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Exploring the Role of Community Health Workers in Providing Cancer Navigation: Perceptions of African American Older Adults

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Abstract

Purpose/Objectives—To obtain experiential data regarding African American older adult survivors' perceptions of and recommendations on the role of community health workers (CHWs) in providing a cancer navigation intervention.

Research Approach—Focus groups.

Setting—Rural Virginia and urban Maryland.

Participants—48 African American solid-tumor cancer survivors, aged 65 years or older, with Medicare insurance.

Methodologic Approach—Analysis was accomplished through a reflexive process of transcript review, categorization, and interpretation.

Findings—Themes and accompanying categories identified were uneasiness surrounding the CHW role (disconnect between identified support needs and CHW role, essential CHW characteristics, and potential application of CHWs), recommendations to adequately address cancer needs (coordinating cancer treatment and unmet needs during cancer), and the importance of individualized interventions. Participants provided specific recommendations regarding the role of the CHW and how to develop supportive interventions.

Conclusions—Study participants had surprisingly limited prior exposure to the CHW role. However, they stated that, in certain circumstances, CHWs could effectively assist older adult African Americans undergoing cancer diagnosis or treatment.

Interpretation—Study findings can be helpful to researchers and to healthcare providers engaged in assisting older African Americans during cancer diagnosis and treatment. The results

lay a foundation for developing culturally appropriate interventions to assist this at-risk population.

Previous studies have shown that African Americans may experience more barriers to quality cancer care than Caucasian Americans (Gornick, 2000). Those barriers include issues related to the high cost burden of cancer treatment and lack of support resources for patients, families, and caregivers (Chang et al., 2004; Halbert et al., 2002). The risk for poor outcomes is additive in the presence of comorbidities and decreased economic, psychological, and social resources (Aday, Begley, Lairson, & Slater, 1998), in addition to aging (Schneider, Zaslavsky, & Epstein, 2002). In fact, cancer-related disparities are projected to notably worsen among ethnic minorities and older adults (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009).

Cancer outcomes are unequally distributed across racial and ethnic groups, with minorities experiencing worse outcomes, particularly in overall survival (American Cancer Society, 2010; Hayes & Smedley, 2004; Ries et al., 2005). Cancer generally occurs later in life, with more than half of cancer diagnoses occurring among individuals aged 55 years or older (American Cancer Society, 2010), thus increasing the vulnerability of older African Americans. African American older adults enrolled in Medicare are more likely to report poor health than their Caucasian counterparts (42% versus 25%) and are much less likely to have supplemental insurance (Chang et al., 2004).

Several groups (Brandeis University, 2003; Institute of Medicine, 2002) have recommended employing community health workers (CHWs) to help eliminate disparities. CHWs have been described as serving in areas of community outreach and follow-up by helping patients to access health-related services. They also have provided informal counseling, social support, health education, screening, detection, and basic emergency care (Rosenthal et al., 1998; Witmer, Seifer, Finocchio, Leslie, & O'Neil, 1995). By identifying and addressing barriers to adherence to cancer screening or treatment recommendations and working with patients to negotiate tailored plans of care, CHWs have improved care access and cancer screening behaviors, as well as reduced healthcare costs in minority communities, including Black and Hispanic communities (Earp et al., 2002; Liberman et al., 2002; Oluwole et al., 2003). However, it is unclear whether CHWs are able to effectively assist African American older adults, particularly those residing in rural areas, with multiple support issues related to cancer diagnosis and treatment, including the financial aspects of cancer care (Viswanathan et al., 2009; Wells et al., 2008).

Cancer navigation was first introduced in the 1990s and initially described a process of case managing patients to obtain necessary cancer diagnostic and treatment services following screening (Freeman, 2006). However, the success of navigation for all populations affected by health disparities remains unclear. Using a focus group approach, the current authors sought to elicit African American older adult survivors' familiarity or potential exposure to the CHW role, along with perceptions of the CHW role and recommendations concerning the application of CHWs in providing navigation support throughout cancer diagnosis and treatment in both rural Virginia and urban Maryland. Those data were matched to other study aims, which have been described in detail elsewhere (Jones et al., 2011; Wenzel, 2009).

Methods

Focus groups are an increasingly popular research approach that allows participants to share their experiences of and reactions to important issues within the context of a set of peers who are likely to share similar frames of reference and with whom they can engage in

dialogues about commonalities and differences in their perspectives (Kidd & Parshall, 2000). Focus groups are a particularly effective strategy for obtaining valid information from members of vulnerable populations, such as minorities and rural seniors. That may be a result of the advantages focus groups present in providing a data collection strategy that can be less intimidating than one-on-one interviews, in addition to being more efficient. Focus groups provide enhanced opportunities for dialogue and dialectic between researchers and participants, drawing on a strong oral history tradition in both African American and rural communities; inviting participants to describe their experiences was anticipated to be a comfortable and effective approach (Madriz, 2000).

