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Psychosocial Concerns of Young African American Breast Cancer Survivors

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Abstract

Thirty-three African American breast cancer survivors age 45 or younger participated in semi-structured phone interviews about psychosocial concerns. Twenty-six percent believed treatment interfered with employment. One third wanted additional emotional support at and after diagnosis. Half felt cancer negatively influenced romantic relationships. Forty-five percent wanted children at diagnosis, but half these women never received fertility information. One third reported sexual problems, but 73% never discussed sexuality with providers. Fifty-two percent lacked information about cancer-related sexual dysfunction. The strength and spirituality of African American women may facilitate cancer adjustment, but cultural taboos surrounding women's health issues may interfere with successful coping.

Keywords

oncology; sexuality; fertility; breast cancer; premenopausal; African American

INTRODUCTION

Premenopausal women make up 25% of breast cancer cases (Bloom, Stewart, Chang, & Banks, 2004). Although women who remain free of disease report good physical health several years after diagnosis (Baucom, Porter, Kirby, & Keefe, 2005–2006; Bloom et al., 2004), they are more vulnerable than older survivors to emotional distress (Baucom et al., 2005), regrets about their choice of treatments (Fernandes-Taylor & Bloom, 2010), sexual dysfunction (Bloom et al., 2004; Burwell, Case, Kaelin, & Avis, 2006; Fobair et al., 2006; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Schover, 2008), hot flashes (Bloom et al.,

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2004; Bordeleau, Pritchard, Goodwin, & Loprinzi, 2007), and distress about infertility (Canada & Schover, 2010; Peate, Meiser, Hickey, & Friedlander, 2009).

African American women may have particularly high rates of reproductive health problems after breast cancer. African American women under age 45 have an elevated risk of breast cancer compared to Caucasian women, especially African American women under age 30, who have breast cancer rates 52% higher than whites (Dunn, Agurs-Collins, Browne, Lubet, & Johnson, 2010). Mortality is also disproportionately high in African American women because of a complex interaction of biological factors and disparities in health care (Dunn et al., 2010). Tumors in young African American women are unusually aggressive in subtype, including tumors negative for estrogen or progesterone receptors; triple negative tumors that also lack receptors for human epidermal growth factor 2; and poorly differentiated basal cell tumors common in women with inherited mutations in the BRCA1 gene (Amirikia, Mills, Bush, & Newman, 2011; Dunn et al., 2010; Ray & Polite, 2010). Most African Americans brought to the United States as slaves came from West Africa where women today also have high rates of aggressive breast cancer diagnosed at unusually young ages (Fackenthal et al., 2011; Ray & Polite, 2010). Recently, BRCA1 mutations that increase cancer risk were identified in 25% of a cohort of Nigerian women with a family history of breast cancer and a diagnosis under age 50 (Fackenthal et al., 2011). Studies with newer gene sequencing technology in African Americans may yield similar results.

Lifestyle factors also may contribute to the risk of aggressive, premenopausal breast cancer in African Americans, including earlier age at menarche and first birth, having more children, and lower rates of breastfeeding (Dunn et al., 2010; Ray & Polite, 2010). Disparities in the care of African American women with breast cancer include delayed diagnosis, fewer referrals for adjuvant chemotherapy, and receiving suboptimal chemotherapy dosages (Summers, Saltzstein, Blair, Tsukamoto & Sadler, 2008; Ray & Polite, 2010). Distrust of the medical system also remains a barrier to optimal health care (Masi & Gehlert, 2008).

We partnered with the national advocacy organization, Sisters Network® Inc. to create a peer counseling program, SPIRIT (Sisters Peer Counseling In Reproductive Issues after Treatment) to improve knowledge and reduce symptoms related to sexual dysfunction, menopause, and distress about infertility in African American breast cancer survivors (Schover et al., 2006). Promising pilot results led to a national study in which 296 women were randomized to receive the full 3-session peer counseling program or a phone counseling version, combining the written workbook with the option to call their peer counselor for up to 30 minutes (Schover et al., 2011). Women in both groups improved their knowledge about reproductive health, decreased in distress, and had decreased hot flashes. Sexually active women had improved sexual function at 6-month follow-up, but not at one year. The full peer counseling program had only very minor advantages over the phone counseling condition, however.

