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ORIGINAL ARTICLE

Keeping us all whole: Acknowledging the agency of African American breast cancer survivors and their systems of social support

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Abstract
While all cancer patients face a bewildering array of treatments, side effects, and emotions, several researchers have shown that African American women with breast cancer experience greater stress and burdens because of unmet supportive needs associated with psychological distress, financial distress, and lower physical/functional well-being. Social support has been shown to improve health outcomes for African American breast cancer patients. The purpose of this paper is to understand the meaning of social support among African American women diagnosed with breast cancer. A total of 47 African American women with breast cancer participated in the in-depth qualitative interviews. Key findings indicate that social support was received in the context of the stability of the extended family network. Moreover, social support was received in the context of distributing the social support received among many members in their personal networks and that social support was only received on patient's own terms. The findings of this paper provide an understanding to the inter-relational and cultural meanings of receiving support by diverse cancer patients. In addition, the findings of this paper have implications for health care professionals working with African American breast cancer patients in understanding how social support can be received.

Keywords Social support · African American women · Breast cancer

Background

Breast cancer is the most common form of cancer among African American women and the second most common cause of death [1]. African Americans tend to be diagnosed at later stages and experience greater mortality from the disease compared to White women [1]. Moreover, a cancer diagnosis is often accompanied by psychological distress [2]. Approximately 50% of breast cancer survivors experienced depression and anxiety in their first year since diagnosis [3]. Psychological distress from a breast cancer diagnosis is often brought on by concerns regarding death, disability, and recurrence [4]. While all cancer patients face a bewildering array of treatments, side effects, and emotions, several researchers have shown that African American women with breast cancer experience greater stress and burdens because of unmet supportive needs associated with psychological distress, financial distress, and lower physical/functional well-being [5–7]. Social support has been shown to prevent long-term depression and anxiety among breast cancer survivors [8]. For African American breast cancer patients, social support improves health outcomes [9]. Despite the benefits of social support, there is very little information on how social support is received and from whom in racially and ethnically diverse breast cancer patients [10, 11].

Linked fate and social support

"Linked fate" is the theoretical framework guiding our analysis of African American women's structure of social support. For African Americans, social support is tied historically to the concept of linked fate. The concept of "linked fate" is a social theory in which an individual's life chances are inextricably tied to their race as a whole [12]. In this research "linked fate" has also been expanded to include a cultural analysis. In

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Black Psychology "linked fate"' is evaluated to include the intergenerational movement of information and conceptualizations of family relationships through often-called "collective consciousness", "cultural montage", and by extension "worldview" [13, 14]. Based on this research among African Americans specifically, the cultural and psychosocial orientation of an individual's survival is perceived through the broader conception of the survival of the entire community, and family in particular. When observing patterns and behaviors of support in the African American community, an example of "linked fate" is the survival thrust and motivation found in the socially supportive networks developed by African American communities. There exists a level of shared consciousness among African Americans regarding life chances as a result of communal cultural practices, racialized history, and contemporary experiences. Thus, the agency of an individual is often shaped by its perceived consequences on one's family and potentially broader racial-cultural community. The observation of linked fate and collective consciousness can be seen through various forms for social support behaviors between families and communities.

Social support, African American women, and breast cancer

For breast cancer survivors, access to a supportive environment has been shown to prevent long-term psychological difficulties and positively impact general well-being [15, 16]. Compared to Whites, African Americans have reported greater psychological consequences due to their breast cancer diagnosis [16]. Researchers stated that this disparity in terms of negative psychological consequences is mediated by differences in unmet social support [15–17]. In terms of these disparities, social support represents a promising point of intervention. Researchers who have studied social support among African American women breast cancer survivors reported that women who have strong, positive relationships with others are able to adjust well to their breast cancer diagnosis and treatment [9]. Additionally, among African Americans with breast cancer, higher social support is associated with higher mental health quality of life [18]. Among African American women with breast cancer, social disconnection was associated with decreased well-being [19].

Although studies on social support and African American female breast cancer survivors exist, most of these researchers have identified the lack of support and the inability of health care institutions to meet the needs of these women. Researchers have shown that African American women with breast cancer lack many formal social supports including lack of resources for continued care, lack of support for cancer caregivers, lack of support services for children of survivors, and culturally appropriated cancer resources [20, 21].

