

Peer-Based Models of Supportive Care: The Impact of Peer Support Groups in African American Breast Cancer Survivors

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Among African American women, breast cancer is the most commonly diagnosed cancer with resultant disproportionate morbidity and mortality (American Cancer Society [ACS], 2011). Breast cancer requires numerous life adaptations from the patient and family. The emotional and physical impacts of breast cancer increase women's need for support (Dirksen, 2000); therefore, seeking support is an adaptive coping strategy (Bourjolly & Hirschman, 2001; Henderson, Fogel, & Edwards, 2003).

Social networks help establish relationships and provide a sense of belonging through social connectedness (Ashida & Heaney, 2008; Keyes, Shmotkin, & Ryff, 2002). The social, emotional, and tangible (e.g., financial assistance) support provided by social networks play an important role in enhancing survivorship outcomes (Ashing-Giwa & Ganz, 1997; Bourjolly & Hirschman, 2001; Shelby et al., 2008; Taylor et al., 2003). Although the basic emotional and information needs of survivors are similar among ethnic groups, how those needs are met may differ depending on each ethnic group's cultural and community context (Ashing-Giwa, Padilla, Tejero, & Kim, 2004).

The Institute of Medicine (2008) stated that emotional and social support are essential components of comprehensive cancer care. Support groups are emerging as a component of the psychosocial safety net of care for cancer survivors (Ahlberg & Nordner, 2006; Coreil, Wilke, & Pintado, 2004). Sharing experiences, coping skills, and information in support groups has social, psychological, and physical benefits (Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004; Moore, 2001; Wilmoth & Sanders, 2001).

Purpose/Objectives: To examine the impact of support groups among African American breast cancer survivors (BCSs).

Research Approach: A qualitative research study.

Setting: Community health and cancer centers and churches.

Participants: 62 African American BCSs.

Methodologic Approach: Focus groups were conducted with African American BCSs to share their experiences with peer-based support groups. A brief questionnaire was administered and assessed demographics, medical history, and support group impact.

Findings: Survivors emphasized that a culturally embedded focus was essential for their participation in a cancer support group. The survivors underscored that cultural-based groups are rooted in the spiritual, linguistic, experiential, and historical contexts of the intended constituents. The peer-based support groups provided multilevel functions, including emotional, social, spiritual, informational, and financial support, as well as patient navigation. The groups' activities fostered personal development and a call to community advocacy that included prevention education and research engagement.

Conclusions: The unique strengths of grassroots community-based support groups are that they are culturally consonant, peer-based, and responsive to cancer-related and personal needs. The contribution and value of those multifaceted peer-based groups expand the paradigm of supportive care, extending the net of psychosocial care to underserved and underrepresented cancer survivors.

Interpretation: Research provides the critical foundation to lead and articulate the studies necessary to bridge peer- and professional-based care to ensure the psychosocial needs of increasingly diverse survivors are met.

Evidence suggests that survivors who participate in support groups are less depressed and anxious (Yaskowich & Stam, 2003), have better social well-being (Ahlberg

& Nordner, 2006), and are more knowledgeable about their illness (e.g., treatment, management of side effects) (Barg & Gullatte, 2001; Carlton-LaNey, Hamilton, Ruiz, & Alexander, 2001). In addition, support groups improve mood, provide information, encourage active coping, and increase self-enhancing behaviors by increasing feelings of belonging, universality, and altruism (Barg & Gullatte, 2001). However, not all cancer survivors are provided with similar opportunities to participate in support groups. Specifically, ethnic minority survivors attend support groups less than their Caucasian counterparts (Coward, 2005). African American breast cancer survivors (BCSs) also are reluctant to participate in mainstream support groups and often drop out because of the restricted structure or the inability to fulfill important needs (e.g., faith-related issues) (Henderson & Fogel, 2003; Henderson, Gore, Davis, & Condon, 2003).