After completing 1-year follow-up assessments, all women under age 45 were invited to participate in a semi-structured telephone interview focusing in detail on their psychosocial concerns. This report summarizes findings from the interviews.

METHOD

This study was approved by the UT MD Anderson Cancer Center Institutional Review Board (IRB).

Subject Recruitment

Eligibility criteria for the larger, SPIRIT study included self-identifying as African American and being at least one year post-diagnosis of breast cancer, off active treatment other than hormonal therapy, and having adequate English skills. Recruitment sources included Sisters Network® Inc. chapters, community events, health fairs, and church support groups. IRB-approved flyers were supplied to beauty shops, car washes, and stores selling mastectomy lingerie and wigs. African American breast cancer survivors trained as SPIRIT peer counselors identified potential participants, who were then screened by phone by members of the research team at MD Anderson Cancer Center. Women were subsequently mailed a written informed consent form along with the baseline questionnaires. Participants aged 45 or younger at cancer diagnosis could agree to be contacted to participate in the interview as an optional procedure. Interviews were postponed until after one-year assessments to ensure that they would not influence the results of follow-up questionnaires.

Semi-Structured Interviews

All interviews were conducted by an African American research coordinator with a master's-degree and experience in mental health counseling (PL). Interviews were scheduled at a convenient time and lasted 45 to 60 minutes. Participants were compensated \$25 for their time and trouble. Participants were notified that interviews would be recorded and transcribed. The interview items focused on the impact of cancer on women's living situations, employment, relationships, fertility, and sexuality. Women were asked about issues or experiences that might be unique to African American breast cancer survivors. Table 1 lists the questions that were asked.

Statistical Analyses

Descriptive analyses were conducted with interview data, e.g., frequencies, mean, median, range, standard deviation). One author (MS) coded responses all 33 interviews. To determine inter-rater reliability, 5 interviews were also coded by two other authors (LRS and PL). Agreement was 91% among the 3 raters across 141 items.

RESULTS

Thirty-three out of 48 eligible women (69%) participated in the interviews.

Demographic and Medical Factors

Table 2 presents demographic and medical factors for the participants. Women's age at diagnosis ranged from 25 to 45.

Impact of Cancer on Living Situation

Only 15% of the women lived alone at the time of their cancer diagnosis. Thirty-nine percent lived with a spouse or intimate partner. After cancer diagnosis, 27% of women moved in with someone or had someone stay with them to give care during their cancer treatment. Not all women had these resources, however:

“White folks, a lot of times, their people jump up. They'll come, and they stay. And this is not for all white folks, but majority of the time, you know. And the folks that were most helpful to me were my coworkers who were Caucasian. And my family, they knew, but nobody could afford to come and spend a week here and there. I drove myself to chemo ...and to work, and God brought me through. So this is why faith made me stronger.”

Almost all women (N=31) worked outside the home at diagnosis. About half (46%) reported that cancer had no impact on their career. About a quarter (24%) reported that cancer had a positive impact on their work life and that co-workers were supportive during cancer treatment. Another 24% of women believed, however, that cancer had a negative impact on their career, including 2 women who reported job loss due to cancer.

Needs for Emotional and Instrumental Support: At Diagnosis and Currently

All but one woman acknowledged a need for emotional and/or functional support at the time of diagnosis. Seventy percent recalled needing emotional support and 56% functional support with daily life tasks. More women reported having received functional support (67%) than emotional support (58%), however. Over a third (36%) wanted more emotional support at the time of diagnosis.

When asked to compare current support needs to those just after diagnosis, fewer women required either type of support, but 36% still felt a need for more emotional support.

“We young women...we need to basically have somebody put their arms around us and say, ‘It’s okay. It’s all right.’”

The vast majority (85%) named a family member as the most helpful person during cancer treatment. A third of women cited a parent, 27% a spouse or intimate partner, and 21% a sibling. Another 21% of women identified God or their church as their most important source of support.

