

After Ringing the Bell: Receptivity of and Preferences for Healthy Behaviors in African American Dyads Surviving Lung Cancer

Karen Kane McDonnell, PhD, RN, Otis L. Owens, MPH, PhD, DeAnne K. Hilfinger Messias, PhD, RN, FAAN, Daniela B. Friedman, PhD, Brandi R. Newsome, MD, Callie Campbell King, BA, Coretta Jenerette, PhD, RN, AOCN®, CNE, FAAN, and Lisa A. Webb, PhD, RN, CEN

PURPOSE: To explore receptivity of and preferences for risk-reducing health behavior changes among African American survivors of early-stage lung cancer and their family members.

PARTICIPANTS & SETTING: 26 African American non-small cell lung cancer survivor–family member dyads were recruited from two cancer programs in the southeastern United States.

METHODOLOGIC APPROACH: Social cognitive theory principles guided the design and implementation of focus groups. Descriptive statistics were used to summarize the data, and thematic analysis was used to interpret the transcripts from the focus groups.

FINDINGS: The following four themes were identified: (a) rethinking recovery and identifying information oversights; (b) needing compassion, hope, and understanding; (c) living longer with lingering symptoms; and (d) being willing and able to compromise and change.

IMPLICATIONS FOR NURSING: Participants emphasized the need for improved provider communication. Pragmatic communication interventions for providers, survivors, and family members may facilitate behavior change and improve outcomes among underserved populations.

KEYWORDS survivors; family members; dyads; African Americans; lung cancer; lifestyle behaviors
ONF, 47(3), 281–291.

DOI 10.1188/20.ONF.281-291

Declining incidence and improving survival rates have contributed to an increasing number of lung cancer survivors in the United States (American Cancer Society [ACS], 2019b). The five-year relative survival rate for individuals with lung cancer is 16% for men and 22% for women, with 23% and 6% five-year relative survival rates for those with non-small cell and small cell tumor types, respectively. Unfortunately, only 16% of lung cancers are diagnosed in a localized stage, which has a five-year survival rate of 56% for Caucasian survivors and 52% for African American survivors (ACS, 2019a). A faster decline in the mortality rates of African American men compared to Caucasian men has led to a considerable reduction in racial disparity in lung cancer mortality, from as many as 40% of African American men in 1990–1992 to 18% in 2012–2016 (ACS, 2019a). Cigarette smoking, which accounts for about 80% of all lung cancer burdens, is the leading risk factor for lung cancer, and most lung cancer survivors are former or current smokers (Vijayvergia et al., 2015). Smoking is often associated with other unhealthy behaviors, such as lower physical activity levels and ineffective stress management skills (Chiolero et al., 2006). However, health behavior changes can positively influence survival and improve health-related quality of life (Campo et al., 2011).

Background

Previous research has examined the prevalence of health-related behaviors in lung cancer survivors and their family members (Cooley et al., 2013; Evangelista et al., 2003; Hawkins et al., 2010; Krebs et al., 2012; Park et al., 2012). In a survey of 183 survivors of

early-stage (I–IIIa) lung cancer with no evidence of disease 1–6 years following treatment, 6% of survivors continued to smoke, and 25% reported no physical activity after completing treatment (Evangelista et al., 2003). In another survey of 142 long-term cancer survivors (\bar{X} = 10 years since diagnosis, SD = 3), Krebs et al. (2012) reported that 13% of survivors continued to smoke after diagnosis, and 28% continued to be exposed to secondhand smoke.

It is unclear whether a family member's cancer diagnosis may cause other family members to change their health-related behaviors and which strategies may enhance the possibility of adopting such changes. Cooley et al. (2013) examined cross-sectional data from 37 lung cancer survivor–family member dyads and found high rates of continued smoking (43% of survivors and 30% of family members) and physical inactivity (84% of both groups). However, within six months of diagnosis, 63% of survivors were ready to improve their physical activity levels, and 88% were prepared to stop smoking. Similarly, 81% of family members indicated a readiness to improve their physical activity, and 91% indicated their readiness to stop smoking. The majority of participants were Caucasian and diagnosed with advanced (stage IIIb or IV) lung cancer (Cooley et al., 2013).

Mazanec et al. (2015) also suggested that receiving a cancer diagnosis or having a family member diagnosed with cancer increases awareness of individual health behaviors and one's own cancer risk. Findings from dyadic research on interventions offered to patients with cancer and their family members have acknowledged that cancer profoundly affects survivors, family members, and friends (Badr et al., 2019; Hu et al., 2019). Survivors may need help modifying their lifestyle and may be interested in helping family members change their behaviors as well, but family members may be averse to such changes (Humpel et al., 2007; McBride, Emmons, & Lipkus, 2003; McBride, Pollak, et al., 2003; McDonnell et al., 2016).

