program. Of the 48 breast cancer survivors who attended one or more programs during the one-year project, only five women were newly diagnosed. Four of the newly diagnosed women attended only one program, and one woman attended two programs. Five other women attending one or more of the programs were one- to two-year survivors, and the remainder had survived as many as 16-25 years after diagnosis. Many who attended did so as a result of personal invitations from the two Sisters Network leaders.

Recruitment Failure and Inability to Implement the Support Group

None of the five newly diagnosed African American women attending the educational programs expressed interest in the support group project. However, from August 2002–April 2003, the PI described the project to nine women who were referred to her or who responded to the project flyer. Five women eventually agreed to participate and completed study questionnaires. Several women were well beyond their initial diagnosis of breast cancer but were enrolled in the hope of having enough participants to start a viable group. Each of the recruited women wanted to attend the support group and did not want to be in the comparison group that only completed questionnaires.

The five participants were not recruited in a timely manner. A woman diagnosed with breast cancer in July 2002 was enrolled in August 2002, a three-year survivor was enrolled in September 2002, and a 16-year survivor was enrolled in October 2002.

The next two women were not recruited until April 2003. One of the women was 11 months postdiagnosis, and the other was two years postdiagnosis. By this time, the first woman recruited was eight months beyond diagnosis. Because of the PI's previous experience with cancer support groups, she was hesitant to start a group with less than eight women. Even if a group with only five participants had begun in April, the first woman recruited would have waited six months and would not have any other newly diagnosed women in the group with whom to share her experience. By July 2003, with the five-year project ending that August, not enough participants had been enrolled for a meaningful intervention or comparison group, nor had enough questionnaire data been obtained to have reportable results. Clearly, the third objective of the African American Breast Cancer Support Group Project was not realized.

Lessons Learned and Meaning Gained Barriers Identified by Project Key Collaborators

An informal debriefing was arranged in August 2003 with the five women recruited to the project and the two Sisters Network leaders who implemented the Sisters Network educational programs. Project leaders, community collaborators, and participants brainstormed about the barriers they encountered in completing the project as envisioned. Several topics were discussed, including project publicity, the number of African American women with newly diagnosed breast cancer in the local area, other commitments for women's time, and suspicion of healthcare professionals' motives.

Although the project had been publicized monthly through flyers, oncology nurses working with local physicians, and Sisters Network meetings and educational programs, collaborators and participants wished more had been done to publicize the project. They suggested placing project information in church bulletins and minority newspapers, which were considered initially but not implemented. Many area churches serve African Americans, but project collaborators' contacts could place notices in only a few bulletins. Notices were not placed in the two African American newspapers because of the cost and because similar notices for an earlier lymphedema support group project had not led to participation or even inquiries.

Another suggested barrier to recruiting enough women was the small number of local African American women. Central Texas 2000 census data for women older than age 40 revealed that 70% were Caucasian, 19% were Hispanic, 8% were African American, and 3% were from all other races. The breast cancer incidence rate was correspondingly low for African American females in Travis County, where the study was conducted. Forty-two new breast cancer diagnoses were made for African American women in 1999, 32 were made in 2000, and 40 were made in 2001 (B. Mokry, personal communication, January 31, 2005). Indeed, Sisters Network collaborators had identified only a few newly diagnosed African American women during the recruitment time period. In addition, only 10%–25% of patients of all ethnicities diagnosed with cancer attend cancer support groups; patients from minority groups are even less likely to participate (Barg & Gullatte, 2001; Taylor et al., 1986; Thiel de Bocanegra, 1992).

Two other barriers were discussed. A social worker participant suggested that newly diagnosed women in the African American community may have worries that are more critical to them than their own health. Fatigue from employment and

childcare responsibilities leave them little time for themselves. Physicians and nurses may not even suggest a cancer support group to such women. The same participant also suggested that African Americans' general distrust of physicians may extend to other healthcare professionals. Interestingly, the woman identifying these barriers contacted the PI at the time of her diagnosis but did not enroll in the project until 11 months later. She was so overwhelmed at the thought of treatment for another cancer after having Hodgkin disease 20 years earlier that she could not reach out for support even from Sisters Network. She occasionally contacted the nonhealthcare professional education director of the local Breast Cancer Resource Center and eventually joined a center-sponsored support group.

Protocol Changes That Might Have Facilitated a Viable Intervention

Several modifications in the protocol for the third objective of the project, although not improving validity, might have led to at least being able to conduct a viable support group. Potential modifications are not presented in order of importance; all of these changes may have been necessary. Self-transcendence theory and support group theory, the conceptual bases of the project, proposed that the best way to improve participants' sense of well-being was a closed support group of women with a similar diagnosis meeting weekly for eight weeks (Coward, 1998). However, because few newly diagnosed women with breast cancer were identified in the local African American community, a group composed of breast cancer survivors regardless of time since diagnosis or a group of women newly diagnosed with any type of cancer may have been more viable. In either eventuality, the support group facilitators would promote group discussion about commonalities and universal concerns among survivors. A closed and time-limited group, although theoretically based, may not be possible in a community with a limited population of potential support group participants who have little experience with cancer support groups sponsored by healthcare professionals. Unfortunately, the project planners (both researchers and community collaborators) were unaware of the small pool of newly diagnosed women. Although they later opened the project to long-term breast cancer survivors and modified the intervention timelines, not enough women were enrolled to conduct the study.