A majority (64%) had regular contact with breast cancer survivors. Support groups (including those sponsored by Sisters Network,[®] Inc.) were the main avenue for meeting other survivors for 61%, but 27% of women met peers through their churches. Romantic Relationships

Among 18 women who were unmarried at the time of cancer diagnosis, 55% had difficulty with dating. Five had not dated at all since the cancer diagnosis and 3 had dated sporadically. One explained:

“Not only do people kind of shy away and they look at you differently, but you get to the point where it’s like if you do want to date somebody and you begin to date somebody, you’re like, ‘Well, when do I say this? When do I—?’ And it’s not that I’m ashamed of it. I mean I didn’t ask for it. But I think that person needs to know. And they may feel like, ‘Well, why get into this relationship and then six months down the road you want to tell me this?’”

However one woman reported dating more often after cancer than she had previously:

“Yes, there have been guys – I always let people know early on so if they have an issue with it, they can move on before the relationship gets serious. I have had people move on, which was okay with me if that is an issue for you. But for the most part, it really hasn’t affected me. Guys are much more accepting of it than I really expected.”

Among women who had a committed relationship at cancer diagnosis, 50% felt that cancer had interfered very much with their relationship and/or that cancer had a strong negative influence on their partner’s emotions. Thirty-one percent of women’s relationships did not change due to cancer. Only two women felt closer to their partner due to the cancer experience. One woman related this story:

“My husband was devastated, he really was. But he really didn’t show it a lot with me. He was really strong with me. We talk about it sometimes. He’d talk about

how he would leave the room and go and cry, or go in the car and cry. I saw some emotion one time with him when my hair started coming out. I just couldn't take those patches. I just told him to take it off. I was like, 'You just got to take this off.' So he and my two kids, we were all in the bathroom. They were crying and upset—my daughter was—and my little son, he just wanted to know when his turn was coming for a haircut. But my husband took my hair off. As the tears rolled down his face I could see him in the mirror.”

The emotional reactions of the women's' partners divided almost evenly into supportive versus withdrawn. Among the 26 women in a relationship at the time of diagnosis, 10 characterized their partner as very supportive whereas 8 reported that their partner withdrew emotionally. Two women reported that their partner was initially supportive and then withdrew. Eighteen percent had been rejected by a partner because of their breast cancer.

Fertility and Desire for Children

Fifty-four percent of the women had at least one child at the time of cancer diagnosis (median: 1 child). Only two women had 3 children and none had more than 3. Women's oldest child at the time of diagnosis had a mean age of 16.8 years.

Forty-five percent of women reported retrospectively that they had wanted a child at the time of their cancer diagnosis, but 48% did not recall discussing the topic of infertility with their medical team. A large minority of women were dissatisfied with the amount of information they received on infertility (21%), the safety of pregnancy after treatment (21%), the health of children conceived post-treatment (18%), or their children's lifetime cancer risk (27%). Of 22 women who had chemotherapy, only 3 (14%) reported having been offered an option to preserve fertility. One additional woman brought up the topic herself. One woman froze embryos and oocytes before her cancer treatment and another cryopreserved oocytes.

Only 4 women became pregnant subsequent to cancer treatment. Between them they had 4 healthy children, 2 stillbirths, and 2 pregnancy terminations. One woman sought treatment for infertility and was currently trying in vitro fertilization. Two women had adopted children after their cancer.

Sexuality and Feeling Attractive

Cancer treatment had caused ≥ 1 sexual problem in a third of women. Thirty percent reported unchanged sexual function and 12% felt sex had improved since their breast cancer. The rest of the women were sexually inactive (18%) or did not wish to discuss sexual issues (7%). Loss of desire for sex was the most common problem (39%), followed by vaginal dryness (24%). Nine percent of women had actual pain during sex, 21% had difficulty feeling excitement and pleasure, and 15% had difficulty reaching orgasm.

Seventy-three percent of women said that their oncology health care providers never mentioned sexuality. Another 9% received some minimal information. Only 18% recalled a reasonable discussion of sexuality and breast cancer. Not surprisingly, over half the women (52%) wanted more information from their medical team regarding breast cancer and sexuality. Taboos about discussing sexuality in the African American community may exacerbate poor communication about this issue with physicians:

“I find that question hard to ask my doctors, even now. That's not something they asked me about and it's not something I bring up.”

About a quarter of women (27%) reported using some type of treatment for a sexual problem. Most had tried lubricants. One was on estrogen replacement and one had used vaginal dilators. Herbal remedies were mentioned by 2 women.

