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“We both just trusted and leaned on the Lord”: A qualitative study of religiousness and spirituality among African American breast cancer survivors and their caregivers

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Abstract

Purpose—Most breast cancer survivorship research focuses on the general population of survivors. Scant research investigates the potentially unique experiences of minorities, especially during and after the difficult transition from primary treatment to post-treatment. This qualitative study explored African American breast cancer survivors’ and caregivers’ quality-of-life in the post-treatment period with a focus on social and spiritual well-being.

Methods—Participants included a convenience sample of African American women with stage I–III breast cancer (N=23) who completed treatment 6–24 months before enrollment. Primary caregivers (N=22) included friends, spouses and other family members (21 complete dyads). Participants completed separate semi-structured telephone interviews. Template analysis was used to evaluate themes related to religiousness and spirituality, both across and within dyads.

Results—After treatment, religiousness and spirituality played a major role in both survivors’ and caregivers’ lives by: 1) providing global guidance, 2) guiding illness management efforts and 3) facilitating recovery. Participants described a spiritual connectedness with God and others in their social networks. Dyad members shared the goal of keeping a positive attitude and described positive growth from cancer. Few future concerns were expressed due to the belief that survivors were healed and “done” with cancer. Beyond practical and emotional support, provision of spiritual assistance was common.

Conclusions—Results highlight the principal, positive role of religiousness and spirituality for African American breast cancer survivors and caregivers after treatment. Findings emphasize the

need to assess the importance of religious and spiritual beliefs and practices, and if appropriate, to provide resources that promote spiritual well-being.

Keywords

breast cancer; African American; spirituality; religiousness

Introduction

Breast cancer (BC) is the most common female cancer [1] and approximately 2.5 million survivors live in the United States today [2,3]. Advances in early detection and treatment have led to better survival rates, which has highlighted a critical need to understand and address BC survivors' needs [4]. In addition to the physical and psychological challenges of BC diagnosis and treatment, survivors face unique challenges during the clinically significant transition from the primary treatment to post-treatment period [4–6]. As the field of cancer survivorship research matures, it is therefore imperative to broaden the research agenda to include studies that address the experiences of minority and other underserved groups [7,4].

While research with African American BC survivors is growing [8,7], there is still much to learn about their survivorship experiences [9,10]. In particular, correlates of African American BC survivors' quality-of-life (i.e., physical, psychological, social, and spiritual well-being [11–13]) are important to consider because this group is more likely to be underserved [9] and may therefore have unique needs. Research with African American BC survivors has begun to identify common physical and psychological challenges faced, many of which are consistent with those of the general population of survivors, including pain, fatigue, sleep problems, fear of recurrence, and body image concerns [8,14–17]. Some studies have found no differences in quality-of-life between African American and White BC survivors [16,18] while others have found better psychological [17,19] yet worse physical [20] quality-of-life in African American survivors. Other aspects of quality-of-life are less well understood, particularly during the potentially challenging post-treatment period [4,5]. In particular, little research has examined social and spiritual quality-of-life factors specifically in the post-treatment period despite African Americans placing a high value on social ties [21–23] and spirituality [24,8].

To help fill a gap in the literature, the current study used qualitative methods to examine the quality-of-life of African American BC survivors, with the goal to develop interventions that address concerns after primary treatment. As little research focuses on the social environment of African American BC survivors, this study also explored the experiences of survivors' primary caregivers. The specific aim of this study was to explore quality-of-life in African American BC survivor-caregiver dyads at the end of primary treatment and in the post-treatment period with a focus on spiritual well-being.