The literature on African American BCSs and support groups (peer-based support groups, in particular) remains sparse. A few studies describe the goals of support groups for African American women, including providing members with (a) culturally responsive opportunities and a safe haven to share their needs (Barg & Gullatte, 2001; Henderson & Fogel, 2003; Henderson, Gore, et al., 2003); (b) education about the disease for a greater understanding of health care, survivorship, and the emotional needs ahead (Coward, 2005; Henderson, Gore, et al., 2003); and (c) culturally appropriate resources and navigation of healthcare, counseling, financial, and vocational services (Barg & Gullatte, 2001; Coward, 2005; Henderson, Gore, et al., 2003). The common approach of African American support groups was to build a safe haven in the context of spiritual healing (Barg & Gullatte, 2001; Coward, 2005; Hamilton, Powe, Pollard, Lee, & Felton, 2007; Henderson & Fogel, 2003; Henderson, Gore, et al., 2003; Roff, Simon, Gardell-Nelson, & Pleasants, 2009). The shared synergy among the participants from a cultural and religious heritage provided the help, encouragement, information, and emotional nurturing for each member of the support group (Barg & Gullatte, 2001; Coward, 2005; Hamilton et al., 2007; Henderson & Fogel, 2003; Henderson, Gore, et al., 2003; Roff et al., 2009). For African American BCSs, the reduced feelings of isolation helped the members share common experiences, foster mutuality, and learn new ways of coping (Barg & Gullatte, 2001; Hamilton et al., 2007). Through the group experience, the individual faces new challenges and finds the strength and faith to be a survivor (Barg & Gullatte, 2001; Roff et al., 2009).

The current study investigated the role and impact of peer-based support groups among African American BCSs and explored support groups' contributions to psychosocial care.

Methods

Five focus groups were conducted with five different peer-based support groups, and separate discussions were conducted with the support group leaders to obtain African American BCSs' experiences with peer-based support groups. The sample of five focus groups was expected to achieve saturation. The study received institutional review board approval from City of Hope National Medical Center in Duarte, CA, and all participants were fully informed and provided written consent to participate.

The preliminary questionnaire included demographic questions on age, education, disease information and stage at diagnosis, and impact of support groups. Impact of support groups was assessed with 11 questions on a five-point Likert scale, each asking about the impact the support group had on different domains of life. Focus group surveys included open-ended questions about breast cancer, sources and of support and their effect, psychosocial needs, and religion or spirituality.

Procedure

The current study espoused a community-based participatory research approach—a collaborative approach that engenders academic and community partners in research to improve community well-being (Israel, Schulz, Parker, & Becker, 1998, 2001). The study mobilized community engagement through the formation of the African American Breast Cancer Coalition (AABCC). In partnership with City of Hope's Center of Community Alliance for Research and Education in Duarte, CA, several grassroots African American health-advocacy groups joined to form the AABCC, catalyzing collaborations and enhancing the community benefit through collective work. Many groups in the AABCC are well established, providing community education and support services to survivors for more than 14 years.

Focus groups: BCSs who were diagnosed in the previous eight years were invited to participate in the support groups and were presented with the study details. The venue and time for the focus group meetings were arranged by each support group's leader. At the beginning of each focus group, African American BCSs were oriented to the study, signed informed consents, and completed the preliminary demographic surveys. Focus groups lasted two to three hours and were conducted by the principal investigator and well-trained, ethnically matched research assistants (Ashing-Giwa, 2005). The research assistants received at least 40 hours of training on breast cancer survivorship, cultural, socio-ecologic, and healthcare system issues for African American BCSs as well as ongoing supervision.

Data Analyses

Descriptive and univariate statistics were used to report demographic and disease characteristics. Audio recordings of the focus groups were transcribed and organized using Atlas.ti, version 5.5. Data were analyzed using thematic analysis, a method that helps organize and describe qualitative data in rich detail by identifying themes (Braun & Clarke, 2006). A team of five individuals conducted the analysis. One team member analyzed the transcripts in their entirety and other team members coded a specific domain among transcripts, which helped to establish data trustworthiness and credibility (Creswell & Miller, 2000; Morrow, 2005).

The transcripts were first organized into manageable text segments representing different domains (Boyatzis, 1998; Braun & Clarke, 2006). Text segments were coded line by line, and codes were identified by searching for similar topics within and among transcripts. Therefore, experiences mentioned across transcripts were considered indicators of emerging patterns. The codes and text were reviewed to define recurring patterns, with the purpose of articulating overarching themes (Braun & Clarke, 2006), and to ensure that they represent the text and were assembled into groups that best represented survivors' narratives.

Data Quality

To establish data trustworthiness, several steps were followed prior to and throughout data analysis. The investigator's previous work with the support groups helped establish trust and enhanced communication, contributing to data credibility. The involvement of the scientific research and investigatory team and community members in the data analyses process also increased data credibility. The team reviewed and provided feedback on codes and theme refinement at every step. To optimize cultural relevance of the results, members of the AABCC participated in the data and findings interpretation, manuscript development, and study dissemination.