Another possibility, also incongruent with the theory that weekly sessions would best facilitate bonding and problem solving, is to implement monthly support group meetings. The Sisters Network monthly education programs were moderately successful in attracting attendees, although few of those attendees were newly diagnosed women with breast cancer. However, the monthly groups did provide an opportunity for some cancer survivors to talk with a few newly diagnosed women. The sense of altruism that evolved in the cancer survivors was paralleled by a sense of appreciation in the newly diagnosed women. Altruism and appreciation are dimensions of self-transcendence that the support group project was designed to promote.

Although lack of time and monetary resources limited widespread publicity about the support group, more publicity, by itself, may not have helped. Flyers described the support group as a project (not a research study) and offered women the choice of participating in a breast cancer support group or being in a comparison group that did not attend the support group. Included on the flyer, however, was the need for both groups to complete a set of questionnaires at two different times. Al-

though women entering the study did not object to completing questionnaires, the data collection nature of the project may have discouraged some potential participants.

Personal invitations and offers of transportation attracted a few women to the Sisters Network education programs. This approach worked with friends and fellow church members but did not attract newly diagnosed women or city breast clinic patients to any program. As mentioned earlier, most of the women attended the programs primarily to support their Sisters Network friends. Child care was provided, but children were brought to only one of the early-evening education programs.

The PI consulted with two respected African American faculty member colleagues and started to build a network in the African American breast cancer community before submitting the project proposal and well before starting to implement a support group. However, a nurse educator and researcher who is not a part of the study population may have needed additional time to become trusted in that community. Partnering with current Sisters Network members on the Susan G. Komen Educational Program Project was a valuable experience for both the PI and Sisters Network, but it did not lead to successful recruitment. Announcing the project in church bulletins might have attracted more participants, particularly if the support groups were endorsed by trusted ministers.

Recommendations

This project was proposed in 1997 after a literature review and an assessment of local need. The current breast cancer literature continues to support the need for all women to become knowledgeable and active in their breast care, particularly in screening behaviors and advocacy for appropriate breast cancer treatment (Bickell, 2002; Ghafoor et al., 2003). As in the earlier reviewed literature, a study in urban Missouri of 1,227 African American women by Holt, Clark, Kreuter, and Rubio (2003) found that a passive spiritual health locus of control was associated with reliance on God for health-related outcomes. Recent research also supports that a breast cancer support group can be a resource for knowledge and empowerment for African American women. Henderson, Gore, Davis, and Condon (2003) reported that positive reappraisal and seeking social support were the most common coping strategies in 86 women with breast cancer in the southeast (the majority of whom were recruited from African American support groups). Taylor et al. (2002) found improved mood and psychological functioning in the 40 African American women with breast cancer in Philadelphia, PA, and Washington, DC, who participated in an eight-week intervention, compared with 33 women who participated in control groups.

ONS (1999) guidelines for cultural competence in research were consistent with the partnering approach used by the PI. However, in retrospect, the PI would not start with the quasiexperimental support group for newly diagnosed women as originally proposed. Participants would be recruited for a pilot pre-experimental group of interested breast cancer survivors regardless of their date of diagnosis. One or two such groups would be conducted and evaluated for six to eight weeks without data collection except for session evaluation. If the pilot group(s) were successful, an exploratory study of the effectiveness of an African American breast cancer support group would be initiated for newly diagnosed women. Recruitment and retention approaches used in the Taylor et al. (2002) study would be explored with Sisters Network collaborators. In that study, participants were compensated for attending group meetings and completing study questionnaires.

Local breast cancer advocacy groups have had only moderate success with outreach to newly diagnosed, low-income minority women. However, several local cancer-related nonprofit organizations (e.g., the American Cancer Society, the Breast Cancer Resource Center, the Susan G. Komen Breast Cancer Foundation, Sisters Network) remain committed to outreach to underserved women. So far, these newly diagnosed women have been located and served best through one-on-one contact at treatment centers, primarily city-funded breast clinics. Perhaps such personal contact is most appropriate for women who lack a strong sense of self-agency (i.e., the belief that one has choices and can take action).

African American survivor advocates Lythcott, Green, and Kramer Brown (2003) discussed access-to-care issues including helping African American women with breast cancer develop a sense of agency. In the event that the African American pilot support groups suggested previously were unsuccessful because of a lack of participants or a lack of relevance to participants, the PI would continue to work to foster an inclusive climate in which all women with breast cancer could find value in each other's experiences and gain from examination of their differences. By working together and valuing and learning from each other's differences, women can obtain pertinent knowledge to help themselves and each other.

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