Only a minority of women (23%) felt sexually unattractive after cancer treatment. Twenty-nine percent rated themselves as somewhat attractive, and 39% felt very attractive currently.

Anxieties and the Emotional Impact of Cancer

The most common anxiety at diagnosis, cited by 61% of women, was fear of dying from cancer. One woman noted:

“I wasn’t educated at all. When they walked up and said ‘breast cancer,’ I just said, ‘I’m going to die.’”

For most women, anxieties had decreased greatly since cancer diagnosis and treatment. Forty-five percent report that they “never” worry about the same issues now, and 48% only feel anxious “once in a while” or “rarely.” Only one woman still worries about the same issues “often.”

Forty-two percent of women reported that cancer did not have any negative impact on their life. However, 21% experienced emotional difficulties and 21% cited changed appearance as a negative result of cancer. In keeping with reports that spirituality is crucial to many African American women in coping with cancer, 52% saw a positive change in their outlook on life. Most explained that their illness gave them a greater appreciation for life.

“Before breast cancer, I was just worrisome: ‘What’s going to happen today? Is my car going to break down, do I have enough money to pay my bills?’ Since cancer – I had never been on an airplane before. After I ... finished treatment I got on an airplane and rode for the first time. I went to North Carolina for a symposium. I mean, I was always asked to go to those, but I was afraid to fly. I was like, ‘Bump this, I’m going to fly now.’ So I flew. I got my ears pierced. I always wanted to get my ears done, and I’d had keloids when I was a young girl. I had them removed, and I was afraid to go... I used to be a cheapo, just didn’t want to spend no money. Just holding on to my last dollar. Now it’s like, ‘Girl, you better spend that money. Some more going to come.’”

Eighteen percent mentioned that having cancer had strengthened their religious faith and spirituality.

“I value each day of my life more, and just the simple things in life: trees and grass and those things. I was very career-oriented and just really didn’t appreciate just simple life... It brought me closer to the people in my life, family and friends. It forced me to rely on people; I was very independent and so it forced me to rely on them and ask for help, and accept the help. So it was good. And I’ve used it to really reach out to a lot of other women that I probably would not have. So it made me a better person, I’d say.”

Special Perspectives of African American Breast Cancer Survivors

Sixty-four percent of participants thought breast cancer had special meaning for them as African American women. Issues cited included the unique strength of African American women – stemming from historical resiliency as well as from spiritual/religious beliefs; the ongoing stigma associated with cancer in the African American community, which prevents open discussion and support-seeking; and the lack of education and resources targeted to African American women, including research on cancer in African American women as well as practical issues such as wigs and skin care. One woman explained it this way:

“And even a lot of times, with the taboos in our culture, it’s like you only go to the doctor unless, God forbid, you’re half dead. It’s like why would you go for a physical, a checkup, something, “Why are you doing that?”... When you have a physician that is not in tune to that, it becomes almost like shocking sitting there explaining something that goes on in your culture. It’s like ...”Why did it take that person so long?” They don’t understand what goes on as far as doctors and African Americans, and it’s just hard.”

Forty-eight percent of the women reported that being African American helped them in coping with breast cancer. Again, these women cited the historical and religious strength of African American women, as well as strong family support. For example:

“I guess we’ve been thrown into this role that we lead. And a lot of Black women, they used to work in fields and do all that work. It’s like we don’t have time for being sick. That might be a motivator, like I got all this stuff to do, I got to get well. I’ve got to do this.”

Some women felt that being African American helped them to rise to the challenge of dealing with cancer:

“Yes... because I’m African American and I’m not of another race, I think that I wanted to overcome it because of the stigma--and because of being African American and having cancer or having hypertension-- we’re always the ones that have everything more than any other race, so I wanted to show that I could beat the odds.”

However, a similar percentage of women (45%) felt that being African American made it harder to cope with breast cancer. They struggled with the stereotypes of African Americans being highly sexual, and then perceived themselves as damaged by breast cancer. They also felt it was more difficult to discuss cancer openly or to find resources relevant to women of their ethnicity. Several mentioned feelings of isolation as a young, African American woman struggling with breast cancer, and wished they had more contact with peers. One woman said:

“Just the fact that those of other ethnic backgrounds, they have a lot of resources available to them, but with us, I think that it brings about a change within us ... mostly spiritually because of the fact that ...all we have to rely on is our faith in God. And I really feel that it changes you. I’m just telling you. I mean I’m just being upright, you’re never the same again, I’m sorry. If you have a lumpectomy or a mastectomy, you’re just never the same again.”

