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Perceptions of Support Among Older African American Cancer Survivors

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Abstract

Purpose/Objectives—To explore the perceived social support needs among older adult African American cancer survivors.

Research Approach—Qualitative design using grounded theory techniques.

Setting—Outpatient oncology clinics in the southeastern United States.

Participants—Focus groups with 22 older adult African American cancer survivors.

Methodologic Approach—Purposeful sampling technique was used to identify focus group participants. In-depth interviews were conducted and participants were interviewed until informational redundancy was achieved.

Main Research Variables—Social support needs of older adult African American patients with cancer.

Findings—Social support was influenced by (a) symptoms and treatment side effects, (b) perceptions of stigma and fears expressed by family and friends, (c) cultural beliefs about cancer, and (d) desires to lessen any burden or disruption to the lives of family and friends. Survivors navigated within and outside of their networks to get their social support needs met. In some instances, survivors socially withdrew from traditional sources of support for fear of being ostracized. Survivors also described feeling hurt, alone, and socially isolated when completely abandoned by friends.

Conclusions—The support from family, friends, and fellow church members is important to positive outcomes among older African American cancer survivors. However, misconceptions, fears, and negative cultural beliefs persist within the African American community and negatively influence the social support available to this population.

Interpretations—Early identification of the factors that influence social support can facilitate strategies to improve outcomes and decrease health disparities among this population.

Patients diagnosed with cancer are living longer. An estimated 11 million cancer survivors are alive in the United States today, and the five-year survival rate for some cancers is as high as 90% (American Cancer Society [ACS], 2010). Cancer survival rates for African Americans also are improving. Since the 1960s, the overall five-year survival rate for African Americans has more than doubled, from 27% to 58% (ACS, 2010). Although these figures show that survival disparities are diminishing, African Americans continue to suffer disproportionately from cancer as they continue to have more advanced disease (ACS, 2010), less access to timely treatments and quality care (Shavers & Brown, 2002), and more comorbidities (Bryant & Cerfolio, 2008). This cancer burden is compounded by a social environment in which social stigma and fatalistic attitudes toward cancer are prevalent (Phillips, Cohen, & Moses, 1999; Powe & Finnie, 2003) and in which healthcare institutions discriminate against the poor and minorities (Burgess, Ding, Hargreaves, van Ryn, & Phelan, 2008; Hausmann, Jeong, Bost, & Ibrahim, 2008). When a diagnosis of cancer is confirmed, African Americans experience a myriad of supportive and unsupportive responses from family and friends (Grange, Matsuyama, Ingram, Lyckholm, & Smith, 2008). These responses are critical because they may affect whether survivors are adherent to recommended treatment and affect their overall quality of life during the cancer experience. However, researchers have not fully explored older African American cancer survivors' perceptions of their social support and the implications of these needs on their survivorship experiences.

The purpose of this study was to explore the social support needs from the perspective of older African Americans diagnosed with and treated for cancer. African Americans' involvement in mutual aid systems of giving and receiving support makes them an exemplar population for studying supportive relationships (Hamilton & Sandelowski, 2003). Their unique experiences in collectively pooling resources to meet their needs, coupled with their experiences of having the highest overall incidence and lowest survival rates of any racial or ethnic group (ACS, 2010) provide the opportunity to analyze the complexity of supportive social relationships among this population.

The social resources available to African American cancer survivors usually come from an extended network of family and friends and from their religious involvement within their church. Within their social networks, African American cancer survivors give and receive emotional, instrumental, and informational support (Hamilton & Sandelowski, 2004; Morgan et al., 2005). They receive emotional support from knowing that others are "there for them" emotionally and physically (Hamilton & Sandelowski, 2004). Instrumental support assists African American survivors with finances, transportation, and maintenance of social roles in their homes, churches, and communities. Instrumental support also includes assistance to continue religious practices. Informational support assists African American cancer survivors in understanding and validating the information they receive from others about their cancer illness. Finally, social networks provide a way for these cancer survivors to give back through sharing what they have learned about cancer with others (Hamilton, 2001).