Methods

Participants and Procedures

The Institutional Review Boards of participating institutions approved study procedures. We recruited a convenience sample of African American BC survivors (stages I-III) who completed primary treatment (i.e., any combination of surgery, chemotherapy, and/or radiation) 6–24 months before study enrollment. We focused on this timeframe to capture a wide variety of recovery experiences including potentially important long-term challenges and also to allow respondents to complete the immediate recovery period to gain perspective on and reflect on their end of treatment experiences. Potential participants were excluded when they had stage IV disease because care and prognosis experiences are significantly different in this group [25]. In addition, participants were excluded when they did not speak English or if they did not have a telephone. At a regional cancer center in the United States, potential participants were identified through administrative clinic databases. In addition, BC survivors who participated in a previous study [26,27] and agreed to be contacted again were invited to participate. Those approached in clinic were screened for eligibility and provided written informed consent while those contacted by mail were screened for eligibility by telephone and provided written informed consent by mail. Once consent was obtained, BC survivors nominated a primary caregiver (i.e., the person on whom they relied most for cancer-related help), and caregivers were asked to provide written informed consent.

The study was grounded in a multi-dimensional quality-of-life conceptual model [11,4,28,29] that includes physical, psychological, social and spiritual dimensions and was adapted to incorporate factors relevant for longer-term cancer survivors [12]. A semi-structured interview guide was designed to broadly query participants' experiences in the post-treatment period (Table 1). After describing treatment experiences, survivors were asked to think back to when they were finishing treatment. They reported concerns they had at the end of treatment, who they turned to for support, and future expectations. Participants were asked about the care they received and about their well-being after treatment. A parallel set of questions was asked of caregivers with additional questions concerning their own needs. Finally, all participants were asked to describe their relationship with the other dyad member. When religiousness and spirituality topics were raised or mentioned, the interviewer asked the respondent to describe in more detail how their faith affected their coping.

After the interview guide was pretested with three BC survivors, enrolled survivors and their primary caregivers completed separate audiotaped 30–60 minute telephone interviews describing experiences in their own words. Routine study team meetings were held to assess interview progress and interviews were conducted until data saturation [30] was achieved. A trained bachelor's level African American female staff member conducted interviews after completing a 4-session training. Sociodemographic and clinical data were collected via self-report.

Data Analysis

After interviews were transcribed and verified, two coders independently read and listened to each interview. When responding to broad questions about well-being at the end of and shortly after treatment, BC survivors and their caregivers routinely described religiousness and spirituality as key factors in their survivorship experiences. Therefore, we developed a codebook based on a literature review of: 1) religiousness and spirituality in African American BC survivors [24,8,31–33] and 2) Ferrell's spiritual well-being domains for cancer survivors [29,34], which consists of these 6 factors: Religiosity, Meaning of Illness, Inner Strength, Transcendence, Hope and Uncertainty. Our initial codebook included the following codes: 1) Religious and Spiritual Beliefs and Activity, 2) Inner Strength, 3) Transcendence, 4) Benefit Finding and 5) Outlook. Independent coders (KRS, JLB) tested the initial codebook on the same eight interviews (4 dyads) and differences were resolved by discussion in an iterative process until full agreement was reached to finalize the coding process. Data analysis employed the template analysis technique [35] where an initial codebook derived from theory and the literature is used, but additional codes can emerge as appropriate. This process ensured data analysis accurately reflected participants' experiences. The data guided us to divide two original codes into two categories: 1) Inner Strength became Coping and Illness Meaning and 2) Transcendence became Spiritual Transcendence and Interpersonal Transcendence. In addition, God as Healer, Return to Normal and Caregiver Support Behaviors were added as new codes. In our analysis, we explored themes across survivors and caregivers at the group level as well as within dyads (i.e., individual BC survivors and their nominated caregivers). Final coding was conducted independently using N Vivo software [36] with routine meetings between coders.

Results

Participant Characteristics

The sample (N=45) consisted of 21 complete dyads, plus 2 independent survivors and 1 independent caregiver. Survivors' and caregivers' socio-demographic characteristics are in Table 2. Many participants reported uncertainty about the nature of their disease and treatment. Roughly half of survivors (52.2%) reported they did not know the exact stage of their BC while 17.4% reported stage I, 26.1% reported stage II and 4.3% reported stage III. Participants were more knowledgeable about cancer treatment, with only 13.0% unsure about this clinical variable. Most participants (60.8%) reported at least two treatment courses (i.e., surgery, chemotherapy and/or radiation). Finally, survivors most commonly nominated a friend (30.4%) as primary caregiver, though family members were well represented (Table 2).