Traditionally, social support has been defined as an informational, emotional, tangible, and appraisal support [22]. Qualitative researchers of African Americans with breast cancer have shown that the kinds of social support utilized included emotional support of "presence," instrumental support, informational support, and assistance to maintain social roles [23]. For African American women, informational and emotional support from other cancer survivors has been perceived as helpful [23]. In a study of African American breast cancer survivors, supportive care factors were identified, which include faith, supportive structures, optimism, and access to information [21]. For many African American women with breast cancer, spiritual support from religious institutions and others is an important form of support throughout diagnosis, treatment, and survivorship [24]. Researchers have shown that spiritual support—including prayers from friends and church communities—play an important supportive role during diagnosis and treatment of breast cancer for African American women [25]. These varying types of support can contribute to quality of life and well-being. Compared to Whites, African American breast cancer survivors have higher levels of spiritual quality of life [26]. For example, within the African American cultural framework, while physical health is not dismissed, it is interpreted as just one aspect of one's total wellness. Psychological wellness and spiritual strength are additionally equated in total wellness, wherein spiritual strength is most highly valued. This is a significant point to underscore because existing literature has often dismissed the significance of spiritual faith among African Americans as a form of denial of medical diagnosis and/or "proper response". Within the African American cultural framework, medical advice is solicited to the extent that it does not subvert or encroach upon their spiritual worldview and practice.

In-depth studies on social support and African Americans with breast cancer have shown that receiving and giving support during this time period is cultural and complex [27, 28]. Hamilton and Sandelowski (2003) suggested that social support for African American women is grounded in reciprocity even through a cancer diagnosis and treatment [27]. Reciprocity in terms of giving back was important to well-being and the networks that they were in. Molina et al. (2016) in a study of African American women with breast cancer showed that respondents who experienced positive and beneficial support during this time period felt a strong need to "give back" and support other women with breast cancer in emotionally peer to peer supportive ways but also in larger community advocacy as well [28]. Their role in helping other women diagnosed with breast cancer was largely framed as being emotionally supportive, based on their previous experiences with social support. Molina et al. found that the type of support women receive during their journey may directly pertain to their perceived roles as resources. Molina et al. (2016) illustrated in their qualitative work of African

American breast cancer survivors that social support received by formal and informal sources often transformed into community/interpersonal advocacy for others diagnosed with breast cancer [28]. Ultimately, community/interpersonal advocacy was seen as a way to improve self-advocacy in their navigation as well in the cancer care for other African American women.

Very few studies have been focused on the inter-relational dynamics of social support among African American women. A gap in the literature exists when reviewing the multi-dimensional, inter-relational, and cultural meaning of receiving and giving support [23, 27, 29]. Social support research has primarily been constructed in two directions: support received and/or support given [27]. The purpose of this paper was to understand the meaning of social support among African American women diagnosed with breast cancer. This paper is part of a larger study that is examining longitudinally the quality of life and social support of breast cancer survivors from diverse backgrounds.

Methods

This sample is a subsample of a larger study of quality of life and social support among diverse breast cancer survivors in the San Francisco Bay Area. To be eligible for the overall study, the participant needed to: (1) have had a diagnosis of breast cancer (Stages 0, I and II) within the past 4 years; (2) have completed primary treatment; and (3) speak and/or write English, Cantonese, or Spanish. For this paper, the investigators identified women who were African American women ($n = 47$) for further analyses. The research team which were made up of research assistants and the investigators conducted 1.5 to 2 h tape-recorded interviews at a place convenient to the participants. Prior to data collection with research subjects, research assistants were trained on survey administration and qualitative interview techniques with diverse breast cancer survivors. Research assistants contacted interested participants to see if they fit our eligibility criteria, and also set-up an appointment for an interview.