The church is a second major source of support for African American cancer survivors. Reaching out to those in the community who are sick has long been a central mission of the church (Lincoln & Mamiya, 1995). In response to the disproportionate rates of cancer among African Americans, many churches have organized cancer support groups (Husaini et al., 2008) and provide formal support services such as assistance with personal care services and housekeeping and transportation to church, stores, and physician appointments (Walls & Zarit, 1991).

African Americans actively involved in a church have higher numbers of physician visits, and this finding may be related to the validation that the church family provides (Manns, 1988).

Clearly, the church community continues to function as a central institution to provide formal social support services to the “sick and shut in” members.

Although research with African American cancer survivors has emphasized types of support that enhance survivorship experiences, situations clearly exist in which support is diminished or lacking. Qualitative studies suggest that African American cancer survivors fear being stigmatized and socially isolated in their families and communities (Grange et al., 2008). In addition, African American cancer survivors may be reluctant to communicate their needs for support in some situations (Jones et al., 2008). However, studies have not fully described ways in which the cancer experience affects social relationships and the support traditionally available from these relationships.

In this article, the authors present findings on the factors that influenced African American cancer survivors’ needs for social support and how the survivors navigated within and outside of their networks to find ways in which their social support needs would be met.

Methods

Participants

Twenty-two African American adult cancer survivors were recruited to participate in the study. The participants in this study were recruited from a list of participants who had completed the first author’s National Institutes of Health-funded study. Participants were recruited through outpatient oncology clinics in a large metropolitan area in the southeastern United States. Eligibility requirements included diagnosis of any type of cancer; being seen in outpatient oncology clinics for initial diagnosis, treatment, or follow-up care; and aged 55–89 years. Participants were selected to represent a range of demographic variables that have been previously found to be related to choice of coping strategies. These variables were gender—women give more support than they receive (Chatters, Taylor, & Jayakody, 1994), education—those with higher levels of education are more involved in their communities and obtain more support (Matthews, Stansfeld, & Power, 1999), marital status—single African Americans receive more support than those that are married (Brown & Gary, 1987; Jayakody, Chatters, & Taylor, 1993), geographic location—urban versus rural (Chatters et al., 1994), and proximity to family—living alone or with someone. Living in close proximity to family or loved ones is related to positive coping strategies and support (Chatters et al., 1994).

Procedure

For the current study, participants were asked if they would be interested in sharing additional information about their survivorship experience to aid in the development of a support-enhancing intervention for other African American cancer survivors. Approval for the study was obtained from the institutional review board of Emory University. Prior to the interviews, written informed consent was obtained. To enhance comfort in discussing their needs freely, participants were encouraged to select the most convenient and comfortable time and place for the interview. Interviews were conducted in private one-on-one sessions or in small groups of two, four, or five survivors, and groups were separated according to gender. At the participants’ request or because of scheduling difficulties, six participants were interviewed in one-on-one sessions. The first author led the interview sessions that lasted from 30 minutes to two hours.

Initial interviews were unstructured and began with a general question that asked: “Tell me how cancer has affected your life?” Other general questions were: “Did relationships with family and friends change?” and “What kind of support did you receive with issues related to your spirituality?” Questions were designed to promote open discussions of social support needs affected by the cancer experience from the survivors’ perspectives and reflected the

interviewer's prior sensitization to concepts in health-related and historical literature on social support and social networks. As the interviews progressed, questions became more directed and pursued analytic lines that emerged in previous interviews. Probing questions were asked throughout the interviews to encourage participants to talk about events important to their cancer experiences. All participants were interviewed once, and the interviews were audiotaped and transcribed verbatim.

