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Cancer Support and Resource Needs Among African American Older Adults

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Abstract

Older African Americans face substantial barriers to state-of-the-art cancer care. Implementing culturally appropriate support throughout cancer therapy is critical to improving cancer outcomes and quality of life for this vulnerable population. The purpose of this study was to obtain experiential data regarding cancer diagnosis and treatment, and analyze survivors' recommendations regarding treatment-related needs, psychosocial support, and strategies and resources. Four main issues emerged from the study: (a) the need for more health-related and cancer-specific education, (b) the importance of faith and spirituality, (c) the availability of

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support, and (d) participants' difficulty identifying and articulating financial needs. Few participants reported requesting or receiving assistance (financial or otherwise) outside of the family during their cancer experience. However, treatment-related medication costs posed a significant hardship for many.

Racial and ethnic disparities continue to pose significant health-related and economic challenges for older African American cancer survivors. This group is more likely to require enhanced and multifaceted cancer support resources because of poorer health status and fewer financial resources compared to older Caucasians (Gornick, 2000; Mosavel & Sanders, 2011). Social support has been linked to feelings of positivity, mutuality, and improved mental health outcomes among older African Americans with cancer (Hamilton, Stewart, Crandell, & Lynn, 2009). However, this population also has reported unmet social support needs during treatment (Mosavel & Sanders, 2011).

Healthcare financing and delivery changes, particularly cost-cutting efforts on the part of insurers, may widen existing gaps in access to services for racial and ethnic minorities, greatly affecting those in rural areas with diminished access to health care (DiIorio et al., 2011; Mathews & Park, 2009). Patients have identified cancer costs as contributing to treatment barriers, increasing stress, and decreasing quality of life (Klimmek, Snow, & Wenzel, 2010; Wagner & Lacey, 2004). The high cost of cancer treatment is borne by patients and caregivers (Chang et al., 2004; Mathews & Park, 2009) and may be a greater barrier to treatment for African Americans (Chu, Miller, & Springfield, 2007; Mosavel & Sanders, 2011) with significant societal consequences (Adler & Page, 2008).

Cancer outcomes are unequally distributed across racial and ethnic groups, with minorities experiencing worse outcomes, particularly regarding cancer burden and overall survival (American Cancer Society, 2010; Chu et al., 2007). Older African American adults enrolled in Medicare are more likely to report poor health than their Caucasian counterparts (42% versus 25%) and are less likely to have supplemental insurance (Chang et al., 2004). Lack of

or inadequate insurance plays an important role in the onset of depression among older African Americans with cancer (Agarwal, Hamilton, Moore, & Crandell, 2010). Health-care disparities should be approached from many perspectives: economic, racial and ethnic, cultural, and rural versus urban vulnerabilities (Coburn, 2002). Rural communities' predominantly older populations are particularly vulnerable to alterations in existing healthcare services (Van Nostrand, 1993) because of issues that place rural individuals at high risk for negative health outcomes such as economic disadvantages, geographic distance, uninsured or underinsured status linked to underuse of health services, and historical resistance to change (Chu et al., 2007; Mueller, 1997; Weisgrau, 1995).

The current study explored rural and urban African American older adult cancer survivors' perceptions of their cancer diagnosis and treatment experiences. Specific aims of the focus group study were to understand cancer support and financial issues related to the care experienced by African American older adults, elicit the resources and strategies that help those individuals manage the financial aspects of cancer care, and explore African American older adult cancer survivors' ability to identify and characterize who they relied on for support with financial and other resource issues during diagnosis and treatment, as well as the impact of support during that period.

Methods

A total of 48 older adult African American cancer survivors (20 rural and 28 urban) were recruited from community-based centers (e.g., churches, barbershops, diners, primary care clinics) in central Virginia and eastern Maryland. Participants had to meet the following criteria: aged 65 years or older, residing in a rural area in Virginia or an urban area in Maryland, and self-classified as a cancer survivor. Individuals diagnosed with advanced or metastatic disease were excluded because their needs were likely to differ from those of other cancer survivors. Recruitment was conducted through gender-specific flyers and advertisements generally seen by or targeted to minority individuals. Snowball sampling capitalizes on participants' social networks and can be helpful in recruiting difficult-to-access populations (LoBiondo-Wood & Harber, 2006). Institutional review board approval was received from Johns Hopkins University and the University of Virginia. Informed consent was obtained prior to focus group sessions.