This study used both quantitative and qualitative data collection methods. At baseline and every 6 months for 2 years, quantitative surveys were conducted on mood, quality of life, spirituality, and social support. Qualitative interviews were done at baseline and the exit interview. Participants were asked a series of open-ended questions about types of social support used at diagnosis, during treatment, and after treatment; spirituality; psychosocial impact of breast cancer; general well-being (quality of life); impact of breast cancer on quality of life; reactions of family members; ways of coping; work experiences; advice to other women diagnosed with breast cancer; and recommendations to the community for programs to support breast cancer patients and survivors. The audiotapes were then transcribed.

For this paper, qualitative interview transcripts from African American respondents were analyzed. The focus of the analysis were the responses on social support at diagnosis, treatment, and survivorship. The qualitative data analysis was conducted through three-step procedure. First, following the procedures for grounded theory analysis, the investigators used open coding used to identify emerging themes occurring most frequently in the transcripts [30]. The lead authors who are experts in qualitative analysis (IF, GY) directed the analysis. Each author who had access to all transcripts independently reviewed them for commonalities and differences. The authors met five times to review transcripts, to re-evaluate initial and emerging coding categories, and ultimately obtain consensus on final themes. A final review through both inductive and deductive methods was performed by authors on the accuracy of each coding category and resulting themes [30].

Findings

The background of the participants ($n = 47$) was diverse. The mean age of the sample was 60 years of age with a range from 34 to 82 years of age. In terms of relationship status, over a third of the women (38%) were married, 23% were divorced, 19% were single, and 15% were widowed. With respect to the meaning of social support, three themes were identified from our respondents. First, the meaning social support was grounded in “keeping us all whole.” Second, social support received was about distributing the weight of diagnosis through extended networks. Finally, when social support was received, it was social support “on our own terms.” A more full description of each theme is delineated below.

Themes

Theme 1: Keeping us all whole

A major theme in our participants’ experiences with social support is their concern for keeping those around them “whole.” African American women were expeditious in considering how their diagnosis would impact those around them. In the interviews, women made direct statements about their diagnosis in relation to those persons closest to them. A belief for many of the women was that even though they were experiencing breast cancer this information needed to be used to support others. They became immediate advocates in their families to encourage others to be informed and tested for breast cancer. They also tended to express the impact of their diagnosis almost as if they were simply the carriers of what was more importantly “family or community news.” Within our sample, African American women reported that one of the hardest things was informing their families, not because of embarrassment or shame, but because they anticipated the grief of their families. Nonetheless, they felt extremely responsible to be strong, as present as possible, a model within their kin networks for resilience, and the ability to use their faith in God as a testament to their commitment to recovery. Their positive relationship to their recovery was interlinked with their sense of responsibility to their family and closest loved ones. For example, a 46-year-old married respondent stated:

> The hardest thing about how it impacted my life [is that] I had to let people help me. And I'm pretty independent...it was pride. I would really get really emotional because I needed help. I couldn't even change the linen on my own bed. And then I couldn't be around a lot of people because I was always nauseous and tired. I don't know. I just had to totally depend on people and God.

This statement reveals how the respondent interpreted the relationship between her recovery and her closest support networks. The respondent speaks of the difficulty of shifting her responsibilities to her loved ones because it was a signifier of her inability to maintain support for herself, but moreover, support for the collective network. In this instance it is not the grief of the respondent or family that elicits worry; it is the concern of the respondent that her lack of independence creates an over dependence on others and thus a weighted shift on the collective. We find this collective self-consciousness to be supportive evidence of linked fate theory. In our study, when this communal orientation to mortality was understood in relation to a breast cancer diagnosis, African American women expressed the impact of their diagnosis by the degree to which it would affect their ability to carry out their regular responsibilities in addition to how it could affect the physical and/or emotional stability of their closest loved ones.

The women in our study typically expressed being very independent and held positions of authority in their homes, families, and communities. Likewise, their response to their own illness was well contemplated before disclosure to their families. Often, they saw themselves as the conduit for informing others in the family and extended trust network about their diagnosis as a form of prevention for others. Linked fate is expressed here through the general sense of "if one of us is not well, we are all not well." Participants expressed that they felt the need to protect and support their families and they intently did not wish to excessively burden their loved ones with new responsibilities associated with their diagnosis.