Data Analytic Strategies

To assess the questions in this study, grounded theory techniques of theoretical sampling and constant comparison were used for the purpose of typology development (Strauss, 1999). Theoretical sampling consisted of sampling interview data for different manifestations of those factors that influenced participants' social support needs. The authors further examined the data for differences in gender, marital status, education level, and proximity to family. Participants were interviewed until information redundancy and theoretical saturation of emerging themes was achieved (Strauss, 1999). Constant comparison analysis techniques were used to identify those themes related to the social support needs of these African American cancer survivors and their social interactions with family, friends, and fellow church members (Strauss, 1999).

Findings

The participants included 22 African American cancer survivors with an average age of 62 years. The majority were educated at the high school level or higher and were not married. Participants were diagnosed mainly with breast cancer or lung cancer (see Table 1).

Major findings of this study identified four key factors that influenced the social support for these survivors, including cancer symptoms and treatment side effects; perceptions of stigma and fears expressed among family, friends, and church members; cultural beliefs about cancer; and survivors not wanting to be a burden to or disrupt the lives of family and friends. Participants discussed how these factors influenced their social relationships and how existing networks responded to their needs for social support. Participants also discussed how they navigated outside their usual networks when necessary and how they were affected emotionally when expectations for support were diminished or absent.

Effects of Cancer Symptoms and Treatment Side Effects

Symptoms and side effects of cancer and treatments influenced the participants' ability to access social support needed from their social networks. Irritability, memory problems, fatigue, depressed moods, and changes in appearance were discussed among men and women in this study as factors that limited their ability to effectively communicate their needs for support or to engage in social activities. A 76-year-old patient with colon cancer recalled how the pills he was taking made him irritable, affecting his willingness to talk to his wife about his needs for support.

I was doing pretty good but, at times, you know, she would say things to me and I would get angry and say things and you know I was out of the way to her ... it's some of the pills I take. I get that they just make me cranky. I don't want her to say nothing to me.

When asked what a nurse could do to help with his situation, he replied,

Well, the same thing you doing now is interview me and talk about it, and then you give me courage to explain myself because a lot of the time I don't explain; I don't talk to her a lot of the time.

Among the women cancer survivors, memory problems were cited as a contributing factor that was a barrier to their maintaining social roles and to engaging in social activities. A 65-year-old widowed high school graduate explained how memory problems kept her from making a cake for her grandson, a tradition at Thanksgiving dinner.

For Thanksgiving, I had to have a big [coconut cake for the children]. . . . The children say, "Well momma, can you make a coconut cake? Granny, make a coconut cake." I said, "I don't know. I done forgot how to make you a coconut cake."

Fatigue was frequently mentioned as a factor that influenced the social support needs of these survivors. Participants needed social support during postsurgical care, activities of daily living, shopping, and banking, and this support often was needed for extended periods of time after treatment.

The following example illustrates how multiple family members helped to support a 67-year-old college-educated breast cancer survivor during her chemotherapy treatments.

With the chemo[therapy], I was just drained. And I had to have a lot of help with getting my medication, getting food; you know . . . they didn't have to bathe me or anything. But anything that required a lot of energy, I had to have help. And most of my family members, they come over and take me, or bring my food over, or do my laundry, stuff like that. I was just dead on my feet. . . . And this went on for just about a year.

A 69-year-old breast cancer survivor talked about her fatigue and her inability to go on shopping trips with her family and friends.

I just can't really go nowhere with anybody because I be getting tired and they be, you know, they, we walking and doing shopping and I can't go like all of them . . . I say, "Ya'll just go."

Depression also was discussed as an experience that resulted in support needs. This same participant described how depression influenced her emotionally and how she believed no medical help existed for her symptoms.

But it could be some days, I just feel like I'm on top of the world. The next day it felt like, Lord, you wish the world would just swallow you up. It's not something that you could go to the doctor for. You know, and sometime a lot of our, I think, feelings and things can be brought on by anxiety.

A 56-year-old breast cancer survivor with a high school diploma and who was separated from her husband talked about being in "low spirits" and how everyone in her family supported her.