The focus groups were described as an opportunity to share cancer diagnosis and treatment experiences, and to contribute to the design of a future cancer support intervention. Participants responded to a series of questions regarding their experiences of cancer diagnosis and treatment, the levels and sources of support during cancer diagnosis and treatment, and suggested support and recommended resources for others.

Data Collection

Because of the possibility that support needs might differ by gender, survivors participated in one of three types of focus groups: all male, all female, or mixed gender. A total of nine focus groups (six gender-separated, three mixed-gender) with separate urban and rural participants were conducted at accessible community facilities for 45–60 minutes. Each

group was kept within a manageable size, an average of four to six participants. Each participant received \$50 for their time and contribution.

Experienced facilitators familiar with the local community were race- and, if necessary, gender-matched to focus group participants. An established protocol was used to standardize facilitator training (Madriz, 2000). A brief, research-generated questionnaire was administered to obtain demographics, co-morbidities, and diagnosis-related information. Facilitators used a semistructured discussion (see Figure 1).

Data Analysis

Professionally transcribed and verified interview data were organized and managed using a qualitative analysis software program (Folio Views®). Tape-recorded focus group interviews were analyzed using a thematic analysis method (Ryan & Bernard, 2003) guided by questions asked in the focus groups. A multistep analysis plan (Lincoln & Guba, 1985) was used to develop themes: (a) identify the smallest units of meaningful dialogue, usually referred to as strips (Steeves, Kahn, & Cohen, 1996); (b) combine strips into categories based on observed similarities; (c) combine categories into larger meaningful units or themes based on observed similarities in the categories; and (d) specify the relationships among the themes to take into account the complete context of the participants (Agar, 1979). Field notes and post-session debriefing notes were used to enrich interpretations. Descriptive statistics were used to summarize sample characteristics. Demographic data were analyzed using the statistical techniques available in SPSS®, version 18.0. Trustworthiness and credibility of the data were enhanced through field notes and the documentation of researcher thought processes and strategic study decisions. A form of member checking occurred by going back to the participants via follow-up telephone interviews to review and clarify data-related issues or questions that were raised during the focus groups. Prior groups' comments and findings were discussed and compared to subsequent groups post-data collection, maintaining participants' confidentiality.

Results

Participants' ages ranged from 65–81 years, with a median age of 74 years. A majority of the total sample (54%) was not married or partnered; however, only 21% reported living alone. Most (67%) had a high school education or less. About 73% of the sample had a family history of cancer, and 93% had one or more comorbidities. Among all participants, 44% reported household incomes of less than \$25,000 per year. Men comprised 48% of the sample, and the median time since diagnosis was about two years. Additional demographics by region are presented in Table 1.

Urban and rural participants were compared on demographic variables. Nonparametric statistics (Chi-squared or Mann-Whitney Utests) were applied because data were skewed. The following statistically significant differences ($p < 0.05$) were noted among urban participants when compared to those in rural areas: shorter time since diagnosis, higher household income and less Medicaid enrollment, and more patients receiving radiation therapy. Although fewer urban participants were married or living with a partner, they had more supplemental insurance, higher full- or part-time employment, and slightly higher

numbers reporting surgical treatment; however, those numbers were not significant. No significant differences existed in the number of participants reporting a comorbid condition, although hypertension was reported more frequently among rural participants.

Themes

Across all participants, four themes emerged: (a) the need for greater health and cancer-specific education; (b) the importance of faith and spirituality; (c) the availability of support; and (d) the difficulty identifying, articulating, and addressing financial needs. Although the research team observed some minor gender and regional differences regarding those issues, sample limitations restricted the ability to draw conclusions specific to either gender or region; therefore, results are reported as one group unless specifically noted. Participant gender is coded (M = male and F = female).