When participants were diagnosed, they conveyed being constantly aware of needing to ask for help but remained motivated to show their self-sufficiency as part of their wellness, and by extension the "fate" of the collective. The participants' goal was to maintain balance among their healthcare needs and what they could contribute within their social network as evidence of the well-being and status of their broader social network. A 60-year-old respondent stated:

> It wasn't the emotional stuff that was bothering me. It was not being able to do what I wanted to do or do what I normally do. The look on my husband's face was devastating. Just painful for me. He couldn't do anything. He couldn't make it better. I tried to find ways to make him feel his contributions were valuable. I wasn't always good at it..I wasn't always able to overcome my own feelings and rise to the occasion but at least I tried.

At the same time, participants also felt that their experience with breast cancer motivated them to keep their social networks whole and healthy. One 47-year-old participant stated:

> It's life threatening. It's impacted my life in a very very big way, such that I feel that I have a purpose of life of healing myself and helping other people do the same thing...It really helped me learn that I'm not a victim, I can take care of things, I can heal myself, and that I can be of support in some ways to other people.

This participant's statement is a mirror of linked fate theory and her community orientation to wholeness. The many aspects of her life and well-being were measured and negotiated in tandem with her perceived community and her ability to participate in reciprocal relationships with herself and others. Her investment in healing herself also reveals the agency African American women exhibit in their own lives. Ultimately, being "whole" for these women was supported by keeping their immediate communities' whole.

Theme 2: Distributing the weight of diagnosis through extended networks

Consistent with the theoretical framework of "linked fate," African American women most often exist within the context of an identifiable community which can include biological relatives in addition to sociological relatives. In African American families, persons who are not related by biology can still hold a similar significance by relationship. These persons are likewise referred to as family or "fictive kin" [28, 29]. In these community networks built on trust and shared experiences, the structural support of friends, family, and institutions such as one's church family, all operate to the same end as an extended network of support.

For women in this study, their breast cancer diagnosis elicited their relational fictive kin support networks in supporting them through this crisis. This support was often about "distributing the weight of diagnosis" wherein others would share in carrying the added burdens of the diagnosis. One 34-year-old respondent discussed this type of distribution of social support through her network. She mentioned that those who were non-family participated in her care and in her overall healing. She stated:

> People would bring me soup or make me special dishes or just come and sit with me and watch tv. You know my mother can come just – come and sit with me, watch tv, try to tell me jokes or just you know pat me on the face. You know or if my body wasn't aching in certain parts, massage you know, but. Even if it was just for a few minutes, having people come and just do the simplest things.

As mentioned by these women, these supportive networks were not often immediate family members but extended relatives and community networks in which there was cultural understanding of connectivity, collectivity, and mutuality. Succinct with linked fate theory, the relationships that forge the extended supportive network or extended family are built for self-preservation and sustainability. Moreover, social support was not only tangible but also emotional and spiritual support.

For example, a 46-year-old single response reports:

> I had probably more support than anyone could ask for, because at my church there were several people there. I really got support. The Lord really blessed me in that area... I mean my friends were here every single day. All my [biological] family are in other areas so my friends are my family and that's what I tell people. Your family is who you make family. Your friends become your family because especially in good times and bad times they come around and they take care of you. So my friends are my family ...A lot of people that I didn't even know came around and wanted to help...One lady brought me food, I didn't even know she knew my name. She brought me food every day for 8 months...I knew her in passing at the church...And this other lady I'd just passed by, she sent me a check every month...They did it because the Lord told them to do it.

For African American women with breast cancer, the context of religion or shared spiritual paradigm, provides them with an extended network of trust that is bound more tightly. Historically, for African Americans, spiritual wellness is connected to their support of others [31–34]. For example, from this perspective the church member who aided the single 46-year-old saw her support as interlinked and mutually beneficial to her church sister as well as her own spiritual development. In many instances where African American women in our sample reported the significance of their faith in God and the support of their church family networks, they located their faith as a logical contributor to their overall wellness in relationship with their social structures of support. Respondents discussed how the spiritual support by others in the form of prayers brought peace and comfort.

A 56-year-old married respondent stated:

> I know we pray for one another… We [church family] talk about sharing and caring and love for the world...it keeps us motivated. For my spiritual being, my God... I just feel so blessed and so protected through the process.