I think that I got just about all of the help that I needed. Because they were down there to bring me through it, bring my spirit up. So I think that if my husband had not been involved and the doctors there, just everything, I don't think I would have made it. I was in a very, very low spirit.

A 59-year-old, separated, high school graduate diagnosed with stage III lung cancer, and unemployed because of his health, talked about his support and feeling isolated and lonely. He lived alone and was caretaker of his mother. Friends he used to socialize with had stopped coming around, and his shortness of breath prevented him from going to church or singing in the church choir. He talked about the effect cancer had on his life and his social relationships.

Having cancer has caused me to change my life dramatically. A lot of things that I wish to participate in such as having a second job . . . and I tried to participate in the choir . . . trying to participate in church activities . . . anything that I had to do physically, I was not able to do. When I'm able to go somewhere in a different

environment, different neighborhood, around different people, and pass the time two to three hours, I feel great ... I sleep better. In so many ways, it's like I'm having to learn to live a different way than I use to live. Like, I never entertain a lot of company. But it seems to me now that, since I have been diagnosed with cancer, it seems like I'm isolated. That I'm basically, I'm just fighting this thing all alone.

Cancer survivors fear that changes in their appearance will affect how family, friends, and church members respond to them. As a result, survivors may withhold illness-related information and direct their energies toward making sure others see them as healthy. Appearance among fellow church members was particularly emphasized among a group of women survivors who were active members of a patient navigator group. A 72-year-old, college-educated, 10-year breast cancer survivor and patient navigator explained the importance of appearing healthy in public.

I had a fear of identity. Instead of saying, "That's M," they would say, "That M, you know she got cancer." And you know that my church people, you know, you said you don't wanna tell your church people. I didn't uh, really tell them [either]. Whenever I go to church or anywhere, I always try to do the best I can to put on my little makeup, put my little hair on, then when I go to church, nobody knows that I have [cancer]. Because some of them will be afraid. They'll ostracize you. They will stay away from you.

Perceptions of Stigma and Fears Expressed Among Family, Friends, and Church Members

Perceptions of stigma and fears about cancer were frequently discussed as factors influencing the support available from survivors' social relationships. Perceptions of stigma varied according to gender and education level. Although these cancer survivors were supported by their families, friends, and church members, when support was not forthcoming, participants believed it was the result of negative beliefs and fears. Quotes in this section illustrate these cancer survivors' perceptions of how expressions of misconceptions and fears from persons within their social networks adversely affected their social support needs. Some survivors directly experienced negative comments or behaviors, whereas other survivors believed that negative expressions would become a reality once their cancer diagnosis became public information. A 61-year-old, married, two-year college graduate diagnosed with lung cancer explained her relationship with her family and friends. She believed her husband's fears kept him from supporting her.

Now I would like for my husband to have been more supportive. But then I think he was scared. And he wouldn't support me. I couldn't ... I still can't talk to him about my cancer.

A 55-year-old widowed, two-year college graduate, and breast cancer survivor recalled how her family was afraid and not able to provide support. Although she had support from friends, she still talked about her experience of being alone during chemotherapy treatments.

I had extremely good support from my friends. My daughter was afraid, she never seen me in uh, a position other than the strong role. I knew she was afraid. And every third Wednesday I would take chemotherapy. ... I drove myself for 36 days to the clinic [in another town].

Subthemes existed within this major category that highlighted the differing levels of social support needs as well as the fact that the survivors may reach out to different people within their networks for different types of support.

Perceptions of abandonment by friends—Survivors described feeling particularly hurt when friends stopped calls and visits. In some instances, survivors were completely abandoned

by long-time friends. The survivors in this study attributed lost friendships to stigmas that persist about cancer.

One woman still in treatment for lung cancer spoke of how she felt stigmatized and socially isolated when friends stopped coming around.

Yeah, but for some reason there is a stigma and everything when people find out you have [cancer]. And, that's how you can tell people that are your friends, because some people don't come around you anymore. You know like maybe it's gonna rub off ... or something. I think they're scared.