Results

Participant Characteristics

A total of 62 African American BCSs participated in the peer-based support groups. Participants ranged in age from 31–83 years ($\bar{X} = 62$, $SD = 12$), with most aged 61 years and older (see Table 1). Length of survivorship ranged from one to eight years. About 81% of participants achieved either vocational or college education; however, 61% reported lower income household earnings.

Survey Outcomes

Preliminary questionnaires revealed that the support groups provided several important benefits to survivors. Because of the support groups, African American BCSs

Table 1. Participant Demographic and Medical Characteristics

Characteristic	n
Age (years)	
31–40	3
41–50	8
51–60	17
61 or older	33
No response	1
Education	
High school or less	12
Vocational training or associate of arts degree	23
College graduate	19
Graduate degree	8
Income (\$)	
24,999 or less	23
25,000–44,999	15
45,000–74,999	9
75,000 or higher	13
No response	2
Occupation	
Homemaker or unemployed	36
Employed	24
No response	2
Stage	
0	2
I	19
II	20
III	8
IV	3
No response	10
Surgery^a	
Lumpectomy	39
Axillary node dissection	17
Mastectomy	24
Mastectomy (immediate reconstruction)	7
Mastectomy (later reconstruction)	8
Treatment^a	
Radiation	36
Chemotherapy	30
Hormonal treatment	36
Cancer recurrence or spread	12
Follow-up care facility	
County or community clinic	6
Doctor's office	38
Hospital outpatient	9
Other	3
No response	6
Screenings (prior 12 months)^a	
Mammogram	55
Pap smear	30

N = 62

^a Participants could select more than one response.

experienced notable improvements in outlook on life, spirituality, hopefulness, ability to talk about cancer, family functioning, quality of the doctor-patient relationship, and symptom management (see Table 2).

Focus Group Outcomes

The findings suggest that the emotional support received from support groups can be organized into

Table 2. Support Group Impact on Life Domains

Domain	Positive Impact	Somewhat Positive Impact	No Impact
Feeling hopeful	50	7	4
Outlook on life	49	3	6
Spirituality or religious practices	49	3	8
Ability to express feelings about cancer	46	8	4
Family life	38	8	12
Health habits	37	20	4
Quality of doctor-patient relationship	37	7	13
Symptom management	37	11	12
Quality of health care	29	9	20
Treatment decision making	24	10	23
Intimate relationship	20	4	19

N = 62

Note. Because of missing responses, domain totals may not equal 62.

five domains: (a) comfort and hope, (b) belonging and companionship, (c) health information and navigation, (d) economic and functional relief, and (e) self-esteem and purposefulness.

Comfort and hope: The sharing of experiences embedded in the support groups provided great comfort and hope for participants and helped them make sense of their own situation.

When people come to a meeting, they get so happy when they hear, "I am a 30-year survivor," and, "I'm 20," and you can see their face light up. You think you are doing all right by yourself but you do better with someone else.

Belonging and companionship: By engaging in each other's lives, BCSs connected to each other and developed trusting relationships. The importance of belonging and companionship was emphasized by the study participants and was considered to be crucial because BCSs may incorrectly believe that they do not need support. Many survivors have dependents and family demands and manage their daily responsibilities despite harboring important unmet needs, such as social support, psychological assistance, or resources.

I'm the first [patient with breast cancer] in my family. My sisters can give me love and support to a certain extent, but they can't give me what everyone here can give me. I'm with women who have been through what I am going through.

We, as Black women, may think we don't need support, but, in reality, we do. Some, before they came here, said they had been busy and had not realized they were not getting the support they needed. I find the more I give and share, the stronger I feel.

The groups provided emotional support by cultivating a sisterhood. BCSs felt reassured knowing that others were experiencing side effects from treatment. They felt understood, accepted, and that they validated each other's experiences. This sense of belonging helped participants stay strong.

Another reason for continued participation was the spiritual component of support groups. Spirituality provides another commonality among members and eases the fear and worry of lack of understanding and relatedness by expressing spiritual beliefs.

African American breast cancer survivors, African American peoples have a commanding will and desire to live that is rooted in our spirituality. All of our groups begin and end with prayer; that's just how we do things . . . we invite the Creator and Healer.

Support groups are a safe place where BCSs can express their feelings and discuss their illness, providing a sense of safety and a venue to talk about breast cancer as part of daily life. Being able to discuss distressing topics in a supportive and caring environment provided the emotional support African American BCSs needed. One survivor said, "In a support group, you are able to get it off your chest and know that you are not crazy; it's happening to others."

