The Meaning of Survivorship as Defined by African American Breast Cancer Survivors

Claudia M. Davis, PhD, RN, CNS1, Hector F. Myers, PhD2, Adeline M. Nyamathi, PhD, ANP, FAAN3, MaryAnn Lewis, DrPH, FNP, FAAN3, and Mary-Lynn Brecht, PhD3

Abstract

Background: While there is an abundance of cancer survivorship research among various racial/ethnic groups, there is a paucity of research on survivors of African descent. To date, the meaning of survivorship has not been reported exclusively among African American breast cancer survivors (AABCS). Purpose: The purpose was to describe and understand the meaning of survivorship among community-dwelling AABCS, mostly recruited from breast cancer support groups. Method: Using a qualitative descriptive approach, an open-ended questionnaire explored the meaning of survivorship among 155 AABCS. An analysis of the content was performed. Results: Among AABCS, survivorship meant having a strong spiritual base, thriving, being resilient, and being altruistic. The survivors self-identified with and embraced the term survivor. Conclusions: These results provide an important understanding of the perspectives and meaning of survivorship among AABCS and may assist in developing cancer survivorship care plans that are relevant, responsive, patient centered, and culturally appropriate.

Keywords

African American women, breast cancer survivors, survivorship, identity, spirituality, resilience, thriving, altruism

Introduction

A cancer diagnosis is no longer an automatic death sentence. There are currently 13.7 million cancer survivors in the United States, and breast cancer survivors who account for 22% of the population, comprise the largest percentage of this group (Siegel et al., 2012). With an aging population, along with an emphasis on early detection and effective treatment, it is anticipated that this number will increase both nationwide and worldwide. Given the growing number of cancer survivors and their awareness of cancer screening, treatment, and control, the emergence of cancer survivorship is an important topic that is gaining attention. This is evident in the recent report, From Cancer Patient to Cancer Survivor: Lost in Transition, by the Institute of Medicine which provides a comprehensive review of the long-term treatment sequelae that cancer survivors may experience (Hewitt, Greenfield, & Stovall, 2005). The Institute of Medicine report also establishes survivorship care plans (SCPs) as a distinct phase of the cancer care trajectory. Four components are identified in this phase of cancer care: (a) the prevention and detection of new cancers, (b) the need for surveillance to identify cancer recurrence and appropriate interventions, (c) the need for psychological management, and (d) the collaboration and coordination between various health care providers to ensure that survivors’ needs are met (Hewitt et al., 2005).

While survivorship care is a critical component, it is also important to gain an understanding of the definition and meaning of survivorship from African American (AA) women who are most likely to experience breast cancer disparities (Sail, Franzini, Lairson, & Du, 2011). Using Surveillance, Epidemiology, and End Results data, the National Cancer Institute (Howlader et al., 2012) reported that AA women have a higher age-adjusted mortality rate than Caucasian, Asian/Pacific, Hispanic, Native American/Alaskan native. Several researchers have reported that AA women have a higher incidence of Triple Negative Breast Cancer compared with other women (Lund et al., 2009; Sturtz, Melley, Mamula, Shrvier, & Eillsworth, 2014) and a notable racial difference in treatment outcomes (Pacheco, Gao, Bumb, Ellis, & Ma, 2013). A landmark study by Elmore et al. (2005) revealed racial differences among AA...
Background/Literature Review

Historically, the term cancer survivor depicted someone who was cancer free for 5 or more years (Feurstein, 2007). More recently, the National Coalition for Cancer Survivorship (NCCS; 2012) defined a cancer survivor as a person who has survived cancer at the time of first diagnosis and who continues to live for months or years thereafter. This definition recognizes that people who are diagnosed with cancer are already on a survivorship journey (NCCS, 2012). The understanding and acceptance of the nomenclature of survivorship varies among women. The meaning of survivorship may be based on a woman’s age, life experiences, disease, ethnicity, or sociocultural background. While the literature is abundant with narratives of Caucasian breast cancer survivors (Documet, Trauth, Key, Flatt, & Jernigan, 2012; Helgeson, 2011; Morris, Campbell, Dwyer, Dunn, & Chambers, 2011; Pieters & Heilemann, 2011; Stanton et al., 2002), there remains a dearth of literature on AABCS.