A 61-year-old lung cancer survivor with a two-year college degree spoke of her experience being abandoned by a long-time friend. For this survivor, her mother was there to provide some support; however, she went through treatments alone.

I have been a survivor and I face what you do with a girlfriend I have been friends with since I was 13. I felt like ... she acted like I had leprosy or something. When I was diagnosed, I went through by myself. I went to my doctor's appointments; I went there, everything [by myself]. I'm talking about everything. Once I got the diagnosis, my mom came down. If it wasn't for my mother, I think I would have had a really, really, hard time.

Many of these survivors were employed at the time of their diagnosis. After being diagnosed with cancer, survivors talked about losing their jobs and contact with coworkers who were at one time also friends. A nine-year breast cancer survivor, two-year college graduate, and employed administrator described her isolation from friends as emotionally painful.

Some of the people at work, where I was working, some of the ladies, they didn't talk to me any more. They didn't speak any more. They didn't call. They didn't do any of these things. And I kind of said, well, wonder why, you know ... and it hurt.

Perceptions of lack of support from fellow church members—Participants' feelings of abandonment were compounded by fears of having church members discover their diagnosis and treat them with pity. For many of these survivors, coworkers and church members were integral to their support networks. Survivors spoke of how church members and ministers came to pray with them and for them. However, in some instances, the support from one's church family was noticeably absent. In a private interview, a nine-year breast cancer survivor, married, with a partial high school education, and still in treatment, talked about the limited support she received from her church family.

Since I had cancer, I haven't had very much support from my church. ... My church, my pastor, you know, she called every now and then. But I haven't heard from anybody else in my church.

A 56-year-old, college-educated, divorced lung cancer survivor described her fears of how her church family might treat her differently and how she turned to other friends.

As far as my church, had I let them know, they would have been there. But I'm like M, I didn't want everybody looking at me saying, "Oh no, you know they say she's not doing good. You know, she ain't gonna be here but a minute." So, my cousin filled in and then my slow dancers [a group of friends] filled in.

Survivors also spoke of the spiritual support they received outside of their churches to help uplift their spirits. God was described as a source of support, particularly when alone at night. A 59-year-old breast cancer survivor, with a 10th-grade education and still in treatment, talked to God at night.

Sometime at night it would kinda come down on me ... and I, I talk to God. Sometime I talk, turn into a preacher, you know. But after I get through, I'm all right with it, you know. I'm all right with it because I got it off me.

Men and women in focus groups spoke of having prayer warriors or prayer buddies for help with spiritual support. These prayer warriors were family members or friends and assisted with spiritual support through prayers, devotional Bible readings, and interpreting Bible verses. The woman who previously spoke of talking to God for support also received spiritual support of prayers and reading scriptures from the Bible from her sister.

My sister. She's a minister. And she would pray with me every day. She had something for me every day. She even brought me books, scriptures to read in the Bible. ... So that just carried me on. Let me know that I was going to be all right ... I could, you know, make it. So, she prays with me now every day. That's my prayer warrior.

Effects of Cultural Beliefs About Cancer

Many of these survivors reported that, in their culture, cancer has always been perceived as the big "C," and death followed for anyone who was the recipient of this diagnosis. Cancer was the one illness that previous generations did not talk about openly; it was kept secret. These cancer survivors wanted others in their communities to be more educated and to know that cancer is not a death sentence. One survivor remembered many relatives who had died from cancer and how the memories of these deaths created fear. There also were memories of cancer as a disease referred to as "an old sore." Women participating in a focus group talked about these beliefs and their inability to talk openly about their cancer diagnosis to others. A 72-year-old breast cancer survivor and patient navigator remembered that cancer was not talked about openly in her family when she was growing up. As a nine-year cancer survivor, she now receives her primary support through her affiliation with cancer survivors and patient navigators.