Religiousness and Spirituality and Other Themes

As described in the sections below, survivors and caregivers consistently highlighted religiousness and spirituality as essential to their survivorship experiences. The major roles played by religiosity and spirituality were in three areas: providing *global guidance* or universal direction in one's BC experiences, guiding *illness management* or efforts to promote management of the BC, and facilitating *recovery* or the process of supporting a return to health after BC. Below we describe key elements of each theme organized in this

hierarchy (see Figure 1) and provide descriptive quotes. In addition, Table 3 provides code definitions and highlights exemplary quotes.

Global Guidance

Religious and Spiritual Beliefs and Activity: Frequently throughout interviews, religious and spiritual beliefs and activities were described as providing global guidance to the breast cancer experience. Both survivors and caregivers commonly reported that God was in control of cancer. This belief was strong and those who held it described comfort because they believed God would not give them more than they could handle.

“Well basically we all have faith that God is in control and so basically reminding her of that and how the whole situation brought me closer to God and I think it did her too. Just letting her know that even though it’s a bad thing going on, there would be good that would come out of it and I would be there if she needed me.”
(Friend, Age 47)

By far, the most commonly described religious and spiritual activity was prayer. Participants said they prayed alone, within survivor-caregiver dyads, and with their larger church communities. Prayer reportedly allowed participants to ask for help, assured them they would be all right, got them through cancer-related challenges, and helped them give thanks at the end of treatment. Overall, participants described building a supportive system around them through prayer.

“Prayer. I could not make it through; I couldn't even make it through a day without just prayers. And I give thanks for everything...for the good, for the bad, whatever crosses my way I give thanks for it. Because to me, it strengthens you.” (Survivor, Age 65)

Transcendence: Spiritual Transcendence: Spiritual transcendence and connectedness stemmed from survivors’ and caregivers’ faith. The positive role of spiritual transcendence in the lives of participants was evident in two ways. First, survivors and caregivers described a strong belief that God hears prayers and intercedes on behalf of people in need, a belief that led to the ability to put cancer-related worries “in God’s hands.”

“And I just had to put faith and trust in God and for Him to take me through it. Once I prayed and gave it to God, I never did take it back...Especially when you hear God talk to you and He tells you everything is gonna be ok. Once I heard His voice, I just went through it.” (Survivor, Age 55)

Second, survivors reported their BC experiences were similar to the trials of historical figures from the Bible (e.g., Jesus Christ, Job), which provided reassurance due to their belief that God is omnipresent. In sum, participants reported feelings of connectedness with God and other individuals they believed God “delivered” in the past, which led to a unique combination of acceptance and optimism.

“You know being around and talking to her, you know, really discussing some things that God promised us he would do...Going back in Isaiah, in the Bible,

talking about how God did things for people in the Bible. I was showing her that he'll do the same for us.” (Friend, Age 66)

Transcendence: Interpersonal Transcendence: Interpersonal transcendence was reflected in participants’ descriptions about their far-reaching social networks and connections with others. Survivors reported that relationships with family, friends, church members, coworkers, healthcare providers, and other survivors were critical to coping with BC. Survivors’ relationships with other survivors were particularly important to affirm that they too could “fight” or “beat” cancer. Many caregivers described appreciating the unique relationships among survivors, and as a result, part of their role as caregivers involved encouraging survivors to engage meaningfully with other survivors (e.g., participation in support groups). Caregivers also acknowledged that survivors’ support systems extended far beyond them, and like survivors, they relied on others for support during stressful periods.

“Her church embraced her, you know. She did something there that she had never done before. She went up before the church...in front of the church. I went with her and she asked the church for prayer. After she did, people just started surrounding her.” (Friend, Age 66)

A lot of emphasis was placed on caregivers “being there” for survivors practically, emotionally, and spiritually. Some caregivers were motivated to support survivors due to the nature of their relationship (e.g., husband-wife, mother-daughter) while others’ motivation was derived from spiritual beliefs. Regardless of motivation, the connection between survivors and caregivers was strong. Sometimes survivors and caregivers described making decisions about whether to disclose or withhold feelings about BC to protect the other person. However, survivors and caregivers alike generally reported positive thoughts and feelings about their social networks and the support received.