From 2007–2008, a convenience sample of 48 older African American cancer survivors was recruited from community-based centers (churches, barbershops, diners, and primary care clinics) and comprehensive cancer centers in Virginia ($n = 20$) and Maryland ($n = 28$). Inclusion criteria for participation in the focus groups were being aged 65 years or older, a cancer survivor as defined by the National Institutes of Health (0–5 years disease-free post-treatment) (Ries et al., 2005), and residing in rural central Virginia or an urban area in Maryland. As the needs of individuals diagnosed with terminal illness were likely to differ from those of other cancer survivors, they were excluded from the recruitment process. Recruitment strategies included the use of gender-specific flyers and advertising in media generally seen or heard by rural minority individuals. Snowball sampling also was employed to maximize recruitment within this traditionally difficult-to-access population. Focus groups were described as an opportunity for participants to share their experiences of diagnosis and treatment and to offer ideas for designing a future cancer support intervention.

Participants who enrolled in the study attended a single 45–60-minute focus group. Nine groups were conducted (six gender-separated, three mixed-gender). During each session, participants responded to a series of focused questions related to their experiences surrounding cancer diagnosis and treatment, as well as types and sources of support received during treatment (see Figure 1). Participants also were asked to provide suggestions and recommended resources to assist others in similar situations. Perceptions of CHWs and what might constitute their role in the context of cancer support were specifically solicited and are the focus of this article. Institutional review board approval was obtained from Johns Hopkins University and the University of Virginia prior to recruitment. All participants provided informed consent.

Procedures

Because supportive needs might differ by gender (and, by proxy, cancer type), three types of focus groups were held: men only, women only, and mixed gender. That maximum variation sampling approach (Sandelowski, 1995) was used to provide the widest range of individuals and groups to account for the possibility that supportive needs might differ by either gender or cancer type, as noted in prior studies (Matthews, 2003). Sessions were conducted at accessible community facilities that allowed for comfortable, nonintimidating environments. Groups were kept to less than 10 participants to minimize potential loss of data (Richards & Morse, 2006) and were discontinued once data saturation was achieved. Participants were assured that their comments would be reported in a confidential manner. To facilitate this, participants adopted pseudonyms at the beginning of each session; the pseudonyms were used during the session and in subsequent transcripts and research reports. Immediately following focus group sessions, participants were given \$50 to acknowledge their time and travel and to show appreciation for the information they had provided.

Experienced focus group facilitators, who were race- and gender-matched to participants (in the case of gender-specific groups) and familiar with the local community, conducted the sessions. Facilitators were trained using a standardized protocol that specified procedures for

conducting the focus groups; all sessions also were monitored by a member of the investigator team. In addition, all research team members were sensitized to issues of openness and culture. At the beginning of each focus group session, a screening questionnaire was used to obtain demographics, comorbidities, and diagnosis-related information from each participant. Throughout the sessions, facilitators used transitional, clarifying, challenging, and probing questions to yield clearer and more in-depth responses from participants. Additional study staff attended each focus group session to assist participants in completing questionnaires, to manage session-related issues, and to take observational field notes to capture additional data (Kidd & Parshall, 2000). All discussions were tape-recorded with participants' permission and transcribed verbatim. Field notes and postsession debriefings with study team members also were used to enrich interpretations.

Data Analysis

Data analysis was directed by topics included in the focus group interview guide (Madriz, 2000; Morgan & Krueger, 1997). Preliminary coding of concepts followed, with categorization and a search for themes. As data refinement ensued, missing information and the need to modify the data collected were examined. Data were analyzed for themes, patterns, commonalities, and variation, and validated continually by referring back to them. Theme variations were examined, and alterations in coding and theme titles were documented along with the purpose of those alterations. Professionally transcribed and verified interview data were organized and managed using a qualitative analysis software program (FolioViews™). The transcripts, as dialogue records, were carefully analyzed to understand the experiences of the informants. Data from the focus group interviews were analyzed using a method of thematic analysis (Aronson, 1994), guided by questions asked in the focus groups. A multistep analysis plan (Cohen, Kahn, & Steeves, 2000) was used to develop themes in the following manner: (a) identify the smallest units of meaningful dialogue, usually referred to as strips (Agar, 1979); (b) group those strips into categories based on observed similarities; (c) group the categories into larger meaningful units or themes based on observed similarities in the categories; and (d) specify the relationship(s) between the themes in such a way as to take into account the complete context of the participants (historical, cultural, socioeconomic, etc.) (Kockelmans, 1965). Researcher field notes and postsession debriefing notes were used to enrich interpretations of the transcribed data. Descriptive statistics were calculated to describe the sample and further inform the research team. Demographic data were analyzed using statistical techniques available in SPSS®, version 18. All questionnaire data were coded and kept separate from dialogue data to maintain confidentiality of participants.