Pieters and Heilemann (2011) explored the concept of cancer survivor and cancer survivorship among 18 female breast cancer survivors from 70 to 94 years of age. The authors reported that the majority of these survivors did not subscribe to the survivorship terminology, that is, cancer survivor or cancer survivorship. In fact, their identity was not attributed to being a breast cancer survivor, and furthermore, they rejected the survivor concept.

Using an exploratory approach, researchers Documet et al. (2012) studied how 112 breast cancer survivors defined themselves, the meaning of survivorship, and the attributed benefit of life experiences as a survivor. The authors revealed that the majority of the breast cancer survivors identified with the survivor term and considered themselves survivors. For these survivors, the meaning of survivorship meant being victorious, conquering the enemy, helping others, being cancer-free, having a new outlook, and holding membership in an exclusive club. Thus, the advantages of their experiences were an overall appreciation of life and a positive improvement in self and immediate relationships.

In a large study of 629 breast cancer survivors, Jagielski, Hawley, Corbin, Weiss, and Griggs (2012) explored survivorship identity. Specifically, their aim was to determine whether women who were long-term survivors considered themselves more likely to be survivors than those who were recently diagnosed. The sample was 91% Caucasian. The authors revealed that 78% of breast cancer survivors (who were further along the breast cancer trajectory) considered themselves to be survivors versus women who were recently diagnosed. These survivors felt that their prognosis was “very good” when compared with other women. It is interesting to note that the survivors were diagnosed with non-invasive ductal carcinoma in situ, which is often debated in the literature as to whether it should actually be called cancer (Leonard & Swain, 2004). AA women are more likely to be diagnosed with an aggressive form of breast cancer compared with other women (Lund et al., 2009), and as such, may have a different characterization about the meaning of survivorship.

In a concept analysis of breast cancer survivorship and of AA survivors, Farmer and Smith (2002) determined that there was a paucity of research on cancer survivorship among various ethnic/racial groups. Furthermore, the authors reported that culturally, cancer survivorship might be perceived quite differently among AA women and other racial/ethnic groups. More important, they indicated that while survivorship is an individualized journey, nurses and other members of the health care team may need a better understanding of the definition of cancer survivorship and its meaning as a precursor to providing culturally competent care.

Helgeson (2011) examined the concept of survivor centrality to determine if the meaning of cancer was central to the breast cancer survivors’ identity. Survivors were asked to state how they saw themselves. The author revealed that among the 240 breast cancer survivors who were 10 years post-diagnosis, women who were younger were more likely to define themselves as survivors.

The body of empirical research on the meaning of survivorship indicates that surviving cancer can be attributed to age, life experiences, and stage of disease. Given that survivorship has many meanings for a number of individuals, what is the definition of survivorship among AABCS? This is a salient question, given that AA women are more likely to experience breast cancer disparities along their cancer trajectory (Lund et al., 2010). Understanding the definition and subsequent meaning of survivorship among AABCS would inform the development of more culturally
responsive, patient-centered health care service delivery model that would inform the team of providers, promote best practices, and provide valuable support for survivors and their families.

Method

Design

The study design was a cross-sectional convenience sample of 155 AA 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 one-time, 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.

The specific aim of this study was to describe and better understand the meaning of survivorship among AABCS. The present analysis was part of a larger study to determine the biological and psychosocial predictors of functioning among AABCS. Qualitative description, which provides researchers with a straightforward description of the phenomena in question and provides answers to questions of particular relevance to stakeholders such as practitioners and policy makers (Sandelowski, 2000), was the appropriate method of choice. In addition, through content analysis, qualitative descriptive studies seek to procure and understand various perspectives and subsequent meaning from participants. Accordingly, it is important that those meanings are reported in a clear, coherent manner. The University of California, Los Angeles Institutional Review Board approved this study.

Sample and Setting

One hundred and sixty-nine AA women were screened, 160 were deemed eligible, and 5 women either missed the session or chose not to participate. A cross-sectional convenience sample of 155 AA adult women diagnosed with breast cancer met the eligibility requirements. Eligible participants were women who self-identified as African, AA, 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. Women who self-identified as being of any other race/ethnicity, who were currently undergoing breast cancer treatment (surgery, chemotherapy, and/or radiation), or who were incapable or unwilling to provide informed consent or were diagnosed with a different primary cancer were excluded.