Health information and navigation: BCSs were able to learn from each other by exchanging breast cancer details and experiences. The support group provided guidance on medical issues, such as what to ask doctors, making medical decisions, and what to expect from breast cancer and its treatments, as well as persistence when seeking appropriate treatments.

It was my friend here, she called me, told me what to expect, provided me with reading materials, she didn't sugar coat anything. I was ready to fight this and without her help I wouldn't have known what to do, what to expect.

I feel a connection and I can talk to somebody who has been through what I am going through. I understood that the effects of the treatment was not just in my mind.

Some BCSs took health efficacy action by becoming more active in their health care. Through coaching skills learned from support group participation, BCSs became self-health advocates and engaged in practices for improved care by asking questions, participating in treatment decision making, and seeking additional medical consultations, which may have increased the health efficacy and education that led to reassurances about their quality of care. One participant said, "I told the doctor, 'You treat me like I'm just a number. I'm a

living and breathing woman; I'll do what you tell me to do, but you have to respect me first."

BCSs also took action by accessing local and Web-based materials and resources. This active involvement provided a sense of control and self-affirmation.

I am more diligent with doctors. Sometimes they would say you can't have this or that and I have found that you can have it, you just have to be persistent. Don't take no for an answer; do the research.

Economic and functional relief: The support groups provided either a formal or informal peer system, and informal and formal peer systems often coexisted. Peers assisted with transportation and financial concerns (i.e., food, gas, utility bills, and medical expenses) and facilitated additional resources and social activities outside of the group. Peers provided personalized emotional and practical support, advocacy, and patient navigation. One participant said, "The second time [breast cancer] happened, I was having trouble getting to [chemotherapy] and I called [a peer] and she said, 'Don't worry, I'll be there to take you.'"

Self-esteem and purposefulness: Other support group members—the experienced members in particular—acted as credible role models of survivorship, resilience, benefit finding (e.g., finding or gaining a purpose from the breast cancer experience), and advocacy for African American BCSs. One participant said, "Breast cancer has pushed me into a renewing life. The group helped me get to the place where I can celebrate each new day with a desire to live."

African American BCSs described their experience as an awakening. They slowed down, reevaluated life, and had more respect and value for life. They were adapting and adjusting to a new way of life. The support group was cultivating optimism in the face of added adversity.

When you hear the big C [cancer], you think about the big D [death], but now I know that I can live. . . . I have things to do; I'm not ready to let [cancer] win.

Survivors revealed a new sense of purpose and fulfillment by sharing their experience with others. The support groups motivated and trained African American BCSs to share their experience as advocates for community breast cancer education and prevention as well as better policies regarding the prevention and treatment of breast cancer (e.g., free screening programs, timely and quality treatment).

These ladies [from the support group] have given me courage to let others know that you need to take care of your body, have a mammogram, because you will be surprised that there are women that have never had a mammogram.

Advocacy was important to the mission of the peer-based groups because of the limited information and

resources specific to breast cancer survivorship in African American women. Survivors spoke about increasing involvement among African American BCSs in the breast cancer movement to get the attention and services they need. They felt their involvement in research was part of the advocacy for the advancement of cancer care.

I couldn't find information on African American women five years ago, that's why I started working with [American Cancer Society]; if we don't make them aware of us, they won't have anything to report.

In addition, advocacy may help to challenge and change the secrecy surrounding cancer in the African American community. Participants described a cancer diagnosis as a "hush scene" and "still taboo." They emphasized the importance of sharing family history because it can motivate others to promote health. They also expressed the importance of survivors working to change the perception of cancer so people will learn that early detection saves lives and that cancer does not equal death.

Our groups help women break the silence and the shame associated with cancer; we impart pride and power in being cancer victors. At our open celebration events, where 500 people gather, women stand proud and tall to be recognized when we honor the survivors among us.

Discussion

The current study examined the psychosocial needs of African American BCSs and the benefits of participating in peer-based support groups. The support groups are grassroots organizations initiated by BCSs who are drawn to roles of advocacy because of a lack of culturally appropriate support services available to African American BCSs in cancer treatment institutions (Barg & Gullate, 2001; Carlton-LaNey et al., 2001; Henderson, Gore, et al., 2003). African American BCSs need a forum that is culturally sensitive and responsive to their psychosocial, spiritual, physical, and informational needs, as well as one that provides resources to promote well-being and optimal survivorship postdiagnosis. Consistent with previous findings (Coward, 2005; Henderson, Gore, et al., 2003), the survivors' narratives revealed that African American BCSs have a preference for culturally and socio-ecologically embedded support groups. The prevailing ideology is that religion and God are common denominators to coping and dealing with the challenges of life, including cancer. Therefore, cultural sensitivity can be attributed to the recognition of the importance of spirituality and the encouragement of spiritual practices as a coping mechanism

(Henderson & Fogel, 2003). The peer-based support group members underscored that the groups were rooted in the essential spiritual, linguistic, experiential, and historic contexts that make the experience uniquely African American.