Trustworthiness was achieved through collection and review of field notes by two observers at the focus group sessions. Researcher field notes were maintained throughout the study and were reviewed for potential researcher bias, as well as possible omissions in data collection. Field notes, analytic memos, and documentation related to study findings also were used to provide a clear decision trail concerning the study, describing and justifying decisions, and actions. Strategic study decisions and researcher thought processes throughout the coding process also were documented (Rodgers & Cowles, 1993). Research decisions and findings were discussed with research team members.

A form of member checking occurred by going back to selected participants via follow-up telephone interviews and having them review and clarify any necessary data-related issues (permission for which was obtained during informed consent) once data were analyzed or interpreted for their particular group. In addition, possible themes from analysis of previous focus group(s) were discussed and compared to those in subsequent focus groups. Anonymity was preserved throughout the process by aggregating data within the focus

groups and by careful review of the transcripts and all study data by the research team to ensure confidentiality.

Results

Forty-eight participants were recruited into the study. Their ages ranged from 65–81 years (median = 74) (see Table 1). Participants were compared using nonparametric methods (chi-squared or Mann-Whitney U-tests) via SPSS on demographic variables between urban and rural participants to assess notable differences by setting. Nonparametric statistics were used because of skewed data. Despite the limited sample, significant differences existed between urban and rural participants. Urban participants had shorter time since diagnosis ($p = 0.005$), higher household income ($p = 0.04$), and more patients who received radiation therapy ($p = 0.019$). In the urban sample, slightly fewer participants reported being married or living with a partner, having more supplemental insurance, and having higher full- or part-time employment. In addition, a slightly higher proportion reported surgical treatment, but those differences were not significant. No significant differences were found in the number of participants reporting one or more comorbidity, but hypertension was reported more frequently by rural participants.

When urban and rural focus group data were compared, few themes differed between groups, so data were aggregated across the two sites. Subtle variations between groups were noted in cases where they were observed. That also was observed when gender-specific groups were compared with mixed-gender groups. The following three themes and accompanying categories were identified across the data set: (a) uneasiness surrounding the CHW role (disconnect between identified support needs and CHW role, essential CHW characteristics, and potential application of CHWs), (b) recommendations to adequately address cancer needs (coordinating cancer treatment and unmet needs during cancer), and (c) a need to individualize interventions.

Theme 1: Uneasiness Surrounding the Community Health Worker Role

Most focus group participants expressed a general lack of familiarity with the CHW role. One participant hypothesized, “I think a lot of people don’t know, because [CHWs] don’t make themselves known, that’s one thing.” When asked to describe a CHW in their community, most related stories of relatives or friends with backgrounds in health care. Some confusion appeared to exist regarding people in the community who might be in the CHW role and those who provided other types of services or support, such as home healthcare workers. One of the few participants who reported some familiarity with CHW activities appeared to be describing a home health aide when she said, “I believe they are community health workers assigned to different—to do different functions such as, maybe help with, you know, someone to go shopping, helping them to clean the house, doing some cooking, and so forth.” One stated,

I know this man [who] used to live not too far from me. These people would come and clean his house and make him make sure he took a bath, they were all men.

They would come up—a group of men would come out to his house, clean his house and straighten it up and, you know, keep his kitchen straight and cook him a meal and make sure he take a bath, but I don’t know whether they were called that or not—a group of people used to come to his house.

Another participant stated,

I had mentioned knowing there are people in the community, but I think they’re connected with Social Service that they are assigned a patient or someone and they go to their house and make sure that they’re okay.

None of the participants reported having worked with a CHW during their own personal experiences of cancer treatment or survivorship.

Disconnect between identified support needs and community health worker role—As discussed previously, focus group participants articulated numerous needs for additional support for older adults with cancer in their communities, as well as roles for CHWs who might meet those needs. However, discussions with both urban and rural focus groups revealed that although participants could envision a potential role for CHWs in the provision of cancer support, most were not able to make an immediate connection between that role and their own supportive needs during their personal cancer journeys. Overall, participants in both groups expressed a desire to have their needs met by a close family member or friend. The general consensus among the groups seemed to be that older adults would continue to prefer the support of a family member or close friend to that of an “outsider,” but in the absence of such a person to provide support, they would consider using the services of a CHW as long as he or she was someone “I could trust and feel comfortable with.” One rural participant focus group member said,

I think most people would rather have their family instead of an outsider, because you know your family. And I’m sorry, the first thing you would be saying, “Well—she better put that back where I had it.” And you feel like your family knows where things are in your home.

