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Understanding Supportive Care Factors Among African American Breast Cancer Survivors

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Abstract

Introduction: Comprehensive breast cancer care includes not only diagnosis, staging, and treatment of cancer but also assessment and management of the physical, psychological, social, and informational needs, collectively known as supportive care. Several studies have documented the importance of addressing supportive care factors among breast cancer survivors. However, there appears to be a paucity of research concerning African American breast cancer survivors (AABCS). Therefore, the purpose of this study was to describe and understand the patient-centered supportive care factors among self-identified AABCS. Method: Using a qualitative descriptive approach, an open-ended question explored supportive care factors that were used by $N = 155$ AABCS. Results: Four supportive care factors were identified: faith, supportive structures, optimism, and access to information. Discussion: An understanding of these factors might facilitate discussion between survivors and the health care team. The resultant effect could also inform and promote the delivery of culturally specific health care to address the supportive care needs among these women.

Keywords

oncology/hematology, clinical areas, breast cancer, supportive care factors, breast cancer survivors, faith, supportive structures, optimism, access

Introduction

Breast cancer survivors constitute 22\% of the estimated 14.5 million cancer survivors (DeSantis et al., 2014), a population that is expected to grow to 18 million over the next decade (de Moor et al., 2013). This growing population represents the increased need for survivorship research that focuses on evidence-based, high-quality, patient-centered supportive care. Effective high-quality patient-centered supportive care after curative treatment for breast cancer is not only emerging as standard practice among high-income countries but also appearing in low- and middle-income countries (Ganz et al., 2013). The Institute of Medicine of the National Academy of Sciences (Hewitt, Greenfield, & Stovall, 2005), the American Society of Clinical Oncology (Khatcheressian et al., 2013), and the National Comprehensive Cancer Network (2014) recommend standards of survivorship care to ensure that cancer survivors receive posttreatment care that addresses the physical and psychosocial sequelae of cancer treatment. Yet, despite the call to action, most studies have not examined this issue in African American women, leaving still much to learn about their survivorship experience (Swanson, Haslam, & Azouz, 2003); there remains a dearth of research about the supportive care factors during their posttreatment period. Identifying patient-centered supportive care factors can facilitate a discussion among patients, family members, and oncology team members to determine what helps these patients as they navigate the survivorship trajectory. These patient-centered supportive care factors may facilitate a better understanding of their survivorship experience.
experience and, as such, promote supportive care interventions to improve their quality of life. Therefore, the purpose of this study was to explore specific patient-centered supportive care factors that were used by African American breast cancer survivors (AABCS) during their survivorship journey.

Background

Many AABCS self-identify and embrace the term survivor (Davis et al., 2015). Cancer survivorship focuses on the health and wellness of an individual’s post-cancer treatment, which includes the physical, psychological, social, financial, late effects of treatment, and quality of life (Office of Cancer Survivorship, National Cancer Institute, 2014). Survivorship, viewed as the Seasons of Survival, encompasses three stages of survivorship: acute, extended, and permanent stages as described by Fitzugh Mullan, a physician cancer survivor (Mullan, 1985). There are no specific time frames within the aforementioned stages and not all individuals experience all of the stages (Mullan, 1985).

Briefly, the acute stage begins with the initial diagnosis, encompassing diagnostic testing and treatment quite often with fear and anxiety. The extended survivorship stage follows completion of treatment and/or remission (Mullan, 1985). Survivors are in a watch and wait period, wondering about signs and symptoms of possible recurrence, with diminished interaction of the oncology health care team (Mullan, 1985). The permanent survivorship stage is characterized as long-term survival and diminished probabilities of recurrence (Mullan, 1985). Yet, in this stage, survivors may experience the sequelae of oncologic treatment (e.g., physiological late effects of treatment, functional issues, psychological, financial concerns, and quality of life concerns). Taken together, survivorship encompasses the whole person, and it is of critical importance to have an understanding of patient-centered supportive factors as seen through the lens of AABCS.