Theme 1. Education is our salvation—Participants strongly believed in the need to disseminate information about cancer and available resources and support in their communities. That information ranged from general health and appropriate cancer screening to knowledge and decision support regarding cancer diagnosis, treatment, and follow-up. Although the theme was present across groups, it was somewhat more prominent among the male groups, particularly urban men. We have to have a certain amount of education so we can find out a way through this maze of information, and we have to live with the system that we've been thrust into. [M] The importance of early and continued delivery of cancer-specific and general health education was noted by participants who believed those messages should be distributed prior to any diagnosis and continued through cancer survivorship. A number of participants became portals for that type of information after their diagnoses. Several women convinced all of their female relatives to get mammograms and begin breast self-examination. Some men reported becoming advocates for prostate cancer screenings in their respective communities.

Theme 2. I gave my cancer to the Lord and left it there—Many participants believed in the importance of faith and spirituality to maintain a healthy, positive attitude. Faith in God was commonly cited as essential in maintaining positive thoughts about cancer outcomes.

[Cancer is] almost like somebody giving the death sentence. And in talking to my pastor, she was able to redirect my thinking back to in whom I believe, and that was where I got my reassurance. [F]

That reliance on faith also helped participants achieve a balanced perspective regarding their lives. Church life and prayer were presented as helpful in maintaining spiritual balance and health throughout the cancer experience; however, some participants pointed out that they did not necessarily equate church life or traditional religious activities with spirituality.

Theme 3. I wasn't left alone—Participants identified family, living companions or partners, friends, coworkers, treatment providers, God, church and their pastor, and support groups as available sources of support. They also reported the importance of support in all aspects of their cancer experience.

I think that it is important to have support when you have cancer. And if some people who step in automatically do things because they want to and usually they're—[you're] never able to do 100% of all the things you used to do the same way. [M]

Family members assisted participants in many important ways, although some participants reported the need to protect family members from knowledge of or contact with their disease. In addition to providing important emotional and decisional support, participants described support networks that extended beyond family and managed everything from treatment and meals to transportation and attending to other daily life activities. Participants expressed tremendous internal and community resources during diagnosis and treatment; however, some also commented on the difficulty of asking for help. Typically, help was accepted rather than requested or even expected. As one woman pointed out, offers of assistance were appreciated. "Any little thing they did was helpful for me. . . . You're used to doing things for yourself—so that you don't want to ask anybody to do anything." [F]

Theme 4. I had no idea down through the years that [money] would get me.

But I just have to deal with it—Even in the study setting, reporting and identifying financial needs were difficult for participants. Despite times of financial hardship, few participants reported requesting or receiving assistance outside of family during their cancer experience. Several who reported receiving assistance from providers, such as medication samples, did not describe receiving this help as a response to a specific request or description of their difficulties. Despite medication costs being a significant burden for many, few reported this as a difficulty when initially asked about financial issues related to their cancer. Discussions surrounding financial concerns were limited among rural and urban men. A few disclosed difficulty with finances, although this was more common in the mixed-gender groups than in the male-only groups. Male participants who did discuss financial issues were more likely to talk about finances in respect to theoretical situations rather than their personal experiences. However, financial concerns were commonly expressed by women, particularly those in the rural group.

My children were there for me—because they had to buy them high-priced pills. I didn't have no money to get them with. I didn't know how I was going to make it, but they were there, and they'd bring money from here and there or whatever, trying to help me. They're still trying to help me with that bill. [F]

Participants also observed that money generally is more of an issue for older adults and retirees. Their reticence to disclose financial difficulties, even when directly questioned, may be explained by the following statement.

I always notice, say, first thing when you come in the hospital, first thing, actually, they want to see your proof of insurance and I have a feeling that maybe if . . . maybe if I didn't have it, would they give me the type of care that I deserve, or the fact that I don't have no money, they might just say, "We ain't going to mess with him too much." [M]

Across the groups, health insurance played a critical role in financing health care. The majority of participants in rural and urban settings believed that if they had not possessed

some type of healthcare insurance, they would not have obtained adequate care because of the high costs of treatment. Having health insurance decreased participants' treatment-related anxiety and reduced the financial hardships that could have resulted in missed appointments and inability to receive treatment.