A few outliers existed, as shown by a comment from a member of the urban focus group.

I would think that if you could get a CHW there during that time, the initial diagnosis—someone other than family, someone who may get you very familiar with the situation—someone just to be your company.... I think that would be a good thing for them.

Essential community health worker characteristics—In terms of qualities possessed by an ideal or effective CHW, trust came up repeatedly in both the urban and rural focus groups. In the urban focus group, participants suggested that ethnicity, age, or background of a particular CHW was not necessarily important, as long as the older adult felt he or she could trust the CHW. “First of all, you’ve got to find a person that you can really trust. That’s where it’s all about trust. You don’t just let anybody come in,” said one participant. “So you can have trust in them. See, you don’t just pick somebody out the street—I don’t care what kind of degrees they may have. I mean you’ve got to trust the person,” said another. That sentiment was echoed in the rural focus groups. “Age and color has got nothing to do with it,” said one participant. Another stated, “It didn’t matter what color you were or nothing ... long as you treat me right.” Concern related to letting a stranger into one’s home or personal space came up repeatedly in both groups.

A lot of people—don’t even want you to come in the house to do things.... To have someone come in to take over for me would be hard, other than my sister. Because she’s like I said, she’s like a mother and she’s a friend all rolled up into one. So for somebody else to come in—I think it would be hard for me.

Although congruence existed among all groups regarding the importance of establishing trust between older adults and CHWs seeking to provide support, participants had a difficult time describing how such a trusting bond might be established. Some participants expressed opposing preferences, as in the case of participants’ responses to how a CHW might make initial contact with an older adult. One participant from the rural group stated, “Come into my house first.... You can look at a person and tell if you’re going to trust that person or not. You can depict somebody like that.” That person felt that contact by telephone made it much more difficult to get to know someone and build trust, naming other activities the

CHW and she might do to establish a rapport. “Maybe go out to lunch or dinner or something ... I could take you to my church, I’d love to take you to my church.” However, that participant’s preference for face-to-face contact with a CHW contrasted with the sentiment of several other participants in both urban and rural focus groups, who expressed anxiety related to any “outsiders” entering their homes.

Participants articulated a number of essential qualities for an effective CHW to the development of trust, including having a sincere, caring attitude toward older adults; recognizing and respecting older adults’ schedules and routines; and maintaining a consistent, constant presence in the older adult’s life. One participant said,

If you’re confident that person is even sincere, okay, then it’s easier to relate to them than it is to somebody who is here today and gone tomorrow. You know, like you say, [another participant] didn’t need [a support provider] today, and here they are. And tomorrow she need them and then nobody ... it’s got to be somebody you believe that cares, and then you have to understand what it is that has to be done.

An ability to comprehend and accommodate older adults’ various schedules and routines also was acknowledged by some participants.

They have to know from the time they leave the facility that they’re going to see Ms. [X] on Thurs-day at 2 o’clock, because if you’re at my house at 2 o’clock, you come at 3 you would probably not get in. I mean not because I’m getting cantankerous, because if I go upstairs—then come back down the steps is not easy for me ... our lives have made us very untrusting people. It’s a sad situation.... I’m used to a planned schedule and these people who come in to see us have to realize that. You have to stick to the plan; you’ve got to kind of know who you’re dealing with.

Potential application of community health workers—By far, the most frequently discussed role in both urban and rural focus groups was that of a supportive, locally available presence (either in-person or via telephone) who could show compassion, sincere concern, and companionship over the course of an older adult’s cancer journey. One participant said, “That would be something they could do—just come and be a companion and ... just console you a bit.” Another participant stated, “Just somebody to talk to, and somebody to tell you some things to do that you don’t know how to do. Because nobody knows how to do everything and it helps them.” The importance of compassion and sincerity was emphasized strongly.

[Older people in the community are] not comfortable talking to anybody abruptly, you have to handle them in a different kind of a ... you can’t be very stiff in what you’re saying to them. You must be caring and they want to feel that you really do care.

After the role of companion or counselor, the next most commonly discussed role for CHWs was that of a resource to assist with financial and insurance-related matters. Participants also felt that CHWs could provide resources and information on other issues, including treatments, medications, and potential side effects. Participants used descriptors such as “tell me what’s going on” and “get you familiar with the situation” when discussing potential roles for a CHW near the time of diagnosis. Others described how the presence of a CHW at appointments, or assistance in formulating questions prior to appointments, might help them to get the information they were seeking from their treatment teams. A general consensus existed among focus group participants that a CHW might be well-positioned to take additional time to provide or obtain explanations that physicians and nurses appeared unable to address during appointments.