There is a small but growing body of literature on these posttreatment issues and the specific factors that African American women appear to experience. A study by Ashing-Giwa and Ganz (1997) reported on the lack of information and supportive care received by African American women diagnosed with breast cancer. The authors interviewed and compared statements obtained from 12 key informants (physicians, nurses, and administrators) and 23 African American adult cancer survivors. These results highlighted the perception of inadequate support and insufficient cancer management information held by the African American survivors.

Coggins and Shaw-Perry (2006) used the Delphi technique, a multiple survey process for establishing group consensus to identify breast cancer survivors’ expressed needs. These investigators mailed three rounds of surveys to AABCS. The findings revealed that the needs of AABCS included affordable, acceptable, appropriate medical care and support services; follow-up information regarding breast cancer treatment symptomology and related health problems; and access to adequate resources for themselves and their families.

Researchers von Friederichs-Fitzwater and Denyse (2012) conducted semistructured telephone interviews of 137 AABCS residing in Northern California to document their experiences and concerns. According to the authors, survivors were uncertain if health care providers knew that AABCS might respond differently to cancer treatments compared to other groups of women. Survivors were also concerned that there was a lack of transparency and less than full disclosure on important cancer management and treatment information.

In a study by Sheppard, Adams, Lamdan, and Taylor (2011), researchers investigated the effects of cultural beliefs and health care factors on African American women’s decisions related to adjuvant cancer treatments. The sample included 49 women who were interviewed in the qualitative study. Although common cultural themes were not revealed, the findings did validate that spiritual beliefs were important and assisted in coping and reframing their breast cancer experience. In addition, the women’s health care provider relationship was the top factor affecting their decision for adjuvant cancer treatment. Women who reported better understanding of their disease process and treatments reported higher adherence to the recommendations for adjuvant therapy (Sheppard et al., 2011).

In the African American community, strong beliefs and support emanate from faith-based institutions, such as the African American church (Giger, Appel, Davidhizar, & Davis, 2008). Faith-based organizations and institutions consist of many individuals who share similar backgrounds, values, and religious beliefs. Historically, within the African American community, the church is an institution that facilitates social networks to its members. Those who attend church frequently are likely to have a greater number of social connections and subsequent interactions and rate their social connections more positively than those who attend church on a less frequent basis (Ellison, & Levin, 1998; Levin, 1984; Levin, Chatters, & Taylor, 1995; Maton & Wells, 1995). While social connections are vital, the importance of having friends and the meaningful role of friendship in the daily lives of many individuals should not be underestimated, as told in the seminal work by Lillian B. Rubin (1986). Family members and social networks often provide the bedrock of support for breast cancer survivors (Sterba et al., 2014), yet some African American cancer survivors reported feeling abandoned by church members, which was attributed to the fear and stigma associated with a cancer diagnosis (Hamilton, Moore, Powe, Agarwal, & Martin, 2010).

Coupled with the aforementioned empirical evidence of inadequate support, the lack of affordable appropriate medical care and support services, a paucity of appropriate
medical care, and follow-up services regarding transparency, support, and the need for patient–provider communication from the perspective of AABCS, it is seemingly appropriate to explore the supportive care factors that were helpful to these women throughout their survivorship trajectory.

This study filled a notable gap as it identified specific supportive care factors that may be target points for enhanced supportive care during the posttreatment phase. This phase has been described as a challenging time, during which cancer survivors grapple with the mixed emotions of treatment completion and the diminished interaction with and safety net of the oncology team (Mollica, Nemeth, Newman, Mueller, & Sterba, 2014).

Method

Design

The study design was a cross-sectional convenience sample of African American adult women diagnosed with breast cancer who had not been in treatment for at least 1 year. In the current study, data were collected via onetime, face-to-face, self-administered questionnaires at the site of each breast cancer support group meeting and among the community-dwelling participants. Assistance was provided to participants who preferred to have their surveys read to them; responses were handwritten, verbatim. For participants who were not members of a support group, the surveys were self-administered in a public or a private location. Institutional review board approval was obtained for this study.