“If I had to get it, I couldn’t have had better people around me to support me; there are no words to describe how wonderful they were to me...because they gave up themselves, they gave up their time, they gave up their concerns, and were supportive 100%”. (Survivor, Age 58)

Illness Management

Inner Strength: Coping: Both survivors and caregivers said their trust in God guided them through the management of the cancer. As stated above, the most common coping method described by participants was prayer. Typically, religious and spiritual coping was described in the context of BC diagnosis and treatment (e.g., adjustment to chemotherapy side-effects). However, this theme was also pertinent after treatment completion as survivors and caregivers reported that God allowed them to leave cancer behind.

“That was my biggest supporter was having my spirituality and knowing what God had already done for me and that this would be a piece of cake for me and so, you know, I had loads of faith.” (Survivor, Age 61)

Inner Strength: Illness Meaning: Many survivors and caregivers claimed God provided insight about the purpose of their BC or their role as caregivers, respectively. Oftentimes,

this theme was related to the belief that God was in control, from which participants reported being able to put complete trust in God's plan and wait to be shown next steps. In rare cases when participants indicated they did not know the meaning/purpose of BC, they reported being comfortable with uncertainty because it too was part of God's plan.

"And that would be the one thing would be not to just ask 'why me?' but my philosophy was 'why not me?' Whatever journey you have and whatever you want to use me for during this ordeal, Father, I'm just waiting for your orders."
(Survivor, Age 47)

God as Healer: One particular religious and spiritual belief guiding survivors' illness management involved God's healing power. Participants primarily described God's healing in the context of BC diagnosis and treatment. Specific outcomes related to God's role as healer included provision of direction about specific treatment providers, prevention of poor treatment outcomes (e.g., radiation burns), and provision of a firm conclusion to the cancer experience. In general, the belief that God healed survivors provided participants with comfort.

"She had two tumors in one breast and it had not spread. And the doctor gave her that information and she just started praising God as we all did. That's where we felt her healing come from and that's it, in all honesty. We prayed for the doctors, we prayed for the precious people that would care for her, but we believed that God was the healer." (Friend, Age 66)

Recovery

Outlook: Having a positive attitude, which was often derived from religious and spiritual beliefs, was a major theme. Survivors and caregivers focused on staying positive as an important part of coping with cancer and caregiving, respectively. Staying positive emerged as a critical interpersonal coping process as survivors and caregivers worked together to stay positive through hardships.

"I try to be uplifting, because the scripture said we're supposed to excite one another, you know, not try to bring your brothers and sisters down. Like I said, I just try to keep a positive attitude." (Survivor, Age 65)

When directly queried about how they felt about the future when they finished primary treatment, positive responses were common and descriptions were often linked to participants' religious beliefs and their active efforts to rely on God to control their cancer. Very rarely were worries reported because most participants said they were leaving cancer behind as God brought them to the conclusion of their BC.

"I just expected to stay cancer free and to just able to do everything I did before, and I am. And I am and I thank God for that." (Survivor, Age 41)

Benefit-Finding: Both survivors and caregivers reflected on positive outcomes from cancer, which were often related to religiousness and spirituality. Specific benefits included personal growth, more awareness of important relationships, insight about ways to help others, and motivation to make positive behavior changes (e.g., increase physical activity,

engage in cancer screenings). Due to the perception of benefits derived, multiple participants expressed being thankful to God for BC.

“I am not going to sit on this and cry about it. I am going to use this opportunity to encourage people to get their mammograms and get their treatment if they are affected and stay on top of things, never take a lump for granted...because God has given me this to help someone else.” (Survivor, Age 39)

Return to Normal: Survivors and caregivers reflected on their own and others' expectations about survivors' return to normal. At the end of treatment, participants commonly referred to the desire to return to their “old selves” and normal way of doing things as well as a return to valued roles and responsibilities.