Several participants suggested that a locally available CHW might provide assistance during the recuperation period following treatment or surgery, including help with shopping, meal preparation, and transportation. In one focus group, those suggestions led to the conclusion that although a CHW might not be prepared or able to provide all those types of services, they might have a role in coordinating those services for an older adult during cancer treatment. One participant said,

The first question I would ask, what is the role of the CHW and how do they see themselves? Because I don't think they see themselves as someone that's going to come to your home and provide this service to you.... I think they look at their self more as a counseling-type person. Provide resource information, that's the thing you got to help someone recommended to do these things ... it might not be the goal for [CHWs] to do all the services, because some might require ... higher level professional services. But perhaps they would coordinate getting those services, because coordination is also quite a job in itself.

Discussions that centered around a CHW's role as a support coordinator also led to conversations regarding the importance of clearly defining CHW roles and responsibilities during cancer navigation.

I think it's very important that you look at [the CHW role] because it would be unjust for someone to think that community health person is going to come and provide all these services, so I think that's something that needs to be outlined real well because, the first time you assign someone, a community health person go and visit a patient, believe it or not, 9 out of 10 patients probably get in their mind, "Well, she'll be back Wednesday and she can do A, B, and C," and that may not be the objectives. And I think it's real critical that we define exactly, up front of what's what.

Theme 2: Recommendations to Adequately Address Cancer Needs

When asked how a CHW might provide support to older adults with cancer in the community setting, participants introduced categories of supportive needs, which included assistance with personal finances and paying for treatments, arranging transportation, and household activities or chores such as meal preparation. Participants in the urban focus group also discussed multiple needs related to patient and family education on treatment-related issues such as medications and understanding protocols or consents, although that need was not discussed at length by participants in the rural focus group. Instead, rural focus group participants spent more time sharing personal stories related to financial difficulties encountered during their cancer experiences. A consensus existed among both groups that older adults with cancer face multiple challenges related to limited or fixed incomes. Participants also discussed a need for information and education regarding treatment-related issues, advocacy during appointments with healthcare providers, assistance with coordination of professional services and providers, and social support.

Coordinating cancer treatment—Participants in both rural and urban groups recognized a need for multiple types of additional support and organizational assistance following cancer diagnosis. When discussing their support needs, several participants talked about the numerous tasks associated with daily life during treatment. One talked about coordination of services as “quite a job in and of itself.” Another stated,

I think that it is important to have support when you have cancer ... you're never able to do 100% of all the things you used to do the same way. Because you have so many different things you have to do if you're going to continue to function.

Participants appeared to recognize that, although the CHW might not be able to directly provide all of the supportive services mentioned during the focus groups, that person could function as a coordinator of locally available resources for patients or their families.

Several participants differentiated between the need for additional assistance with household tasks and the need for more professional assistance such as home health care. The fact that those types of aid often were obtained via Medicare, Medicaid, or private insurance companies was seen as a potential barrier for some people, particularly those without private insurance plans. One participant said,

It might not be a goal for [the CHW] to do all of the services, because some might require some higher level of professional services. But perhaps they could coordinate getting those services....

Unmet needs during cancer—Participants in every focus group spent considerable time devoted to discussing the need for assistance with transportation issues during treatment, particularly for older adults who did not have a family member or other caregiver who could transport them to and from appointments, pick up medications, and run other errands such as grocery shopping. Many participants were aware of community services that could provide transportation through vans or buses, although how those resources could be accessed was not always clear. Others reported difficulties related to the fact that their insurance would not cover transportation costs. One participant said, “See, Medicare won’t pay for my transportation. Because, see, I was under Medicare, not Medicaid.” Another stated, “They tell you not to drive, I had to drive myself, maybe once or twice.... Back and forth and take my own treatment. But that would be one of the things—you could drive me around.”

Overall, participants agreed that many older adults would benefit from someone to help guide them through financial issues associated with cancer treatment. One said, “You can tell people stuff, but they don’t have the money to do it.” Another stated, “Sometimes they don’t have carfare; sometimes they don’t have money. They live from ... one month to another.” One participant summarized that notion.

There are some patients who don’t have the slightest idea or knowledge about the financial part of it. How it gets paid, someone might need to deal with the insurance companies. And I think there is a role for [CHWs] there.

Multiple participants brought up financial need related to their medications. Several reported difficulty obtaining their prescriptions during treatment, related to lack of insurance coverage or inadequate funds because of other financial obligations or living on a fixed income.