Discussion

Creation and dissemination of culturally targeted materials through reputable agencies and foundations has been widely accepted as a strategy for delivering health information to culturally diverse populations. However, according to the current study's participants, that approach to health education and, specifically, to cancer-related education, has failed to fill significant health literacy gaps among minority patients, caregivers, and community members. That finding was echoed in another qualitative study of urban African American cancer survivors and their caregivers (Mosavel & Sanders, 2011). Participants in the current study reported their perception of barriers in bringing such information to their communities persisting effectively.

Demographic issues should be acknowledged when implementing cancer-related interventions. Low household incomes were particularly prevalent among rural study participants. Noticeable treatment differences existed among rural and urban participants, with more combined modality treatment reported by urban participants. That may represent differences in access to health care, such as higher concentration of cancer clinics and comprehensive cancer centers in urban areas. Patient preferences for therapeutic regimens requiring less travel also may be a byproduct of the special challenges incurred by rural residents (Van Nostrand, 1993).

One of the important study themes was the nature and degree of family and community support experienced by participants. Participants demonstrated internal and external resources for strength and highlighted those resources as important sources of physical and spiritual support during diagnosis and treatment, when family members and a variety of other individuals provided support and assistance with the management of daily living. Similar to the current findings, African American survivors in previous studies reported giving back in the form of providing support to family, friends, and other cancer survivors as an important coping strategy and source of social support (Hamilton et al., 2009; Swinney & Dobal, 2011). However, previous research with the survivors also revealed some perceived stigma and a lack of support related to cancer, leading to additional isolation during treatment (Hamilton, Powe, Pollard, Lee, & Felton, 2007).

Participants also emphasized the centrality of spirituality as an important source of support. Spirituality has been shown to be associated with well-being during cancer treatment (Visser, Garssen, & Vingerhoets, 2010). Multiple qualitative studies of African American cancer survivors have suggested a link between the spiritual and religious practices of the survivors and perceptions of social support from God and their faith communities (Hamilton et al., 2007, 2009; Swinney & Dobal, 2011; Thompson, Littles, Jacob, & Coker, 2006). Interventionists have demonstrated the value of incorporating spirituality into cancer support programs for African Americans in rural areas (Hamilton et al., 2007, 2009; Martin et al.,

2011; Powell et al., 2005). Recognizing that cultural traits, including spirituality, may serve as sources of support and resiliency in the context of cancer treatment is important when working with African American older adults.

Participants recognized the importance and potential impact of disease-related expenses on the family unit as a whole. As in other studies (Klimmek et al., 2010; Mathews & Park, 2009), few participants reported having discussed financial limitations related to treatment with their providers. Men were particularly unlikely to admit to or raise issues of financial inadequacies or difficulties. A number of participants denied financial issues related to care on initial questioning but later related problems obtaining medication during treatment because of an inability to pay for their prescriptions, underscoring the importance of engaging this population in discussions about financial issues related to cancer care. Older African American cancer survivors from low-income urban neighborhoods face multiple financial challenges related to treatment and medication (Mosavel & Sanders, 2011). In another study, privately insured individuals with cancer were more likely to have better survival rates than individuals with any other insurance (e.g., Medicaid) (Richardson, 2004), demonstrating the vulnerability that comes with low socioeconomic status (SES) and other disadvantages. Insufficient financial and social support also translate to limitations in access to services and higher rates of cancer morbidity and mortality (Antoni & Lutgendorf, 2007; Bayliss, Steiner, Fernald, Crane, & Main, 2003; Jerant, von Friederichs-Fitzwater, & Moore, 2005; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Therefore, racial and ethnic minority cancer survivors with low SES experience worse mortality rates compared to Caucasians of any SES and other racial and ethnic minorities with higher SES (Chu et al., 2007).

The study population was sampled purposively, and study results cannot be generalized to all African American older adults or to all cancer diagnoses. However, the inclusion of men and women from urban and rural communities did yield a broader perspective of barriers faced by African American older adults. Future studies should include more diverse sampling, with greater regional balance in SES.