All participants were residents of California and were recruited through three methods: (a) 12 different AABCS groups within Southern and Northern California, (b) word-of-mouth, and (c) flyers in key community locations, for example, 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 key locations in the support groups. Interested individuals were instructed to contact the PI by calling a designated research telephone number. Women who were members of a support group met the PI (who was also AA) in a designated area at their monthly support group meeting. 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 a community site of their choosing. Eighty percent of the participants were members from the support groups and 20% percent of the participants were community dwellers.

Participants were informed about the purpose of the study and all questions were addressed. Written informed consent was obtained and all were informed that it would take approximately 1 hour to complete the questionnaires. All data were collected through self-administered questionnaires. Assistance was provided to participants who preferred to have their surveys read to them and responses were handwritten, verbatim. Upon completion, all participants received a $10 Target gift card for expenses associated with gas and local travel.

Measures

As part of a larger comprehensive study, several biopsychosocial predictors and psychological functioning were investigated. Thirty-two close-ended questions collected sociodemographic data including age, relationship status, religion, education, annual income, and health history data including questions about breast cancer treatment inclusive of stage of breast cancer, type of treatment, and years of survivorship. The following open-ended question explored the definition and subsequent meaning of survivorship: Survivorship has many different meanings for a lot of people. From your experience, how would you define survivorship?

Data Analysis

Descriptive statistics, including means and standard deviations, were calculated to represent the participant’s sociodemographic data. Descriptive statistics provides a summative snapshot of the participants. Further statistical analysis for this study was previously reported (Davis et al., 2014). These data were analyzed using SPSS 18 Statistical software (SPSS Inc., 2009).

Qualitative description may be diverse, with different hues, tones, and textures, such as categories; the underlying
tenets include sampling, data collection, analysis, and representation (Sandelowski, 2000). In terms of sampling, qualitative description purports that the investigators may choose a purposeful sample (Trost, 1986). In our study, we chose a specific racial group, AABCS in particular, as the mortality rate of breast cancer among this particular racial group is among the highest in comparison with other racial groups (Howlader et al., 2012). Data collection in qualitative descriptive research is often geared toward discovering three important areas, essentially who, what, and where of the event/experience and primarily includes open-ended questions (Sandelowski, 2000). In our study, the participants self-identified as AA. The concept of “what” they shared was their varied definition of survivorship and its meaning to them. The concept of “where” was akin to their standpoint of being a survivor. Qualitative descriptive research provides an interpretation of the data, where the data are similarly coded and a summative statement is produced (Sandelowski, 2000). Finally, the outcome of the data (data re-presentation) is a summative statement and a variety of ways to arrange the data, for example, most common to least common themes (Sandelowski, 1998). In our study, the themes are reported from most (1) to least prevalent (5), but all were important, as it provided a description from their perspective.

**Results**

Over 43% of the participants were married. Over 81% identified themselves as Christians, a small percentage reported as Muslim (9.0%), and a few (5.8%) had no religious affiliation. Nearly half were college educated (over 26% had a bachelor’s degree and 19.4% had a master’s degree). Over 38% had an income of less than $39,000 and over 42% had an income that ranged between $40,000 and $79,000 (see Table 1).

Overall, the years of survivorship ranged from 1 to 27 years ($\bar{X} = 9.7, SD = 6.8$). Age at diagnosis ranged from 31 to 77 years ($\bar{X} = 51.7, SD = 10$). The women reported various stages of breast cancer at diagnosis, with a small percentage (3.2%) diagnosed with carcinoma in situ. Roughly 80% of the women reported Stage 1, 2, or 3, with Stages 2 and 3 representing 38.1% and 23.2% of the cancers, respectively. Stage 4 cancer represented 11% of the sample (see Table 2).

**Definition of Survivorship**

When their experiences were organized into a meaningful whole, they were interpreted to represent the following five themes: (a) having an identity as a survivor, (b) exuding a strong spirituality, (c) thriving, (d) having resilience, and (e) helping others (altruism). The following provides an example of each theme, which was ranked from most to least prevalent.