Thirty percent reported that being African American had a negative impact on their medical and/or psychosocial cancer care. Several remarked that their insurance had not paid for high quality care.

“I think that it’s a struggle for African American women...who don’t have a career that has the insurance coverage... My insurance coverage was 80 percent, and that 20 percent that I had to pay on a regular basis – and at the time, I was single, and I had to ...continue with my bills because I didn’t want to have things to become past due and so forth. So I maintained my bills at the risk of not even having enough money to buy food at times...when I was taking chemotherapy. So I think that might be a significant difference for some Caucasian women. And then also knowledge, you know. Some African American women are not knowledgeable enough when it comes to our health, and we don’t do enough research, and even when we find out about our illnesses. And even talking for myself at this time still, we don’t do enough to maintain our health because we’re so busy doing so many other things. And this might be true for other women, but primarily, I think it’s

more so for African American women working out, eating right, that kind of stuff, and myself included right now. I'm gaining so much weight from the tamoxifen, feeling premenopausal, and then I'm craving junky stuff. And then when I get home from work, I'm so exhausted, I don't have time to go – the time that I could go, well, walking, do some kind of exercise, I'm just exhausted.”

Some women also felt alienated by the lack of African American physicians. One participant said:

“A lot of women have told me that they wish that more of their treatment team looked like them.”

Twenty-one percent felt that their oncology health care providers had dismissed the importance of fertility more than they would have for a white woman. In some cases, the lack of attention to fertility issues may have been linked to the aggressive tumor features common in young, African American women. As one woman recalled:

“My doctor basically had told me that the type of cancer I had was so aggressive that he wouldn't advise any pregnancies or anything like that because ‘you might not even live.’”

DISCUSSION

Younger African American breast cancer survivors share the same psychosocial concerns reported by cohorts of primarily Caucasian women diagnosed before age 50 (Baucom et al., 2005–2006; Bloom et al., 2004; Burwell et al., 2006; Fernandes-Taylor et al., 2010; Fobair et al., 2006; Ganz et al., 2003), but their problems with their relationships, their distress about infertility, and their lack of information about sexual dysfunction appear to be more prevalent and severe. The impact of cancer on these psychosocial issues may be exacerbated by the often aggressive nature of their disease (Amirika et al., 2011; Dunn et al., 2010) and the continued stigmatization of cancer in their community. African American cancer survivors are more likely than white women to live in poverty. Consequently, stress in their environments has a significant impact on both mental and physical health (Ashing-Giwa & Lim, 2009). Our sample was more affluent and well-educated than average for African American women. Only about 30% fell below the white collar occupational level and a similar proportion lacked adequate practical support at home or at work during cancer treatment. However, a third wished for more emotional support, and that need did not diminish over time.

In a recent study of job loss among over a thousand breast cancer survivors of varying ethnicity, Latina women were the group most likely to have vocational problems (Mujahid et al., 2011), but African American women had higher unemployment rates than white women. The 10% rate of job loss reported for African American women in that study is similar to the rate in this small sample.

Despite their strong spirituality, many of these young women felt isolated, even among other breast cancer patients, by the combination of their youth and ethnicity. Furthermore, as in other surveys of African American women, there was a general distrust of the health system and a feeling of alienation (Germimo et al., 2011; Masi & Gehlert, 2008).

Even with their young age at diagnosis, over 20% of these women did not recall receiving information on fertility and breast cancer treatment. Only one woman out of 15 (6%) who had wanted a child at diagnosis attempted fertility preservation, an even lower rate than has been reported among predominantly Caucasian women (Lee, Heytens, Moy, Ozkavukcu, &

Oktaý, 2011; Partridge et al., 2008). Post-treatment pregnancy rates were also lower than in a well-educated, Caucasian cohort (Lee et al., 2011).