Prescriptions are a tremendous financial burden on a lot of people. And if you don’t have—I mean a lot of times, your prescriptions are not covered so you get five pills a week, and not being able to get the other 25, or whatever you need for a long time and, in some instances, if you’re a regular patient at a particular pharmacy—well, I used to drive up to [street name] and the pharmacist up there is very nice. He could probably lose his job giving us five pills at a time, I’m sure. I’ve seen him, “Well honey you come back now,” you know, “get your next 5,” because people just don’t have the money.

Several participants from both rural and urban focus groups discussed the need for additional assistance at home following treatment. Those needs ranged from help with grocery shopping and meal preparation to answering the telephone to simply having someone available to help when needed. Some support needs appeared to be treatment specific. One participant reported,

If I had surgery, I would definitely need someone to help me, because I live alone. And I wonder if [a CHW] could fulfill that requirement. That is whatever is needed during that period of my recuperation from the surgery.

Another participant said that the absence of someone to help them following surgery impacted their treatment decision making.

If I knew [a CHW] was available, I think I would have selected surgery. One reason I selected ... directed toward the radiation was that I felt I didn't have anyone who could help me. Once I had the surgery, I was there alone. So that person could be someone who could help me.

Although urban focus group participants were more likely to mention a specific desire for additional treatment-related information, participants in both urban and rural focus groups discussed the need for someone who could not only provide patient education related to treatments, side effects, and day-to-day life during cancer treatment, but who also could "take the time" to perform this role at a pace that would allow older adults to understand and ask questions. As one participant said, "More elaborate answers, you know, more than quick answers that you normally get when you go to a doctor, because he doesn't have the time, and that I understand, but I think that would be very, very helpful." Types of information desired included additional education on treatments and the best ways to prepare for treatment, medications and their side effects, and better explanations of protocols and consent forms. One rural participant also brought up the need for someone to provide anticipatory guidance to family members on appropriate caregiver roles during treatment. The participant related this example of the well-intentioned efforts of caregivers who did not fully comprehend their treatment complications.

It's like everyone was saying, food—when you can't eat your food you feel bad and [family members] cooking all that good food for you and you just smell it and it makes you sick and then some of them would leave and say, "By the time I get back—have that finished," and you're saying to your family, "Right!"

Participants also mentioned the value of having someone accompany them to appointments. They noted that when they had a companion during meetings with physicians or other healthcare professionals, their questions were answered more often and more completely than when they went alone. When older adults were accompanied by a cancer survivor, they perceived that those individuals helped them to "ask the right questions." One participant described how her family members had served as important advocates for her during her appointments with her oncologist: "The questions that they ask [the treatment team] that I wouldn't even think about asking them, they were very good ... I could not go to an appointment without someone being there."

Many participants stressed the importance of additional support for older adults living alone in the community setting. In describing useful types of social support during treatment, they discussed the need to have someone to "sit with you," as well as a desire to have "someone I could just talk to." In at least three instances, participants also discussed the role for a counselor, or someone who could help them "psych up" for difficult treatments such as climbing into a claustrophobic apparatus for radiation treatments.

Even participants who felt they had adequate social support throughout their cancer treatment identified other people in their communities who they felt were at risk for poor outcomes as a result of social isolation. Participants in the study identified older adults living alone as a group who might derive particular benefit from support provided by a CHW in the community setting. One participant reported,

There are lots of people, like lots of people at my church, they don't have anybody.... Just somebody to talk to, and somebody to tell you some things to do that you don't know how to do. Because nobody knows how to do everything, and it helps them.

Another said,

Everything you said is true. I think that when you've been with an older person, because you see a lot of older people don't have any support system. They live alone, they're by their self, they don't have anybody to come in and say, how are you doing, is there anything I can do?

Theme 3: Importance of Individualized Interventions

Discussions regarding cancer needs and the appropriate people to fill them led participants in both groups to emphasize the importance of individualized approaches to the provision of support to older African Americans with cancer. As one urban focus group participant explained, "Everyone's need is a little different.... I think there is a need for some real interfacing and counseling with patients to find out exactly what they need." Another participant said, "I'm sure we all react just a little differently towards our treatment or even cancer itself."

Discussion

African American rural and urban patients with cancer experience multiple health disparities. CHWs are featured predominantly in many interventions to ameliorate existing cancer disparities for minority populations and are now fixtures in some cancer centers, in addition to being implemented through organizations such as the American Cancer Society. However, survivors in the current study largely were unfamiliar with the CHW role, with some noting confusion between CHWs and home health aids. That finding was not surprising in rural Virginia, where professional patient navigators and CHWs have not been widely used, but the general lack of awareness was unexpected in Central Maryland, where longstanding CHW programs have been available to address health disparities across multiple conditions, including cancer screening and hypertension, particularly among African Americans. Therefore, the discussion surrounding CHWs was focused on potential or hypothetical patient needs during the cancer experience, including recommendations regarding the potential inclusion of CHWs in cancer care.