**Theme 1: Having an Identity as a Survivor.** The construction of survivorship has many dominant meanings and some participants embraced those meanings. For example, a 16-year survivor stated, “I am a survivor and will be a survivor for the rest of my days and will live my life freely.” Another statement by a 10-year survivor declared, “I am still here!” Another survivor indicated that for her, “Survivorship is a mental attitude, understanding that life has just begun.” One study participant defined survivorship as:

“The ability to know that life is to be lived one day at a time. To have overcome the associated fears and myths associated with a disease such as cancer, by grieving each loss and embracing the new me of priorities and relevance.”

<table>
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<th>X</th>
<th>SD</th>
<th>Range</th>
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<tr>
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<td>1-27</td>
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<td>8.4</td>
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<tr>
<td>Divorced</td>
<td>34</td>
<td>21.9</td>
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<tr>
<td>Living together</td>
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<td>Widowed</td>
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<tr>
<td>Christian</td>
<td>128</td>
<td>82.7</td>
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<tr>
<td>Muslim</td>
<td>14</td>
<td>9.0</td>
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<tr>
<td>Buddhist</td>
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<td>No religion</td>
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<td>5.8</td>
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<tr>
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<td>38.1</td>
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<td>40,000-79,000</td>
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<td>≥80,000</td>
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<tr>
<td>Did not respond</td>
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<td>6.5</td>
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**Table 1.** Demographic Characteristics of Participants ($N = 155$).

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<th>SD</th>
<th>Range</th>
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**Table 2.** Stage of Breast Cancer ($N = 155$).
Another survivor defined survivorship as “restoration to life as usual with a positive attitude in spite of having one big and one small breast.”

While the majority of the participants considered that they were survivors and fully immersed themselves in the identity, one participant did not consider herself to be a breast cancer survivor. Her identity as a survivor was not linked to breast cancer; it was seen more in alignment with her embodiment as an individual to whom her sum is greater than her parts. She stated, “It’s a word that is very unfamiliar to me. I don’t use it, seems over used. Today, I’m a whole survivor on this planet.”

**Theme 2: Exuding Spirituality.** Almost all of the participants discussed their spirituality as central and critical to their survivorship. Several participants described their spirituality as multidimensional and holistic that encompassed their lives from diagnosis, treatment, and after treatment. A new survivor revealed, “Survivorship involves being diagnosed, going through surgery, going through treatments, surviving, maintaining contact with your doctor, taking medications, believing in God.” This view was also expressed as, “Being thankful each day and praising God … staying alive.” Another survivor reported, “I made it through by the grace of God! I’m still here.” Another survivor revealed, “Survivorship to me is a daily will to live and enjoy every moment that God has offered you.” Finally, a 7-year survivor (first diagnosis, 8-month recurrence) stated that her faith was what kept her together. She said, “Survivorship is getting through it, with God with you.”

**Theme 3: Thriving.** Several women indicated that despite their diagnosis, they viewed survivorship as “coping with, adopting life changes, and living joyously.” To some participants, survivorship meant creating a new normal and living life, not just being alive,” in other words, “thriving.” The underlying theme of survivorship was described as “being grateful for every single breath, a commitment to live unto my joy.” Thriving transcends the number of years of survivorship. For example, the 9-year survivor revealed that “Survivorship is walking through the experience of a dangerous illness with as much hope, faith, determination I can have while keeping fear at a minimum [and] experiencing each day with as much joy as I can.”

One participant was very eloquent when she stated, “I define survivorship when my thoughts moved from one day at a time, to planning for the future.” For example, a survivor mused, “Wanting to do things, whereas I was thinking short term.” Spending time with family was also important, as another stated, “I get to see my children grow up.” A double survivor, right breast 4.8 years, left breast 1.3 years, stated survivorship as:

“Being alive!! Free of active cancer cells, feeling confident, ability to function and perform as I did prior to diagnosis and treatment. To have the stamina to spend time with grandchildren and participate in their activities, acknowledging the gifts of God and the support of family and friends . . . loving and being loved.”

A 10-year survivor stated, “Not being afraid of the word cancer and realizing that it’s a word and not a ‘sentence.’”