Sample and Setting

One hundred and sixty-nine African American survivors were screened, 9 were deemed ineligible (due to current breast cancer treatment, different primary, African American male breast survivor), 160 were deemed eligible, and 5 women either missed the session or chose not to participate. A cross-sectional convenience sample of $N = 155$ African American adult women diagnosed with breast cancer met the eligibility requirements.

Inclusion/Exclusion Criteria

Eligible women who self-identified as African, African American, Black, or Black American; were 25 years of age or older; had been diagnosed with breast cancer; were at least 1 year post–active cancer treatment; and were capable of providing informed consent, met the inclusion criteria. Women were excluded if they self-identified as being of any other race/ethnicity, were currently undergoing breast cancer treatment (surgery, chemotherapy, and/or radiation), or were incapable or unwilling to provide informed consent or were diagnosed with a different primary cancer.

Recruitment and Procedure

All participants were residents of California and recruited through three methods: (1) 12 different AABCS groups within Southern and Northern California, (2) word of mouth, and (3) flyers in key community locations (e.g., civic groups, nonprofit organizations, local churches, hair salons, and unisex barbershops). The principal investigator (PI) was invited and attended each of the support groups at least twice prior to the initiation of the study. Recruitment flyers were placed on bulletin boards and other key locations in the support groups. Interested individuals were instructed to contact the PI by calling a designated research telephone number and an institutional review board–approved script was followed. Women who were members of a support group met the PI (who was also African American) in a designated area at their monthly support group meeting. In all, 80% of the participants were members from the support groups and 20% of the participants were community dwellers. Community dwellers (defined as women who were not members of a support group) met with the PI. The community-dwelling AABCS who were not members of a support group and who were recruited by word of mouth or via recruitment flyers, met with the PI at conveniently agreed-on locations within their community, such as coffeehouses and libraries.

Participants were informed about the purpose of the study, and all questions were addressed. Written informed consent was obtained, and all were informed that the survey would take approximately 1 hour to complete. Assistance was provided to participants who preferred to have their survey read to them and responses were handwritten, verbatim. On completion, participants received a $10.00 Target gift card for their willingness to participate in the study and to assist with travel expenses.

Open-Ended Question and Closed-Ended Questions

In an attempt to explore the supportive factors that were used by AABCS, the following open-ended question was asked, “In looking back, what do you think has helped you the most during your experience of becoming a cancer survivor?” In addition, 32 closed-ended questions collected sociodemographic data including age, relationship status, religion, educational level, annual income, health history, years of survivorship, and breast cancer stage.

Data Analysis

Descriptive statistics, including means and standard deviation, were calculated representing sociodemographic data. These findings represented a summative snapshot of the participants in our study. These demographic data were analyzed using SPSS 18 Statistical Software (SPSS Inc., 2009). The Demographic Data Questionnaire was developed to
Data Quality

Ensuring trustworthiness of the qualitative research is of critical importance as it validates scientific rigor of the study. The four elements of establishing trustworthiness include the following: credibility, transferability, dependability, and confirmability (Guba, 1981; Shenton, 2004). Specific procedures were in place to promote confidence. For example, a small pilot study \( N = 25 \) was previously conducted to determine feasibility. In addition, prolonged engagement with the directors of the support groups was achieved to develop trust and facilitate discussion. In this purposive sample, the line of questioning was developed to obtain an understanding of patient-centered specific resources that were deemed helpful to AABCS. In the area of transferability, a full contextual description of the inquiry was provided in the background and methodological approach of this study. A similar research inquiry that employs the same methodological approach (but with a different demographic) could be of great value and thus add to the scientific literature. Dependability posits that in-depth details of the research design should be attended to in order to provide a thorough understanding and enable future researchers to repeat the work. The current and previous descriptions of the research design were provided (Davis et al., 2015). Regarding confirmability, a data-oriented approach was used that led to the formation of recommendations for health care providers, team members, families, friends, survivors, and advocacy groups.