“It wasn't so much talking about what she was going through as it was getting back to normal conversations. You know, the old [Survivor] started to show more and more. She could be really...what's a good word for it...? Feisty! And you know, that started to come back...at the end of the treatment.” (Friend, Age 59)

Obstacles in the way of a return to normal, while only occasionally reported, included both physical (e.g., fatigue, pain) and mental (e.g., adjustment) challenges, and some survivors described frustration about their recovery pace. Overall, however, participants reported positive expectations about returning to normal.

Caregiver Support Behaviors

Caregiver support behaviors were exhaustive, and included practical (e.g., financial, cooking) and emotional (e.g., encouragement, “being there”) assistance. Almost all reports of caregiving were framed in a positive manner.

“So it was a shared responsibility and then everybody had their role to play. Like my nieces or my nephews would come in and clean my bathroom for me...This friend of mine, she would, on her trips to do her grocery shopping; she would pick up...things that she knew that I could drink.” (Survivor, Age 51)

“Just continue to be encouraging...continue to give them encouraging words. Tell them, hey, you know what, you were victorious, you won. And if you got over this, you can definitely get over anything.” (Daughter, Age 36)

Spiritual assistance was also commonly reported as caregivers used prayer and other faith expressions as support.

“But I think in the end it's what both kept us strong. Whenever I felt something about a situation I'd say that's how I felt. And then we'd pray and we'd have our laughs and our talks and he was very supportive.” (Survivor, Age 63)

Survivors and caregivers reported that support changed somewhat after treatment completion. While practical assistance with transportation, attendance at clinic appointments, and assistance with meals and other household chores were most commonly reported to occur during treatment, participants reported that these tasks decreased after

treatment. As described above, a unique support behavior emerged after treatment: helping survivors get back to normal.

“She doesn’t do the vacuum thing very well now either because she’s got lymphedema in her right arm, so some things she just can’t do because of the swelling in her arm. But I’ll let the flowers droop in the courtyard instead of hosing them down so she might. I let her drive more than I used to... I just to try to—number one—try to get her into the routine of doing things for herself.” (Friend, Age 59)

Differences in Survivors’ and Caregivers’ Experiences

Overall, there were few distinct differences between the role played by religiousness and spirituality for survivors versus caregivers. Both groups equally emphasized the influence their religious and spiritual beliefs and practices had on their BC experiences, including the extent to which they facilitated positive adjustment. Furthermore, both survivors and caregivers described a spiritual connectedness with God and others that provided guidance and helped them frame positive expectations about the future. Specifically among survivors, there was mention of the ability to identify with certain Biblical figures who, like them, turned to God for assistance during stressful life events. Unique to caregivers was the perspective that they were “called” to be a caregiver. Consequently, key support behaviors entailed reminding survivors about God’s healing and helping survivors cope by directing their focus on God’s ability to restore health. Additionally, many caregivers explicitly mentioned prayer as a way to lift survivors’ spirits. Finally, while it was more common for survivors and caregivers to consider the benefits experienced by survivors, caregivers also described being thankful for renewed awareness about their own health.

Discussion

Few studies concentrate on the experiences of African American BC survivors and their caregivers during and shortly after the transition from primary treatment to post-treatment. This study helps fill this gap in the literature as it examined the role of religiousness and spirituality in the end of treatment experiences of African American BC survivors and caregivers. The majority of the religiousness and spirituality themes we explored were derived from prior work [29,12] and focused on the role of spiritual and religious values and behaviors in coping with BC. In general, we found a good fit between the participants’ reports and the domains in Ferrell’s spiritual well-being model [29] as well as high concordance between themes reported by survivors and caregivers concerning the importance of religiousness and spirituality in BC.