And I had about 35 healthcare providers—my support group. That's what I had. And, um, I had not reached a point where you discuss cancer. My generation, that's secretive. We were taught and it's embedded in us to not discuss your cancer with anybody. That's private. So that's what I did. So it's still hard for my generation to talk about it. And I only talk about it with someone who's gone through it.

A 61-year-old lung cancer survivor, patient navigator, and focus group participant also remembered how patients with cancer were kept out of sight in her community.

And, years ago, I can remember my great, my great-grandmother and grandpop; they would take a room on the house. The back room, scrub it, clean it out, burn sulfur in there and put that sick person in there. And they would call it an old sore. ... And they would clean it. Paint that room. ... And that floor would be like all white ... but you know what, my mother, father, grandfather, and several of my siblings have passed. And for the longest time, I was in such fear. I didn't wanna talk to nobody, because I was afraid of what they'd say.

She continued to explain how this experience influenced her reluctance to talk openly about her cancer diagnosis. However, she found new friends and support through membership in a cancer survivors' choir.

That's why I'm extremely proud to be a part of our Cancer Survivors Mass Choir. I can speak freely. Because each of us has, each of us have gone through it. So we know exactly what it is. But to talk to total strangers, well they'll back off.

Survivors' experiences with family and friends show that stigmatizing, negative attitudes toward cancer persist. Misconceptions expressed among families and friends of these survivors

included those that cancer will spread if treated surgically and that cancer is contagious. A nine-year breast cancer survivor with a college degree talked about a friend who believed that cancer was contagious.

Well, I, I have a friend that actually thought that cancer is kinship to AIDS and that it's contagious. That she would catch it from me, you know, or it was contagious so it could be transmitted.

Survivors talked about the need for cancer information so that family members, friends, and fellow church members would understand that cancer is not a death sentence. If the community were better educated, they believed, people would not be afraid. She continued to share her opinion on how to alleviate the stigma attached to a cancer diagnosis.

And then, if, the more your family knows, you know, the more educated they are about what you're going through, I think the better they're able to help us. 'Cause [if they are educated] they can understand, you know, without being afraid and second-guessing. I wish my family and church members, my pastor, and everybody were more educated. If they knew more, they would have known better how to pray for me and help me. Sometimes your pastor is a good ... he would be good because he would help to educate some of the other people from the pulpit.

Survivors talked about the need to educate family and friends about cancer at the individual level. A 68-year-old breast cancer survivor, with an 11th-grade education, counseled other survivors about their broken relationships.

It's not that they don't love us; it's just that they are scared. We have to reach out to them. Because when I first told a friend of mine, she started crying. And I said, "Well, why are you crying?" "Well, I don't want you to die." I said, "Well, who says I'm dying? Just because I have cancer, it doesn't mean that I'm dying." And see, I said, with what I have to do now is map out what I'm going to do. And I said, "I'm gonna be fine. All I need is your support through my treatments."

Survivors Not Wanting to Be a Burden or Disrupt Lives of Family and Friends

Survivors hide their illness or details of treatments to protect those close to them. They did not want to be a burden or the direct cause of family members losing their jobs. A 56-year-old, college-educated survivor of lung cancer, still in active treatment, told of a conversation she had with her son.

My son would take off and come with me as well to all my treatments and then finally ... he's an independent contractor ... and I finally had to tell him, you can't keep coming with me. You won't have any work.

Another patient, also a mother, shared her experience of hiding illness-related information from her son with whom she also had a close relationship.

I was in the hospital and people didn't even know I was there. Like my son, he was getting ready to go to Mexico. I'll never forget it. And I got sick the day before he was supposed to go. And uh, while I was in the emergency room, I asked the doctor ... "Am I goin' die over the weekend?" And so he said, "No." I said, "You sure?" I said, "'Cause if I'm not goin' over the weekend, then I'm a let my son go take his trip to Mexico."