Survivor participants' recommendations were accompanied by some reservations regarding the CHW and patient relationship. Despite a lack of familiarity and some wariness regarding the CHW role, participants emphasized the importance of comprehensive supportive care throughout the cancer experiences and provided key suggestions for the CHW role based on particular support needs they had experienced. Meeting participants' expressed preferences and priorities in establishing an effective and trusting CHW relationship during the process of pursuing cancer diagnosis and treatment was noted by the study team to be a rather daunting task and may require rethinking, reframing, and further evaluation of that proliferating role prior to widespread implementation.

Participants reported formal and informal caregiving support needs during cancer diagnosis and throughout treatment. In addition, some participants revealed their efforts to "protect" or buffer family members from knowledge of or contact with their disease. The tension between downplaying personal needs as a patient and protecting others from the effects of a cancer diagnosis may contribute to unmet needs and suggests the potential for an additional psychosocial burden for patients, which typically is not recognized. Thoughtful

implementation of nurse-led CHW interventions may provide an opportunity to offer necessary levels of support for patients and family members.

Finances also were featured in participant discussions regarding the potential for CHWs to assist in addressing cancer-related health disparities and unmet needs during treatment. High costs related to health care can cause great financial and emotional strain for individuals and can interfere with patients' ability to adhere to their treatment regimen (Wagner & Lacey, 2004). Participants pointed out multiple ways in which financial issues could potentially affect or impair treatment (e.g., transportation, obtaining prescriptions), but access to obtaining assistance with financial resources clearly was limited in this population. Few reported receiving any financial support, counseling, or referrals during treatment, probably because participants in the current study did not routinely report financial resources to their providers. Difficulty paying for treatment among older minority individuals is a topic that needs to be recognized and addressed by providers, particularly as studies have shown that limited financial and social support are associated with higher rates of cancer morbidity and mortality (Jerant, von Friederichs-Fitzwater, & Moore, 2005; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Trained CHWs may be able to help fill that gap because of their greater understanding and familiarity with local economies and available community-level and national resources.

Limitations

The study's sample characteristics may have been a limitation as the majority of the participants were married, had insurance, and lived with at least one other person. Although generalizability is not a usual goal for most qualitative descriptive studies, the current findings should be cautiously interpreted to older African Americans in the mid-Atlantic region of the United States. Finally, participants had little, if any, prior experience with or knowledge of the CHW role, so their recommendations regarding the potential use of this role were not rooted in personal experience.

Despite those limitations, the current study provides data on care coordination identified as problematic for African American older adults living with cancer; a deficit of care coordination support, particularly related to issues surrounding care-related costs, has similarly been reported by women with breast cancer in a previous study (Wenzel & Steeves, 2008). In addition, the participants were able to identify features of the CHW role that could be redesigned to meet cancer-related needs. Specifically, the findings shed light on possible reasons why existing CHW interventions have not proven to be more effective in this population (Viswanathan et al., 2009; Wells et al., 2008). The inclusion of both men and women and of potentially disparate regional groups yields a more comprehensive perspective of barriers faced by African American adults and provides participant-initiated directives to explore intervention-tailoring opportunities.

Conclusions and Implications for Nursing

Clearly, patients and survivors are concerned about their cancer treatment outcomes, but they also must deal with myriad other issues (e.g., financial, emotional, spiritual, social) that affect their lives. Overcoming some voiced reservations, focus group participants reported the potential usefulness of the CHW role as a way to reserve energy for high-priority needs during a difficult time and to maintain emotional and physical well-being throughout their cancer experience. In addition to general support, the role of CHWs in providing financial counseling and referral to community-level and national cancer resources for patients and families is well supported by the current data. Survivor participants had positive views of healthcare providers, particularly physicians and nurses. Provider recommendations or

referrals to CHW-led interventions and nurse supervision or oversight are strongly recommended based on the current study's findings.