Consistent with some prior research, we found the multidimensional constructs of religiousness and spirituality are critical aspects of quality-of-life in African American BC survivors [37,24,38,8,39]. We found religiousness and spirituality were deeply embedded within participants’ cancer and caregiving experiences in the post-treatment period, as has been the case in studies that focused on the diagnosis and treatment periods. Specifically, participants described religiousness and spirituality playing three major roles: 1) providing global guidance, 2) guiding illness management efforts and 3) facilitating recovery. They

described an all-encompassing spiritual connectedness (e.g., [40,38,41]) that provided guidance and support as they coped with BC and caregiving. Survivors' and caregivers' strong beliefs in God's healing (e.g., [42,43,24,32]) were evident and played a major role in how they faced BC and caregiving tasks because participants believed that God was in control. Participants' religious and spiritual beliefs and behaviors were not only used to cope with BC (e.g., to make sense of the illness and manage the physical and emotional aspects of BC [44,45,41,38,32]), but also helped shape their attitudes about the future. Overall, the results of this study converge with the small, but growing literature on African American BC survivors' spiritual well-being. However, in contrast to other research highlighting the experience of illness as a test of faith (e.g., [42,40]), our participants did not emphasize religious strain [46]. This could be because our participants truly did not struggle with spiritual challenges such as feeling punished by God [47] or it could be because we did not query directly about negative spiritual experiences.

The role of caregiving in cancer is well established, but most studies examining survivor-caregiver dyads focus on married couples [48–50]. In contrast, we asked survivors to nominate their primary caregivers and the most common type of caregiver selected was a friend, highlighting the importance of considering wider social networks in this area of study. In addition to diversity by relationship type (e.g., friend, coworker), the majority of caregivers had other family and work responsibilities, which emphasizes the multiple burdens often experienced by caregivers [51,52]. As described above, religiousness and spirituality played a major role in caregiving and provided guidance about specific support behaviors (e.g., prayer, reminders about God's function as a healer). Thus, caregiving tasks went beyond the common emotional, instrumental, and appraisal support [53] to include a special emphasis on spiritual support. While little research has examined spirituality in dyads, one study [54] examined coping in African American BC couples and found praying together was a key coping strategy, and another study found survivors' feelings of connectedness with others was closely linked to their spirituality [40]. As research suggests survivors place emphasis on interpersonal relationships, the inclusion of caregivers in survivorship research can yield important information pertinent to survivors' post-treatment quality-of-life experiences.

Another unique aspect of the current study was the focus on the end of treatment. Survivors and caregivers both reported that God helped them by allowing them to leave the stressors of cancer behind because they were healed. This belief system provided a clear conclusion to the cancer experience as many expressed certainty that survivors would recover and remain cancer-free. This finding is in line with the *deferring control* religious coping method defined by Pargament and colleagues [55]. Importantly, there are two facets of this coping method including *active religious surrender* ("an active giving up of control to God in coping" [56], p. 522) and *passive religious deferral* ("passive waiting for God to control the situation" [56], p. 522). Participants' reports in the current study were more consistent with the active than passive process as they described their faith and trust in God as purposeful and action-oriented. Implications of use of this deferring control strategy after completing treatment are unknown. One longitudinal study with recently diagnosed, primarily White, breast cancer patients examined relationships among "deferring control to God", breast

cancer concerns, and quality-of-life, finding that ultimately this coping strategy was associated with worse well-being over time [57]. More work is needed to explore these longitudinal processes in African American breast cancer survivors.

Despite the focus on the post-treatment period, our analyses did not reveal clear examples of the role of religiousness and spirituality in follow-up care. A study that examined barriers to follow-up care in African American BC survivors [58] found religious faith was an important motivator for adherence to follow-up care. In contrast, participants in this study emphasized being “done” with cancer, a finding in need of more study as this attitude could have positive or negative implications for follow-up care. Given the central role played by religious and spiritual beliefs in participants’ post-treatment experiences, it is critical to understand how survivors’ religiousness and spirituality impact attitudes about follow-up care, surveillance and lifestyle behaviors.

Despite our broad focus on well-being after treatment, participants reported remarkably few physical and emotional concerns. Given prior research on survivors’ needs (e.g., pain, distress, fear of recurrence) at the end of treatment [4,59,60], we anticipated a focus on the physical and psychological challenges associated with the aftermath of BC diagnosis and treatment. Instead of focusing on negative remarks about functioning, including symptom severity and/or interference, participants consistently reported a focus on acceptance of the past and a positive future outlook. It is unclear whether participants’ actual symptoms were modest because we did not directly assess symptoms in this study. Both survivors and caregivers described celebrating certain aspects of their cancer experience, in particular the completion of treatment, partly due to their religious and spiritual beliefs. Such a positive attitude is associated with cancer-related post-traumatic growth, which in turn, is associated with spiritual and religious resources in BC cancer survivors [44,61,62] and caregivers [63].