Results

Participant Characteristics

Demographically, almost half of the participants had college degrees. Socioeconomically, a significant number of the participants were middle class, and over 43% were married. Not shown in the table (Table 1) are the various occupations of the participants, which included teachers, nurses, social workers, authors, lawyers, homemakers, retail workers, hair stylists, and retired civil service workers. The most commonly reported breast cancer stages were Stages 2 and 3 (previously reported Davis et al., 2014). The majority of the participants identified themselves as Christians, had an average age at diagnosis of 51.7 years \( (SD = 10.03) \), and had a survivorship range of 1 to 27 years (Table 1). Over one third of the participants were retired, 32.3% worked full-time, and close to 15% were disabled (Table 1).

The participants’ experiences were organized into a meaningful whole and interpreted to represent the following four themes: (1) faith, (2) supportive structures, (3) optimism, and (4) access to information. The following sections provide an example of each theme, which was ranked from most to least prevalent.

Theme 1: Faith

Unequivocally, the participants indicated that their faith formed the primary support for their continued survivorship. Religiosity, described as a faith in God, attending church, and ongoing prayers, was seen as a primary means of helping participants cope during their survivorship experience. For example, several survivors noted the importance of the grace of God and “my faith in God.” One survivor noted that the value of her prayer group at church was significant in her ability to cope and survive, while another survivor found support by “putting God first in my life.”

Theme 2: Supportive Structures

Social support is often recognized as a vital component of physical and psychological well-being. A majority of the participants indicated that their support came from family, friends, spouses, and health care providers. One survivor indicated that “help
from my twin brother, my niece, and my two friends” was what helped her during this time. Another participant indicated that music and support from her mother, girlfriends, and two support groups provided care and were important to her. Many survivors indicated that they developed some new bonds with other survivors along the illness/wellness trajectory. One participant was thankful for the many different surviving sisters and chemo friends whose path she would not have crossed were it not for breast cancer. Another stated that it was “the support of individual members in my support group at various stages of the cancer journey” that provided resources she was able to use. Participants also said that having health care providers (medical doctors and nurses) who were caring before, during, and after treatment was “paramount” to their survivorship.

**Theme 3: Optimism**

Having optimism and maintaining a positive outlook and a positive attitude during all phases of survivorship were reported as being important. Having a positive attitude helped participants during this survivorship journey; a positive outlook was described as “living stress-free and not allowing people to stress me.” Another double survivor (4.8 years right breast, 1.3 years left breast) reported that she was “confident enough to reach out and walk with a person who had recently been diagnosed.” She understood the importance of a positive attitude and outlook and felt that she was beyond the initial stage of survivorship and could reach out to a newly diagnosed patient. One survivor said that volunteering to “help with transportation, meeting other survivors, and hearing their testimonies” gave her strength and helped her develop a positive outlook.

**Theme 4: Access to Information**

Access to information is the educational process of receiving and obtaining cancer information for the survivor regarding what was important during medical visits, in treatment compliance, and during the survivorship experience-helped the women during their daily lives. Several participants mentioned the importance of having the appropriate access information to make the right decision and having a collaborative health care team approach. “Choosing doctors to do their best” and having “excellent medical care” helped place the survivor in a position of knowing what to expect throughout her cancer care experience. A survivor indicated that “having good doctors and nurses” and “having a very understanding doctor” were important to her. Knowing the importance of “taking all of my medications” helped a 5-year survivor during this time. Another revealed that “the care I received at the center where I received treatment” assisted her with “knowing” how to survive. Survivors reported gaining information primarily via the Internet and other online media sources. For example, one survivor stated that “the American Cancer Society website, information that I received from the American Cancer Society” helped her during her ongoing survivorship. Another stated that talking to other women in the same situation was instrumental in providing her with additional information. One survivor put it very bluntly, stating that reading, reading, and more reading, that is, getting educated, was most important.