Several participants believed that physicians were more likely to discount African American women's concerns about fertility. Oncologists have reported not mentioning fertility preservation to patients who may be unable to afford it financially, which may contribute to this perception (Quinn et al., 2009). Furthermore, most referrals for fertility preservation come from oncologists at academic medical centers which tend to treat more affluent women (Lee et al., 2011). An Australian study of 111 young women facing breast cancer treatment found that those with less knowledge about fertility preservation also had more conflict about whether or not to pursue it (Peate et al., 2011). Long-term regrets have also been observed in women who wanted children at the time of cancer diagnosis but were never able to fulfill their longing (Canada & Schover, 2010).

Although women who receive chemotherapy (two-thirds of this sample) are at high risk for sexual dysfunction associated with premature ovarian failure (Burwell et al., 2006; Ganz et al., 2003; Schover, 2008), 73% of our participants did not recall any mention of sexuality by their oncology health care providers. In contrast, 44% to 68% of premenopausal breast cancer patients in predominantly Caucasian cohorts report receiving information on sexuality and menopause (Duffy, Allen, & Clark, 2005; Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2011; Thewes et al., 2005). The taboos within the African American community on talking openly about sex may have made women less likely to be assertive in bringing up sexual questions themselves. Although women of all ethnicities have complaints about the lack of sexual counseling during breast cancer treatment, the lack of information given to this group is extreme. Rates of sexual dysfunction in our sample were similar to or somewhat lower than those in cohorts of predominantly Caucasian survivors of premenopausal breast cancer (Burwell et al., 2006; Fobair et al., 2006; Ganz et al., 2003; Malinovsky et al., 2006). Some women may have overcome sexual problems because of the SPIRIT intervention, which had a goal of increasing women's information about the impact of breast cancer treatment on sexuality, as well as educating them about self-help and medical solutions for sexual problems (Schover et al., 2006; Schover et al., 2011). In both the pilot and national studies, women with sexual dysfunction improved from baseline to 6-month follow-up, although in the national study, sexual function regressed somewhat by 1-year post-treatment.

Only 39% of women in this sample were in a committed relationship, compared to rates of 78% to 96% in samples of largely white, non-Hispanic survivors of premenopausal breast cancer (Avis, Crawford, & Manuel, 2004; Bloom et al., 2004; Burwell et al., 2006). The frequency of women reporting negative impacts of cancer on both dating and committed relationships in this sample is also much higher than usual in surveys of premenopausal breast cancer survivors (Bloom et al., 2004; Fobair et al., 2006). This is a striking finding worth further investigation. In a recent prospective study of 100 newly diagnosed breast cancer patients, women with distressed relationships remained more depressed and had poorer physical outcomes as long as 6 years after initial assessment (Yang & Schuler, 2009). Relationship problems have also been strongly related to several dimensions of quality of life in a previous survey of 202 women diagnosed with premenopausal breast cancer and followed for about two years (Avis, Crawford, & Manuel, 2005). The lower marriage and cohabitation rates among African American women have been well-documented (Hummer & Hamilton, 2010), but may add to the difficulties that women experience in trying to avoid abandonment when a chronic illness occurs (Glantz et al., 2010).

Limitations

Only 33 women participated in our interviews. They are almost certainly better educated, more liberal, and more informed about breast cancer than the average African American survivor, since most belonged to an advocacy group and were willing to participate in a study about breast cancer and reproductive health. Women in active treatment for advanced breast cancer were not included in the peer counseling study. Although this is a relatively privileged group of African American survivors, we would expect more underserved women with poorer prognoses to have even more problems with inadequate emotional support, relationship fragility, and lack of counseling on reproductive issues. At the least, this survey suggests a need for more detailed assessment of a larger and more economically diverse cohort.

Implications for Clinical Practice

African American women have the highest rates of premenopausal breast cancer of any ethnic group in the United States (Dunn et al., 2010). They may also have special needs for psychosocial intervention. Even in our relatively affluent sample, problems with relationship strain, sexual dysfunction, and unmet needs for counseling on fertility appear more common than among young Caucasian survivors. Women with less education or lower incomes may have even fewer resources. Given the limited insurance coverage available to most people for mental health care, the remaining stigma on counseling in the African American community, and women's perceptions of poor communication with oncology health care providers, a peer counseling or patient navigator model may be helpful.