This study was limited by a convenience sample of African American BC survivors and caregivers living in the southern United States, and therefore the clinical and religious experiences and our findings are not generalizable to the broader population of survivor-caregiver BC dyads. Because we enrolled participants who completed treatment 6–24 months prior to enrollment, it is also possible that recall bias may have influenced discussions about quality-of-life. Another study limitation was the use of self-reported clinical data preventing our exploration of differences in recovery trajectories, symptoms or spiritual experiences by time since treatment completion. Also, as with any study that investigates the sensitive topic of spirituality, it is possible social desirability impacted participants’ self-reports in the interviews; however, the broad nature of the interview questions limits this possibility. Despite these limitations, this study adds to the survivorship literature due to its use of in-depth interviews with a diverse group of dyads and an empirically supported conceptual model to guide data analysis. Future research should examine longitudinal relationships among religiousness and spirituality, quality-of-life, symptom experiences, and coping behaviors. In addition, future research should examine whether healthcare providers are sensitive to survivors’ religiousness and spirituality and the influence of religiousness and spirituality on cancer survivorship attitudes and behaviors over time in survivors and caregivers. Consistent with professional standards that call for increased emphasis on spiritual concerns in patient-centered care [64,65], greater sensitivity

to religious and spiritual beliefs and practices and attention to survivors' spiritual needs are needed [66].

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Figure 1.
Religiousness and Spirituality in African American Breast Cancer Survivor-Caregiver
Dyads at the End of Treatment

Table 1

Interview Questions

Inquiry Area	Question
Treatment	<ul style="list-style-type: none"> Think back to when you were in treatment for your breast cancer. What were the biggest challenges you faced in getting through the treatment?
End of Treatment	<ul style="list-style-type: none"> Now think back to when you finished your treatment for breast cancer. What was your last day of treatment like? Did you have any specific worries or concerns? What were your expectations at this time? Did your doctor or nurse discuss your follow-up care with you?
Time Since Completing Treatment	<ul style="list-style-type: none"> Since completing your treatment, which doctors have provided you with follow-up care for breast cancer? From your last treatment up until now, how have things been? What have been the biggest challenges you've faced?
Support	<ul style="list-style-type: none"> For this study, we asked you to identify the one person who was your main support person over the course of your breast cancer. Can you describe your relationship with this person?

Note. Parallel questions were asked of caregivers (e.g., “*Think back to when your loved one was in treatment for breast cancer...*”). For all questions, general probes concerning physical and emotional well-being were used (“*What have been some of the challenges related to your health? What about emotionally?*”). When religion or spirituality topics were raised, the interviewer asked participants to describe how their faith affected their coping in more detail.

Table 2

Sociodemographic Characteristics in Survivors and Caregivers

Variable	Survivors (n=23)	Caregivers (n=22)
Age (years) *	57.4 (8.4)	50.1 (14.7)
Education (years) *	13.1 (3.4)	13.7 (3.2)
Race (% African American)	100.0	86.3
Gender (% Female)	100.0	86.4
Partner Status		
Married or Partnered	21.7	50.0
Separated	8.7	4.5
Divorced	17.4	9.1
Widowed	17.4	13.6
Single	30.4	22.7
Employment Status		
Full-time or Part-time	56.5	50.0
Retired	13.0	22.7
Unemployed or Disabled	30.4	27.2
Relationship to Survivor		
Spouse		13.0
Daughter		17.4
Sister		17.4
Other Family Member		17.4
Friend		30.4

Note. Unless otherwise noted, data are percentages.