Support groups are particularly important during the postdiagnostic, treatment, and post-treatment phases when medical, emotional, informational, and functional needs are most acute. BCSs found the peer-based groups to be inherently culturally responsive; therefore, members felt that they were in a comfort zone. By being able to relate to other members with similar cancers and cultural experiences, survivors felt a type of sisterhood in the support groups. The current study identified an overarching theme that African American BCSs support group members benefited from the therapeutic experience of the support groups and were able to contextualize and articulate their breast cancer journey through a cathartic emotional lens that allowed an acceptance and strength in their approach to survivorship. The groups modeled and reinforced psychological and emotional connectedness and allowed for free verbal expression of their breast cancer experiences. Therefore, their support needs, experiences, and practices are revealed in clear language of emotion and personal insight, and they have given themselves permission to share their cancer journey openly. In addition, the social network perspective of those groups emphasized social connections and the importance of growth through positive relationships (Ashida & Heaney, 2008; Keyes et al., 2002). Therefore, the groups function as fictive kin or an extended familial-type network that is based on sociocultural and spiritual principles.

Limitations

Despite efforts to obtain broad representativeness from African American BCSs, sample and selection bias may have occurred. As such, the findings highlight favorable outcomes only. Future studies should include other voices, such as those for whom support groups did not help. This would establish a more complete understanding of the unmet needs of all BCSs and provide valuable information to support group leaders to enhance group function and success.

Conclusions

The study presented the multiple roles and impacts that peer-based cancer support groups have on African American BCSs. The findings can inform navigation and survivorship programs, as well as studies to help reduce the burden of cancer and enhance outcomes, particularly among underserved survivors. In addition, the current investigation provided evidence for the con-

sideration and appreciation of diverse models of psychosocial care. The scarcity of psychosocial resources that are culturally salient for African Americans, combined with the growing number of African Americans suffering with cancer (ACS, 2011), make a compelling call for targeted responses for cancer care for the African American community. Peer-based support groups may serve as a practical community-based component in the psychosocial network of care. However, more studies of peer-based support groups are needed to examine the effectiveness (cost and otherwise) of the components before such approaches are recognized and accepted as legitimate supportive care services.

The unique strengths of the grassroots community-based support groups are found on the multifaceted nature of the groups. They are culturally consonant, peer-based, and responsive to personal and cancer-related needs. The contribution and value of the groups expand the paradigm of supportive care and extend the net of psychosocial care to underserved and underrepresented cancer survivors. In addition, the inherent socio-ecologic factor of the peer-based group seemed to cultivate fertile ground for group members' personal development, particularly empowerment and purpose. That purposefulness translated into advocacy action for community benefit, which includes prevention education, screening programs, patient navigation, policy involvement, and research engagement. In addition, support group leaders commented on their study-related experiences, noting that they felt the BCSs' narratives validated their roles and experiences while the community partners built on their research capacity.

The themes of acceptance, belonging, and validation were woven throughout the interviews. African American women often are leaders in worship, services, and social associations in their church. The support groups can be extensions of this way of life with an added focus on breast cancer. Therefore, peer-based support groups provided the nurturing environment to cultivate personal development, empowerment, advocacy, and status in the African American as well as the broader BCSs advocacy communities.

Implications for Nursing

The findings increased the knowledge of and appreciation for the roles of peer-based support groups for cancer survivors. The results suggest that support groups provide African American BCSs with emotional sustenance by paralleling the role and benefit of spirituality, church, and family. The support groups provided a cultural, spiritual, and emotional safe haven that empowered study participants to strive toward becoming breast cancer victors. Nursing research provides the critical foundation to lead and articulate the studies

necessary to bridge peer- and professional-based care to ensure that the psychosocial needs of increasingly diverse survivors are met. The support that African American BCSs gain through participation in support groups is important. Ensuring nurses comprehend the benefits of peer-based groups can lead to referrals to these support groups and alleviate some of the cancer burden African American BCSs experience. In addition, nurses can participate in research focusing on increasing culturally sensitive and relevant survivorship education and to better care for African American BCSs.

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