Conclusions

Healthcare providers must recognize the many facets of patients' lives that can be affected by cancer diagnoses and treatment. Reticence on the part of minority older adults to broach topics such as difficulty paying for treatment is a particularly important area of provider awareness. The current findings corroborate the importance of both social support and perceived financial assistance and support throughout the cancer experience.

For the current study population, support extended beyond family, although providers commonly assign primary support roles to family members. Therefore, differences in types and sources of support may be important to note when developing population-level interventions, or when considering patients' cancer resource needs. Support received during cancer diagnosis and treatment allowed participants to focus on essential life events and promoted emotional and physical well-being.

Study findings can be helpful to providers seeking to address cancer health disparities. The current study addressed an important gap in the understanding of cancer support needs among older African Americans, notably how financial barriers to care continue to be insufficiently addressed even for those patients who are insured. Future studies also should focus on developing interventions to improve supportive resources for patients with cancer, thereby providing patients with the opportunity and resources to focus on their health (Jones, Steeves, & Williams, 2010; Klimmek et al., 2010; Wenzel & Steeves, 2008).

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Implications for Practice

- Healthcare providers must recognize the critical importance of the content and delivery of health education, particularly regarding cancer-related illness.
- Nurses should keep in mind that patients' support networks can come from a variety of sources, including family, significant others, friends, coworkers, and God or church.
- Healthcare providers should engage patients in discussions about specific financial issues related to cancer care.

- What was it like when you found out you had cancer?
- Who were the most important people providing you help during the time you were diagnosed?
 - What were the things that they did for you that were particularly helpful?
 - Were there things that they were not able to do for you that you wish they could have done?
- What issues were most important to you when you had cancer? How did you deal with these issues?
- If there were financial concerns, can you tell us how these concerns impacted your treatment? What would have been the best type of support for you in helping you manage your finances during that time?

FIGURE 1.
Questions for Focus Group Discussion

TABLE 1

Demographic Characteristics by Region

	<u>Rural (N = 20)</u>	<u>Urban (N = 28)</u>	
Characteristic	X ⁻	X ⁻	p
Age (years)	75.4	72.8	0.358
Weeks since cancer diagnosis	276	104	0.005*
Characteristic	n	n	p
Gender			0.952
Male	11	12	
Female	9	16	
Relationship status			0.019*
Married or partner	12	10	
Widowed	4	10	
Single or divorced	4	8	
Number of people in household			0.234
Lives alone	3	7	
Lives with one or more people	17	21	
Education level			0.272
Less than 8th grade	4	1	
9th–11th grade	4	6	
High school graduate or GED equivalency	8	9	
Technical or vocational school	–	2	
Associate degree/some college	2	2	
Bachelor's degree	1	4	
Advanced degree	1	3	
Other	–	1	
Annual income prior to diagnosis (\$)			0.04*
Less than 8,000	4	–	
8,000–14,999	4	6	
15,000–24,999	5	2	
25,000–34,999	–	4	
35,000–49,999	2	2	
50,000 or higher	2	9	
Declined to answer	2	5	
No response	1	–	
Employment status			0.871
Working full-time	1	2	
Working part-time	2	2	
Retired	10	17	
Disabled or unable to work	3	3	

Characteristic	<u>Rural (N = 20)</u>	<u>Urban (N = 28)</u>	p
	X ⁻	X ⁻	
Not working	4	4	
Insurance^a			
Medicare	17	24	0.945
Medicaid	3	1	0.014
Private	7	15	0.498
Cancer type			0.08
Breast	7	16	
Prostate	11	12	
Other	2	–	
Treatment received^a			
Surgery	11	13	0.562
Chemotherapy	5	6	0.774
Radiation	12	25	0.019*
Other	4	4	0.604
High blood pressure	18	21	0.578

* p < 0.05

^a Participants could choose more than one option.

Note. All statistics were calculated using nonparametric methods (Chi-squared or Mann-Whitney Utests) via SPSS[®], version 18.0.