Healthcare providers must recognize that many facets of patients' lives can be affected by a cancer diagnosis and accompanying treatment. A survey of oncology nurses demonstrated that they believe nurses have the primary responsibility for addressing patients' psychosocial needs, and the area of assessment and documentation of psychosocial needs can be improved (Gosselin, Crane-Okada, Irwin, Tringali, & Wenzel, 2011). The current findings corroborate the importance of evaluating and appropriately addressing issues surrounding social support and financial assistance during cancer diagnosis and treatment (Institute of Medicine, 2002; Klimmek, Snow, & Wenzel, 2010). Although CHWs are an essential component of many interventions targeted to populations affected by health disparities and are becoming more widely recognized, neither urban nor rural participants in the current study had prior experiences with that particular role. In addition, participants expressed certain reservations that could decrease the overall effectiveness of an intervention solely dependent on CHWs. However, CHWs' prior success in the areas of informal counseling, social support, health education, and basic health care (Rosenthal et al., 1998; Witmer et al., 1995), as well as reduced healthcare costs in minority communities (Earp et al., 2002), are in line with participants' suggestions regarding how that role could be implemented effectively as part of a cancer support intervention targeted toward African American older adults.

More research is needed to better connect all patients with cancer with resources to overcome existing health disparities and improve treatment outcomes. Although the role of the CHW in delivering cancer support interventions has demonstrated some promise in populations affected by health disparities, additional research continues to be needed to evaluate effectiveness. Future studies also should focus on testing and evaluating individually tailored interventions to improve supportive resources for patients with cancer, thereby providing patients with opportunities and resources to focus on optimizing health in all areas of their lives.

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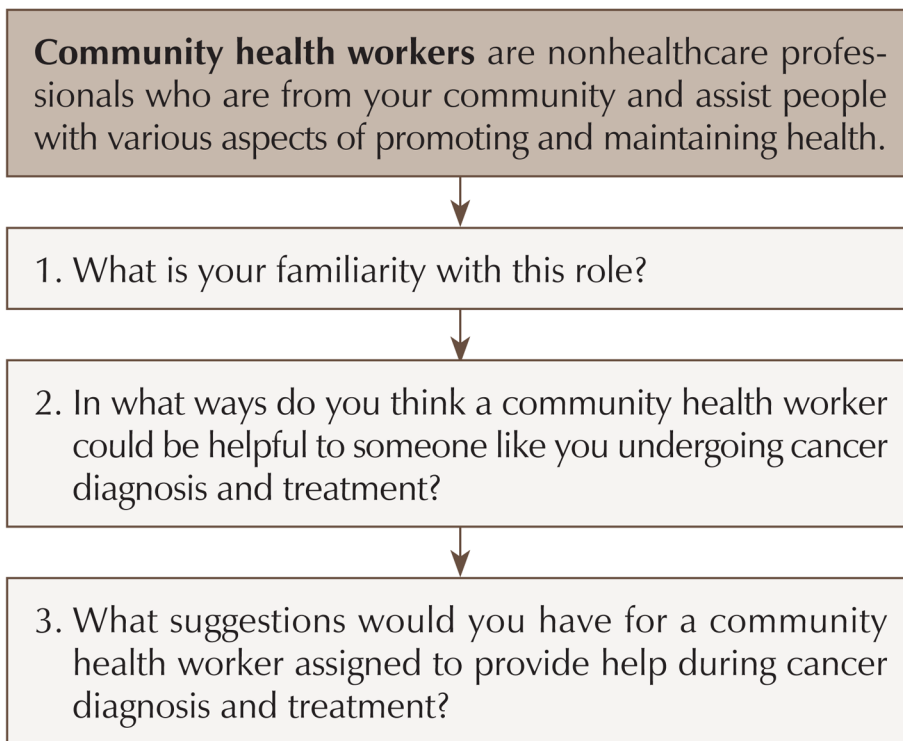


Figure 1.
Focus Group Guide

Table 1

Demographic Characteristics

	<u>Rural (N = 20)</u>	<u>Urban (N = 28)</u>	
Characteristic	X̄	X̄	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 partnered	12	10	
Widowed	4	10	
Single or divorced	4	8	
Household			0.234
Live alone	3	7	
Live with one or more	17	21	
Educational level			0.272
Less than high school	8	7	
High school graduate or GED	8	9	
Technical or vocational school	–	2	
Some college or college degree	4	9	
Other	–	1	
Annual income before diagnosis (\$)			0.04*
Lower than 8,000	4	–	
8,000–34,999	9	12	
35,000–49,999	2	2	
50,000 or higher	2	9	
Declined to answer or missing	3	5	
Employment status			0.871
Full- or part-time	3	4	
Retired, disabled, or not working	17	24	
Insurance^a			
Medicare	17	24	0.945
Medicaid	3	1	0.014*
Private insurance	7	15	0.498
Treatment received^d			
Surgery	11	13	0.562
Chemotherapy	5	6	0.774
Radiation	12	25	0.019*

Characteristic	<u>Rural (N = 20)</u>	<u>Urban (N = 28)</u>	p
	\bar{X}	\bar{X}	
Other	4	4	0.604
Self-reported high blood pressure	18	21	0.578

*
p < 0.05

^aParticipants could select more than one response.