Discussion

Data for this study comes from interviews with outpatients in oncology clinics and included men and women at various points along the cancer trajectory. Participants represented a range

of education levels and marital status. Income levels for the majority of participants were generally low but consistent with that of the median income of older Americans (U.S. Department of Health and Human Services, 2008) and may be attributed to their employment status of being retired or unemployed for health reasons. Data analyses revealed factors that influenced social support needs within a network of family, friends, and church members. Methodologic limitations of this study include a small sample size and limited ability to probe for details related to participant experiences in the focus groups.

Despite these limitations, the findings helped the authors glean a better understanding of the factors that influence social support needs among older African American cancer survivors. Consistent with other research, the findings show that symptoms and treatment are determinants of social support for the cancer survivor. In comparison to Caucasians, African Americans with cancer have more advanced-stage tumors (Gregg, 2009) and experience higher levels of symptoms such as fatigue and depression with cancer (Eversley et al., 2005). Therefore, the cancer experience for African Americans is more of a burden for families of these survivors, particularly when incomes are low and when treatments continue over extended periods of time (Siefert, Williams, Dowd, Chappel-Aiken, & McCorkle, 2008). In addition, increased symptoms and a deteriorating health status, consistent with advanced-stage cancers, are more likely to lead to decreased independence and social isolation, particularly when resources are limited (Fitzsimons et al., 2007; Gilbert & Smith, 2009). Finally, the affect of cancer symptoms and treatment side effects on body image is a concern to cancer survivors (Hagedoorn & Molleman, 2006; Wilmoth & Sanders, 2001). Research suggests that African American patients with cancer refuse certain surgical treatments that are likely to result in visible scars (Esnaola et al., 2008; Neighbors et al., 2007). However, the cancer survivors in this study limited their participation in their churches, which has historically been recognized as one of the most important sources of social support within the African American community. Interestingly, although the survivors limited their church attendance, they still sought out spiritual support from family and friends, identified as prayer buddies or prayer warriors, suggesting that spiritual support outside of religious institutions was an important coping mechanism in their fight with cancer.

Optimally, support from family, friends, and church members contribute to healthy outcomes for African American cancer survivors. However, some cancer survivors experience fatalistic and stigmatizing attitudes in their communities (Powe, Daniels, & Finnie, 2005). Although few studies have focused on the adverse outcomes from these stigmatizing interactions with African American patients with cancer, studies with African American patients with HIV confirm that these attitudes create barriers to accessing medical treatments and to adhering to medications (Edwards, 2006; Konkle-Parker, Erlen, & Dubbert, 2008). Stigmatizing attitudes also affect the receipt of support from one's social network. African Americans' who fear being stigmatized isolate themselves and refuse to disclose information about their illness to others, and that further limits the support available to them (Galvan, Davis, Banks, & Bing, 2008). In some instances, when survivors felt stigmatized and not supported, they were able to navigate within their networks to get needed support either from other family members or friends. When support was lacking, survivors also turned to the support available through affiliations with patient navigator programs and a cancer survivor choir.

Cultural beliefs, attitudes, and knowledge about cancer are known obstacles to cancer screening with the African American community (Simon, 2006). Well-known and negative cultural beliefs are that "cancer treated is worse than if untreated" and that "cancer is a death sentence" (Simon, 2006). Another perspective is that cancer is a punishment from God, possibly for some sinful behavior (Mishra, Aoelua, & Hubbell, 2000). Cancer survivors in this study not only recalled experiences with cancer being referred to as the big C and a death sentence, but they also recalled growing up in a time in which patients with cancer were "put

away” and not talked about. Therefore, cancer survivors familiar with these cultural beliefs and attitudes are less able to talk openly about cancer to family and friends for fear of being ostracized.