**Discussion**

The specific aim of this study was to describe and gain an understanding of the supportive care factors that were used by AABCS during their survivorship trajectory. Factors such as faith, supportive structures, optimism, and having access to information were instrumental to their survival. Participants viewed their faith and spirituality as critical to their survival. Faith and spirituality were seen by participants as a means of coping and comfort, which provided a multidimensional support base encompassing an unwavering belief in God, attending church, and ongoing prayer as vital
components. Indeed, the participants had a high degree of religious homogeneity, as 75% self-identified as Christians.

This study supports prior findings that faith is an integral component throughout the breast cancer journey for AABCS. Within the African American community, spirituality, faith, and the presence of God are often revered as a comforter, healer, and sustainer in times of despair (Musgrave, Allen, & Allen, 2002), and while the first responses to breast cancer exposure were negative, spirituality was used to positively transform the experiences of AABCS by affirming their beliefs and finding strength (Gallia & Pines, 2009). Researchers Lackey, Gates, and Brown (2001) reported that African American women relied on God throughout their diagnosis, treatment, and their breast cancer journey. Thus, paying attention to the spiritual aspects of life was likely to be helpful for AABCS (Coughlin, Yoo, Whitehead, & Smith, 2015).

Consistent with the literature, Russell, Von Ah, Giesler, Stormiolo, and Haase (2008) and Davis et al. (2015) reported a high reliance on one’s faith and/or spirituality among AABCS. Among AABCS, there was a strong relationship between spirituality and quality of life (Leak, Hu, & King, 2008). More recently, spirituality and faith were found to be quite prominent among AABCS survivors (Davis et al., 2015; Gregg, 2011; Sterba et al., 2014; Torres, Dixon, & Richman, 2016).

Our findings revealed that supportive structures were primarily a network of individuals (family, friends, breast cancer survivors, and health care personnel) who were viewed as being helpful, caring, encouraging, and understanding during survivorship. These supportive structures can act as an amalgam of emotional, tangible, informational, and experiential support. Emotional support makes an individual feel better, more secure, and/or better understood, focusing on love, trust, caring, and empathy (Chantler, Podbilewicz-Schuller, & Mortimer, 2005). Tangible support was defined as any specific resources that others (family, friends, support group members, and neighbors) may provide to the individual, such as a monetary loan, a ride to a medical facility, cooking, household chores, and child care (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). It was particularly important for those individuals who experience fatigue and may need additional support (Bellin, Oktay, Scarralone, Appling, & Heizisouer, 2015). In addition, the participants in our study exuded a degree of openness about their disease to family members, friends, and each other, contrary to what was found in the literature, where instances were reported in which others felt the need to conceal their disease from their families or friends (Byrne, Ellershaw, Holcombe, & Salmon, 2002).

The results revealed a plethora of emotional support, primarily coming from, but not necessarily limited to, spouses, family, and siblings, consistent with the literature (Sanders, Wilmot, & Lowry, 2004). In addition, experiential support was often a key source of support for AABCS as most of the survivors were members of support groups. Breast cancer support groups are often seen as safe, nurturing, supportive environments, in which members can share their cancer experiences and offer support, advocacy, awareness, education, and research. Additionally, ethnic support/advocacy groups broker the all-important cultural familiarity, kinship, and compatibility (Ashing-Giwa et al., 2012; Erwin, 2009). Sharing experiences and information with others may provide a sense of belonging and social support (Adamsen & Rasmussen, 2001). Collectively, these survivor-advocates, by virtue of their life experiences, have a deeper understanding of the breast cancer continuum/breast cancer trajectory (Lythcott, Green, & Brown, 2003).

Optimism is a personality trait often viewed as the generalized expectation that good things will happen. The participants revealed that being optimistic and having a positive attitude helped them cope throughout their survivorship trajectory. Others have validated this premise as well (Henderson, Gore, Davis, & Condon, 2003). Optimism has been significantly associated with cancer outcomes and other health outcomes in a meta-analysis (Rasmussen, Scheier, & Greenhouse, 2009). Optimistic women (post–breast cancer surgery) reported a higher level of support and felt more attractive (Abend & Williamson, 2002). Encouraging and supporting positive expectations and optimism may help survivors cope with supportive care issues, including long-term treatment-related side effects.