* Data are mean (standard deviation)

Table 3

Religiousness and Spirituality *as Described by African American Breast Cancer Survivors and their Caregivers*

Theme	Definition	Survivors	Caregivers
Global Guidance			
Religious and Spiritual Beliefs and Activity*	Religious or spiritual beliefs and practices related to breast cancer and caregiving	Once you start praying you keep on going through. And that's what we focus on, we focus on prayer. Yeah you know, you read your word, you got your pastor, you got your good people and hey, you will be here with them. (Age 55)	So we kept looking to the Lord, when we would get a little down, we would pray, sometimes she didn't even know I was praying and I'm pretty sure sometimes I didn't know she was... And God, you know, he hears all of that. And he's there with his children so we leaned on each other and we both just trusted and leaned on the Lord. (Friend, Age 53)
Transcendence*			
Spiritual Transcendence	Feelings of connectedness – or lack thereof – to spiritual beings, nature, or the afterlife	Before He knew He was going to be crucified...He spent hours in the Garden of Gethsemane praying to God, asking '... If there is any other way that we can do this, let's do it.' But He couldn't. It was all in the plan for Him to die for our sins...And I thought about that...there is no other way for me to escape this except for me to confront it head on just like Christ. (Age 39)	He's gonna keep her on the path that He's got her on. And I also become afraid but those are the times where I say, 'God, I know you're there, I know you got this. I don't have to worry.' And I just back away...and I leave the worries on Him. (Friend, Age 59)
Interpersonal Transcendence	Feelings of connectedness – or lack thereof – to others	I had strong support from family, friends, church and my community. And so really...it wasn't hard for me. (Age 47)	And I said, 'Darlin, well if it was me, you would have been there for me. And I didn't do this for form or fashion. I did it because we is friends. And if you can't be with your friends in the good times and in the bad times, you not a friend... I carry my friends in my heart.' (Friend, Age 69)
Illness Management			
God as Healer	Feelings about God's role as healer directly or indirectly through treatment providers	You have to have faith in yourself and in God. The doctor plays a good part, but there has to be God to control him. And they looked like God had left all those good cells and took all the old ones from you. (Age 63)	Oh, I was thrilled. I was thrilled, I mean you know, to me, it was another case of God's total and complete healing. (Friend, Age 66)
Inner Strength*			
Coping	The role of religious or spiritual beliefs or practices as a means of coping with breast cancer and/or caregiving	Be strong and have faith in God and trust in Him with all your heart, soul and mind and know that God is God all by Himself. And He will pull you through. (Age 38)	You know, my faith told me it's gonna be alright. You know, the faith thing kicked in. You know, if God had brought her this far, I know he gonna finish His job. (Friend, Age 66)
Illness Meaning*	The role of one's religious or spiritual beliefs or practices as a means of making sense of breast cancer and/or caregiving	I wouldn't have been able to get through this without God. This was His plan and it was His plan for me to get through this. (Age 59)	When somebody goes through something, [she] was hand-picked...There was a reason why you had to endure it...This is not just for yourself, but for others. (Daughter, Age 36)
Recovery			
Outlook	General perspective about the future – negative or positive – related to implications	Future...I'm looking forward to living a long life; I don't have no worry that it might come back or not or something like that. (Age 61)	Just think positive and you'll be fine. Everything is going to be fine. Constantly tell yourself that and it

Theme	Definition	Survivors	Caregivers
Global Guidance			
	of breast cancer and/or caregiving		works out.... I knew she was going to beat it. (Husband, Age 49)
Benefit Finding	Feelings about breast cancer or caregiving as a catalyst for positive life changes	I was privileged to become a volunteer. I was able to give back just a little bit of what was given to me. (Age 58)	I think I'm more aware and cautious for myself now. You know, I'm always telling the doctors "check me, please check me" and I'm checking myself. (Sister, Age 40)
Return to Normal	Description of expectations or experiences about a return to the way things were before breast cancer	I felt different. I felt free that I didn't have to look forward to...everyday five times a week of radiation. I just felt relief, I just felt normal. (Age 53)	I expect my momma to be back to the old her. (Daughter, Age 29)

* codes adapted from Ferrell and colleagues [12, 13, 29]