When survivors fear they may burden or disrupt the lives of family members, they are, therefore, reluctant to disclose their cancer diagnosis or even include family in aspects of their cancer care. Although there may have been an underlying need to maintain control and independence, another plausible explanation relates to the economic and financial resources of their social networks (Tsigaropoulos et al., 2009). For example, these survivors were likely aware that extended absences from work would result in a loss of employment for their family members. African American family caregivers also are more likely than other groups to have multiple roles (Manns, 1988). As a result, being strong and going it alone to cancer treatments is out of necessity. This fact coupled with the fear of cancer held by some family and friends of the survivors may further explain the survivor’s reluctance to share the information about the cancer diagnosis.

Lastly, although not addressed within the context of this study, issues such as lack of cancer knowledge, access to care issues, lack of insurance, and lack of provider recommendations for cancer care are historically known to influence cancer care for African Americans. Although beyond the scope of this discussion, the historical realities of poor or substandard care for this population likely resulted in many of the themes that now emerge within this data and, thus, contribute to the disparities in care that remain for African Americans. This study is unique because it is one of a few that begins to identify the social support needs of African American cancer survivors. Ideally, interventions should address these types of needs while also working with providers to educate and improve access to cancer care needs to decrease stigma, enhance screening, and encourage state-of-the-art care.

Implications for Nursing

The support from family, friends, and fellow church members is important to achieving positive health outcomes for older African American cancer survivors. However, during times that are extremely stressful and when support is needed most, factors discussed in this report may limit the support available through traditional sources. Nurses have the unique ability to intervene with patients at various points of the cancer trajectory to enhance the support available to this population. During treatment, for example, nurses can assess the effect of symptoms and side effects of treatment on family relationships. Nurses also should understand that older cancer survivors may be particularly reluctant to discuss issues related to their cancer with strangers and need support in one-on-one sessions. Work and family responsibilities may prevent family members and friends from accompanying the survivor to treatments, particularly when administered over extended periods of time. However, older African American cancer survivors may be reluctant to ask for the support of strangers (Hamilton, 2001) and need support from a hospital- or community-based support group without having to ask for it.

After treatment, there may be an expectation that when survivors are cured, they should be able to resume prior roles and responsibilities. However, the authors’ findings suggest that survivors experience treatment side effects long after the treatments have ended. As such, clinicians may need to reach out to family members and help them understand that the recovery process does not end with the eradication of the cancer (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2009).

Finally, researchers can use the findings from this study to design interventions that strengthen existing networks of the cancer survivor. Alternative sources of support are used among African American cancer survivors; however, whether these sources positively affect health outcomes remains to be determined.

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Table 1

Sample Characteristics

Characteristic	n	%
Gender		
Female	15	68
Male	7	32
Age (years)		
50–59	9	41
60–69	10	46
70–80	3	14
Marital status		
Widowed	7	32
Separated	5	23
Divorced	4	18
Married	4	18
Never married	1	5
Partnered	1	5
Education		
Junior high school (grades 7–9)	2	9
Partial high school (grades 10–11)	5	23
High school diploma or GED	4	18
Two-year college	7	32
College	3	14
Graduate school	1	5
Job		
Skilled	6	27
Administrative	4	18
Unskilled	3	14
Sales, technical, clerical	2	9
Machine operator	1	5
Management	1	5
Other	5	23
Income (\$)		
2,500–9,999	9	41
10,000–14,999	5	23
15,000–19,999	1	5
20,000–24,999	1	5
25,000–29,999	2	9
30,000–34,999	–	–
35,000–39,999	1	5
40,000–44,999	1	5
45,000–99,999	1	5
100,000 or more	1	5

Characteristic	n	%
Type of cancer		
Breast	9	41
Lung	4	18
Colon	2	9
Prostate	2	9
Bladder	1	5
Head or neck	1	5
Pancreatic	1	5
Squamous cell carcinoma	1	5
Other	1	5
Time since diagnosis (years)		
Less than 1	9	41
1–2	4	18
3–4	3	14
More than 4	6	27
Religion		
Baptist	12	55
Methodist	3	14
American Methodist Episcopal Zion	1	5
Holiness	1	5
Nondenominational	1	5
Other	4	18

N = 22

Note. Because of rounding, not all percentages total 100.