Regarding access to information, survivors were eager to obtain pertinent, relevant, and updated information, whether from another survivor, via the Internet, via support/advocacy groups, health care team providers, or just reading anything that was relevant about their specific experience. The AABCS survivors in our study valued information from their oncology health care team as a critical component during their survivorship trajectory. In line with similar studies that addressed the patient–provider communication among AABCS (Sheppard et al., 2011), survivors valued a collaborative approach from the oncology team, being given vital information, being understood, and having access to compassionate health care professionals to assist them. This is an important issue to note, as some AABCS have concerns regarding physician transparency and treatment (von Friederichs-Fitzwater & Denyse, 2012; some African Americans report having brief office visits and lower overall satisfaction with physicians who were of a different ethnicity (Cooper et al., 2003). Others have also reported racial/ethnic variations of care among women (Williams, 2008).

The limitations of the study are as follows: The sample exclusively targeted AABCS in the state of California. Thus, findings from the study cannot be generalized to the larger population of women with breast cancer. Future studies should also purposely include women (and men) of other ethnicities beyond those included here and should encompass other areas of the country. There are unique differences within the African American population, with varying
Implications for the Health Care Team

Findings from this study add new insights, specifically in the area of supportive care, in which the oncology health care teams must plan and be prepared to address the psychosocial impact of cancer on survivors and their families as they continue on the path of retooling their lives through the posttreatment period. Faith and the support structure of one’s family, friends, and chemo sisters are important supportive care factors to consider when addressing the range of ever-changing resources available to survivors. In addition, understanding the factors that were revealed from the AABCS group may promote a more culturally responsive patient-centric health care service delivery model. This delivery model would inform the team of providers and may also provide valuable support for the survivor herself, as well as others. Thus, exploring those factors through the lens of the African American woman who is traversing the road as a breast cancer survivor is a valuable tool for improving the efficacy of cancer care and Survivor Care Plans (SCPs) throughout the entire supportive care period.

This descriptive study begins to fill an important gap in knowledge of supportive care factors that may inform future inquiries. Improving survivorship outcomes will require a multidisciplinary approach and subsequent interventions by members of the health care team. Additionally, a coordinated approach of continued research and practice is sorely needed to address survivors’ long-term psychosocial, medical, and practical needs across the survivorship trajectory (de Moor et al., 2013) for AABCS. This information should be available not only to breast cancer survivors and their families but also to all medical team members. These medical team members include oncologists, surgeons, radiologists, oncology nurses, oncology social workers, psychologists, patient navigators, advocacy groups, and others who may need to understand what is important, what is considered very meaningful, and what is helpful from the standpoint of the culturally diverse survivor. In doing so, the multidimensional supportive care needs of these survivors can be met and can improve both their quality of life and their survivorship trajectory.

Conclusion

Collectively, these findings from our study provide a clear understanding and add new insight into the psychosocial factors that contribute to the overall survivorship of African American women as they recover from breast cancer and enter the next phase of supportive care. This study adds to the small but growing body of research on cancer survivorship among AABCS. These findings may guide the refinement of SCPs that are relevant, culturally appropriate, and patient-centered. Recent findings in a population-based study suggest that the lack of discussion of concerns leads to potential missed opportunities for cancer-related supportive care (Forsythe et al., 2013). Identification of specific supportive care factors may lead to an understanding of the multifaceted, cultural, psychosocial services that are needed (Kayser, 2016). The Institute of Medicine highlighted the phases of survivorship care (inclusive of psychosocial care, utilization of SCPs, and supportive care) during posttreatment care (Adler & Page, 2008). Therefore, it is imperative to gain an understanding of the patient-centered supportive care factors, which will inform health care providers, family members, and oncology team members of their patients’ needs and what works for them.

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References