As in our SPIRIT study, African American breast cancer survivors can be trained to provide education and emotional support to new patients. They can share written materials that are medically accurate and that provide a variety of potential coping strategies. The SPIRIT program focused on menopause symptoms, sexual function, and fertility issues. We are currently collaborating with the Centers for Disease Control to expand and tailor our SPIRIT intervention for African American women diagnosed under age 45.

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Table 1**Questions for the Semi-Structured Interview Table 1. Questions for the Semi-Structured Interview**

1	How old were you when diagnosed?
2	Who was living in your household?
3	How many children did you have?
4	How old were they?
5	Were you working outside the home?
6	Profession?
7	Who helped you most during your cancer treatment?
8	What type of support did you need most at the time of diagnosis?
9	What types of support did you receive?
10	What types of support were missing?
11	What types of support do you need currently?
12	How much contact have you had with other women your age who have gone through breast cancer?
13	How did you meet these women?
14	Did your living situation change as a result of your diagnosis?
15	If you had a dating or committed relationship when you were diagnosed, how did cancer affect it?
16	When you found out about your cancer, were you interested in having (more) children?
17	What were your biggest anxieties when you found out you had breast cancer?
18	How often do you still worry about these issues now?
19	What positive impact has your cancer experience had on your life?
20	What negative impact has your cancer experience had on your life?
21	What impact did cancer have on your job/career?
22	Have you been pregnant since your cancer?
23	If not, have you tried to become pregnant?
24	Have you seen a doctor about fertility? If not, why? If yes, what tests or treatments have you had?
25	Do you have menstrual cycles?
26	How much did your medical team (doctors, nurses, social workers) tell you about cancer and fertility?
27	Was information you received not enough, about right, more than you wanted?
28	Were you offered any option to keep your fertility, like taking special drugs during chemotherapy or freezing embryos or ovarian tissue?
29	Did your medical team talk to you about safety of getting pregnant after breast cancer treatment?
30	Was the information you received not enough, about right, more than you wanted?
31	Did your medical team talk to you about whether children you had after cancer would be healthy i.e. no birth defects related to your cancer or treatment?
32	Was the information you received not enough, about right, more than you wanted?
33	Did your medical team talk to you about whether your children would have an unusually high risk of cancer?
34	Was the information you received not enough, about right, more than you wanted?
35	If relevant: What has dating been like for you since your cancer?
36	If relevant: How did your partner react emotionally to your cancer?
37	Has a partner ever rejected you because of your breast cancer?
38	How do you feel about your sexual attractiveness now?
39	How has your sex life changed since your cancer treatment?

- 40 Describe sexual problems you have experienced.
 - 41 Has anything gotten better about your sex life compared to before cancer?
 - 42 How much did your medical team tell you about breast cancer and sexuality?
 - 43 Was the information you received not enough, about right, more than you wanted?
 - 44 Have you used any kind of treatment for a sexual problem (lubricant, herbal remedy, seeing a doctor, etc.)?
 - 45 As an African-American woman, do you think breast cancer had a special meaning for you that might be different than for a woman of another ethnicity?
 - 46 Is there a way that being African-American helped you cope better with breast cancer?
 - 47 Is there a way that being African-American made it harder to cope with breast cancer?
 - 48 Do you think that African-American women cope differently with problems relating to sex or fertility?
 - 49 Do you feel that being African-American had an impact on your medical care for breast cancer?
-

Table 2

Demographic Characteristics of Participants (N = 33)

Variable	Value
Age at diagnosis of breast cancer	37.39 ± 6.00
Living with spouse or partner at time of diagnosis	39%
At least one child living in home at time of diagnosis	45%
Wanted to have a child at time of diagnosis	45%
Childless at time of diagnosis	45%
Current menstrual status	
Menopausal	50%
Irregular cycles	27%
Regular cycles	23%
Occupational Category:	
Professional	6%
White collar	64%
Blue collar	6%
Pink collar/low wage	15%
Not working	6%
Missing	3%
Changed living situation as result of cancer:	
No change	70%
Moved someone in, or moved in with someone to get help	27%
Missing	3%
Change in relationship due to cancer (N=26)	
Interfered a great deal	48%
Interfered somewhat	12%
No change	31%
Became much closer	9%
Change in job due to cancer	
Lost job	6%
Mild/moderate negative impact on job	18%
Positive impact/supportive workplace	24%
No change	46%
Not working outside the home	6%