A 60-year-old married respondent stated:

> Once I had prayer and determined that this was going to be ok...I didn't have any worries about this... Religion is the primary reason that I function.

As respondents have identified, because support is not predicated by biological relationships, the burden of being diagnosed with breast cancer was distributed throughout a broad network. Also noted, a significant type of psychological support given and received by their extended network included spirituality.

Theme 3: Social support: "On Our Own Terms"

For the majority of our respondents, their social role within the family structure mediated the terms of support that they were willing to receive from loved ones. As part of their wellness, women reported a need to maintain a balance in their participation of their family role and social responsibilities. Their personal barometer used to measure their sense of recovery and mental well-being was affected positively or negatively by the extent that they could participate in their own wellness and secondly, by the extent that they could carry out their routine responsibilities. They reported the need to actively participate in their own wellness and assert autonomy for two salient reasons according to interview responses. Firstly, apathy or ambivalence toward self-care was perceived as "losing hope", "selfish" in relationship to their loved ones, and/or "spiritually ungrateful" toward the life granted to them by a higher spiritual force. Secondly, complete dependence on others for support and care, particularly on the extended family, was perceived as an irresponsible shift of the burden of diagnosis onto loved ones. Women in this study consistently reported the need to balance caring for others and themselves. Many discussed the various offers of support and the reluctance in accepting support.

A 45-year-old married respondent stated:

> I didn't ask anybody for nothing because that's me. I do it all by myself. I ain't gonna ask somebody for nothing. They volunteered. Like when a friend said she would

> take me to my chemotherapy treatment, I told her that's okay. My husband will take me. She was like "No. I'm taking you. You tell him he needs a break and I'm taking you." And I was like "no" and she said." "I'm grown. I can do whatever I want to do... So just be ready." ... I'll crawl to the doctor before I ask anybody to take me. She was telling me." I'm coming to your house to get you." And I was like, "Okay, guess I better be ready." [laughs]

These women interpreted both their diagnosis with breast cancer and their trajectory for recovery through a pluralistic framework insofar as their decision-making for support was weighed by how their care options would affect those persons closest to them. As aforementioned, a majority of respondents found it difficult to step away from their caregiver role. Many sought to maintain that role during diagnosis and treatment. Several respondents discussed the process of accepting support. For example, a 47-year-old divorced respondent stated the difficult process of when she would finally ask for support from her adult children:

> My daughter, the baby, had to come wash my back. Tears would just roll down my eyes cause to be the head of the household for all those years and then you're depended on someone to do something as simple as to wash your back.

By accepting support on their own terms, African American women in this study felt they contributed to the stability of their social network and remained responsible in carrying out their family roles. The women diagnosed resisted identities of sickness or being placed in a state of needing total care. In their vision of support and wellness, they reported wanting to maintain as much as possible their normal routines and ability to serve their families and broader community. This autonomy lent them the agency they desired to be a participant in their wellness rather than a recipient of care. By extension, these women welcomed the social support they received particularly from their extended family because persons in these roles respected the wishes and authority these women held in their social networks.

A 49-year-old divorced woman with two sons stated:

> My mother or my father would take me to my treatments. I would never let them sit there with me. I told them to drop me off and pick me up. Cause you know seeing someone hooked up to this machine, pumping all this stuff in you. It was bad enough that they had to take me and deal with their daughter being sick.

An interdependent support structure was favored and revealed as most important to the recovery of African American women diagnosed with breast cancer within this study. An interdependent support structure is defined here as a bilateral system of support whereby a person's need for care is linked to his or her ability to care for others, concretizing a support structure that necessitates reciprocity and neutralizes the potential for exploitative forms of dependency. For example, a 60-year old respondent stated:

> My family was more heartbroken and more hurt than I was. They cried tremendously....I was going to get through it without any stress and a whole bunch of crying. I just lean and depend on the Lord and he brought me home.

The observable interdependent support structure applied by women in this study placed value on individuals being responsible for their independence to provide the space and viability to care for someone else as needed. This form of support is intended to sustain the wellness of an entire network of people over individuality at any given time. As a result, interdependence services independence and vice versa.