Many survivors viewed surviving cancer as an improvement in personal wellness that enabled them to thrive and live abundantly. Women described survivorship as “waking up every morning and facing a new day, proper diet and exercise, positive mind-set.” Survivorship was seen as both a threat and an opportunity to change and improve one’s life. Survivorship is “having been diagnosed with a life-threatening disease and then beginning the process of healing in every way, mind, body, and spirit as well as coping with the challenges that the illness brings.” Others stated that a lifestyle change and/or validation of the need to “change some of my habits, eating more nutritious foods” were associated with survivorship. “Staying active,” stated a 12-year survivor.

**Theme 4: Having Resilience.** Many study participants saw themselves as having resilience. “Beating cancer” was another term that was used by a survivor to describe the experience. Others viewed “the battle [as] going against the odds without falling and giving up.” Another participant considered, “Survivorship to me means a term that implies one has challenged an obstacle and overcame or lasted through a challenging situation.” Essentially, these women felt that not giving up or giving in was “dealing with adversity—meet it, greet it, and defeat it.” Survivorship was “living life after breast cancer’s attack, keeping a winning attitude for the future.”

Survivorship also meant “endurance and perseverance” to several women. One survivor stated, “There are challenging times and may be rough times, but keep on.” She stated, “Survivorship to me means one who overcomes a life and death situation and could proudly say, ‘I’m still standing,’ also most of all, thank God, I survived that illness.” A 21-year survivor stated that survivorship means, “The ability to experience a situation; get through it physically or emotionally, to move beyond the situation, and begin a different life after the situation.”

**Theme 5: Showing Altruism Toward Others.** Several participants mentioned that having breast cancer and surviving cancer gave them a sense of urgency to help others. For example, a 23-year survivor indicated that survivorship includes the “ability to share my experience to help others out.” The need to help others by way of information or by caring was evident in the words of the survivors. Some survivors were very specific and considered survivorship as doing cancer outreach with others “to get the word out.” Others defined survivorship as “being free of cancer and helping others.”
Another survivor reported that “being around other survivors, talking and sharing” was essential for her survivorship, since “survivorship means helping others through their ‘crisis.’”

**Discussion**

This study explored the description and meaning of survivorship among AABCS. The meaning of survivorship was more than added years to the survivors’ lives; it meant a continued and strong spirituality in maintaining a relationship with God, having resilience, thriving, and being altruistic. The significant role of spirituality in AA women’s breast cancer experience has been extensively documented (Abrums, 2004; Ashing-Giwa, 1999). Historically, spirituality is a major part of the AA culture and is seen as an essential component assisting one to rise above and deal with adversity (Giger, Appel, Davidhizar, & Davis, 2008). “It is what pulls you through” (Rev. T. Denyse, personal communication, April 18, 2010). While spirituality can be loosely defined as the degree to which individuals maintain a relationship with God or a transcendental force that brings meaning and purpose to their existence, which affects the way in which one operates in the world (Armstrong, 1996); the survivors in our study revealed that their spirituality is a vital and integral component of their survivorship. The survivors’ spirituality was reported to be a strong part of daily living and formed a sense of strength and feeling that they “were not alone.”

Several studies have documented that faith and spirituality are an important and significant component in the lives of many AABCS (Ashing-Giwa & Ganz, 1997; Phillips & Smith, 2001) and acts as a form of coping throughout their breast cancer experiences (Gregg, 2011; Tate, 2011). Moreover, the findings of our study closely paralleled those of Holt et al., (2009), who examined the role of religion in coping with breast cancer among 23 AABCS. Findings revealed several themes, including the role that their faith played relative to their recovery and healing. The similarity of findings from this study and that of Holt et al., (2009) validates the premise that for AABCS, spirituality should be acknowledged and supported by health care providers throughout the cancer care trajectory.

**Survivor Identity**

Although others often represent breast cancer survivors as triumphant, victorious, happy, healthy, and feminine (King, 2008), these faces may not be the faces of AA women (Moore, 2001). In fact, according to Moore (2001), several survivors voiced concern over the public image that breast cancer is perceived to be a disease that affects other women, specifically Caucasian women. However, with the media release of recent breast cancer diagnoses of several prominent AA women, specifically Robin Roberts and Wanda Sykes, these images of AA women may have changed the public face of breast cancer (Caslin, 2012). They may have helped AABCS illuminate their new identity as survivors and helped validate that breast cancer does affect AA women. In our study, many AABCS identified themselves as survivors, fully embracing the identity. However, these findings differed from those of a qualitative study of middle class, Caucasian, breast cancer survivors who were from 3 to 18 months after treatment and rejected the social identity as survivors (Kaiser, 2008).

**Resilience**

In this study, we noted that the participants exuded resilience, were able to be challenged, were able to overcome adversity, and provided evidence toward strength and determination in overcoming cancer. The findings were consistent with Woods-Giscombe’s (2010) early formation of the Superwoman Schema, a multidimensional conceptual framework based on the personal or sociohistorical contextual factors that may be apparent for AA women. Specifically, Woods-Giscombe (2010) posits that the AA women may exhibit tenacity, strength, and a willingness to help others. Therefore, in order to survive, AA women must demonstrate the wherewithal to cope with chronic stressors that may be manifested on a daily basis, coupled with being diagnosed, treated for breast cancer, and giving of themselves.

**Altruism**

Many AABCS revealed a personal sense of agency, which was evident in their altruistic narratives. While they were engaged in the care and treatment of their disease, there was a clear conviction by participants to “share my experience to help others out.” Study findings were similar to the results of a qualitative study of 24 AABCS in which one of the major themes was “health activism” (Wilmoth & Sanders, 2001). The survivors felt that it was their duty to inform AA women about the risk of breast cancer (Wilmoth & Saunders, 2001). Thus, the crusade to share and inform other women about their breast cancer journey was very important for AA women.

**Limitations**

There are several limitations in this study that merit discussion. The sample was a convenience sample that exclusively focused on AA women in the state of California with breast cancer. The sample was quite heterogeneous in terms of the years since treatment. Demographically, our sample reported a higher level of education and higher income, indicating a higher socioeconomic status. Most were members of breast cancer support groups, which may have contributed to their positive views and attitudes. These findings are applicable to the selected sample of our study.
Implications for Practice and Conclusions

The open-ended question in our study highlighted the most personally meaningful definition and meaning about survivorship for AABCS. Considerable empirical work remains to be done to explain the meaning of survivorship and its contributory role in predicting psychological functioning among these women. Additional qualitative studies are needed to gain an understanding of the resources that may be utilized by AABCS during their survivorship trajectory.

Our results provide an important understanding of their perspectives and may help in developing SCPs that are relevant and culturally appropriate, thereby improving coordination and quality of care. SCPs are personalized plans of care, provided by an oncology clinician, that summarize the individual’s diagnosis, treatment, and possible residual effects of treatment; address medical and psychosocial concerns; facilitate adherence to screening guidelines; and provide pertinent resources. The outcome is to provide a multidisciplinary comprehensive care that improves the physical, psychosocial well-being and quality of life of survivors.

There is a strong evidence of the value of an SCP and its role in improving communication between providers (Burg, Lopez, Dailey, Keller, & Prendergast, 2009; Kantisper et al., 2009; Miller, 2008), yet many survivors report unmet needs (Hodgkinson et al., 2007), and in particular, the needs of AABCS appear to be woefully unmet (Ashing-Giwa et al., 2013; von Friederichs-Fitzwater & Denyse, 2012). A number of studies revealed a fragmented delivery care system (Bourjolly, Hirschman, & Zieber, 2004) and barriers to communication (Tapin et al., 2012). Given that many AABCS embodied and embraced the definition and meaning of survivorship and the resulting themes (altruism, spirituality, resilience, and thriving), they appear to be well equipped and should be sought for the role of Survivor’s Navigators. As Survivor’s Navigators they have the potential to make a significant difference in the overall quality of life of survivors (Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011).

An understanding of the definition and meaning of survivorship among AABCS may promote a culturally responsive patient-centric health care service delivery model that would inform the team of providers and may also provide valuable support for survivors and their families. This study adds to the small but growing body of research on AABCS. These findings fill the void in understanding the definition as it relates to these particular breast cancer survivors. Because these women are in the process of retooling their lives after being diagnosed and treated for breast cancer, the process of building meaning around their illness trajectory is of critical importance. Early conceptualizations attached to an experience can, and indeed do, shape subsequent actions (Swidler, 1986).

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