Discussion

For African American women with breast cancer, it has been confirmed that an array of psychological and social side effects such as depression, anxiety, stress, and financial burden compound the challenges of successful recovery [5–7]. However, this study was focused on locating the systems of existing support among women that can be nurtured and extended for better health outcomes in African American breast cancer patients. For African American women, the distribution of the weight of their diagnosis within their existing structures of support aided their recovery from breast cancer and contributed to their overall quality of life during and post operation. The most salient forms of structural support for African American women in our research study includes: kinfolk (biological and nonbiological relationships operating as family) and preexisting social institutions (e.g. church). For most of our respondents, their nucleus of support was their own sense of spiritual strength and faith. This centralized agency within themselves was structurally nurtured and strengthened by kinfolk and the social institutions they held membership within. The received social support for many of our respondents came from social networks that were also intergenerational. These extended networks of support were an outward development of African American communities that African American women had varying degrees of access to depending on their environment and community participation.

The negotiations of African American women and their support networks continue to be complex and deserving of more attention. For example, thematically, the balance of keeping everyone whole and distributing the weight of the diagnosis may seem contrary. However, it is this very tension between maintaining a level of independence while including the family in the personal aspects of one's life that anticipates the third important theme being social support on one's own terms. African American women's commitment to maintaining a sense of responsibility to their own needs was necessary to avoid an overdependence or exploitive relationship on the collective; similarly, they also valued the significance of information related to their diagnosis because of the service it could provide to the collective. Distributing the weight of the diagnosis was translated through the interviews more so as a means of psychological relief and service to others. Talking about their diagnosis with their support networks also maintained a level of trust necessary to bind the "linked fate" relationships. African American women who were diagnosed often felt a responsibility to share their diagnosis with their kinfolk to champion for others to be informed about their own health and for others to bear witness to their ability to survive. This simultaneously serviced the women with the diagnosis because they received the collective support of their communities during the process of sharing information.

The collective expectation of African American communities to be responsible for individuals in need may also show some significant reduction in the shame and social isolation felt by women in other communities with similar diagnosis. The distribution of a range of psychological, emotional, and material weight that affects breast cancer patients is more likely to be managed by members already in the lives of African American women based on our study. As more research develops on social support within the African American community, researchers should consider extended networks of support built on connectivity, collectivity, and mutuality which often pre-exist circumstances of hardship.

Traditionally, social support is characterized as any combination of emotional, tangible, appraisal, and informational support. However, like other researchers, we found that spiritual support that came from families and friends was an important source of support for our respondents [25]. This form of social support was important to the survivor's well-being. As studies have indicated, for African American women, various forms of social support serve as important factors which help women with breast cancer to adjust and cope, and can have positive impacts on the survivor's health [8].

Further research should investigate the significance of the familial and social relationships African American women with breast cancer consider most valuable in their sustainability from diagnosis to survivorship. Traditional social support research among breast cancer patients has been primarily done with white populations and focused primarily on partner support [35]. Our research identifies that nuclear family models are not most representative in the constructions of social support important to African Americans. Research across different racial/ethnically diverse breast cancer patients shows that support from spiritual and religious networks and family members such as siblings, adult children, and extended family member play a significant supportive role. For example, among Latino women with breast cancer who finished surgery, more positive informational and instrumental support was received from adult female family members than from adult male family members [10]. In a qualitative study of young Asian American breast cancer patients, they were reticent in sharing their diagnosis with children and spouses for fear of burdening their loved ones and rather sought out support from female friends and breast cancer survivors [36]. Like other studies have shown, spiritual families and networks along with friends and extended family members are critical in the support systems of African American women [25, 31–33]. In several qualitative studies of other racial/ethnical breast cancer patients, similar results indicated that spiritual resources and organizations played a key source of support [29, 37, 38]. As indicated in the findings and discussion, social support as a construct needs to continually widen to include multiple experiences and perspectives which include examining the relational and reciprocal nature of receiving and accepting social support as well as the possibilities of social support received transforming into resources for others.

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Compliance with ethical standards

Conflict of interest None.

The authors have full control of all primary data and allow the journal to review if necessary.

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