African American lung cancer survivors are often underrepresented in research. Although a lung cancer diagnosis may motivate the uptake of positive health behaviors, little is known about the receptivity of and preferences for these changes among African Americans. To address this gap in knowledge, the current study explored the social and behavioral factors associated with risk-reducing health behavior changes among dyads of African American lung cancer survivors and their family members.

Methods

Theoretical Framework and Study Design

A social cognitive theory approach was used to guide this qualitative descriptive study. Social cognitive theory aims to explain why and how people change health behaviors, with a focus on the potential of individuals to alter their environment (McAlister et al., 2008). Focus groups were used to evaluate health behavior changes and experiences of living with lung cancer among family dyads (Marshall & Rossman, 2011). Three researchers developed a focus group discussion guide, which consisted of questions and probes designed to explore the following key concepts of social cognitive theory: reciprocal determinism, outcomes expectation, and self-efficacy (Cypress, 2017) (see Figure 1).

Participants and Recruitment

Adult African American survivors diagnosed with non-small cell lung cancer (stages I–IIIa) from 2008 to 2014 who were willing to invite a family member (defined as a supportive relative or close friend) to participate were eligible for the study. After receiving institutional review board approval from an American College of Surgeons–approved cancer program in the southeastern United States, 178 potential participants were identified by reviewing cancer registries from two American College of Surgeons–approved cancer programs. A one-page recruitment flyer was mailed to each address with a toll-free telephone number to call to register for one of three in-person focus groups.

Participants consisted of 26 survivor–family member dyads. Sixteen survivors were diagnosed after 2012, six survivors were diagnosed before 2010, and four survivors were diagnosed from 2010 to 2012. Family members consisted of six spouses, six siblings, six daughters, one son, and seven close friends. In general, survivors were older than family members and had lower levels of educational attainment. Most participants in the study sample were female (n = 39) and unmarried (n = 30). Sample characteristics are presented in Table 1.

Setting and Focus Group Process

The three focus groups were conducted on separate evenings during a six-week period at a private conference center in a community hospital. The conference center offered free parking, easy building access, and safety. After an informed consent process, participants completed a 20-item self-administered questionnaire that included demographic, health status, and health behavior information. Fruit and

vegetable intake and physical activity levels were measured using five questions from the Behavioral Risk Factor Surveillance System, which is available on the Centers for Disease Control and Prevention website (www.cdc.gov/brfss/questionnaires/index.htm).

A trained African American moderator conducted the focus groups with an assistant serving as a notetaker. The moderator posed semistructured, open-ended questions to facilitate discussions about the transition period following the completion of treatment; participants' confidence in making health behavior changes; the pros and cons of working together to implement those changes; and participants' receptivity of and preferences for changes related to cigarette smoking, diet, and physical activity relative to the time of diagnosis (Stewart & Shamdasani, 1990). The research team discussed the process and participants' responses to the individual questions between each focus group session. To enhance continuity among groups and reduce bias, the same facilitator and setting were used for all focus groups. Each participant received financial compensation (\$50) after completing the focus group session.

Data Analyses

Descriptive statistics were used to summarize responses related to participant characteristics and health behaviors. Frequencies and percentages were used to calculate categorical variables; means, ranges, and standard deviations were used to calculate continuous variables.

A professional service was used to transcribe audio recordings from the focus groups. Each transcript was reviewed for accuracy, and six members of the research team independently read all of the transcripts to become familiar with the content of the discussions. Transcripts were analyzed by three research team members using a six-step thematic analysis method (Braun & Clarke, 2006). To encourage reflexivity, the research team met to discuss initial thoughts, assumptions, and understandings of key concepts (Dowling, 2006). An iterative approach was used to understand the participants' viewpoints, and each researcher independently coded the full transcripts line by line to search for themes. Three of the research team members met on several occasions to compare the individually identified codes and themes and to discuss how well the themes reflected the data. The researchers identified specific quotes that were representative of the themes. Analysis continued until the research team agreed on a consensus.

Findings

Four survivors were current smokers, lived with other smokers, or allowed unrestricted smoking in their homes. Twenty survivors stopped smoking either prior to or immediately following their diagnosis, and two survivors described themselves as having never smoked. Most survivors ($n = 18$) reported consuming five or more servings of fresh, frozen, or canned fruit daily compared to only 12 family members. Overall, participants had a low daily vegetable intake. Only one participant reported engaging in strenuous exercise, such as vigorous

FIGURE 1. Focus Group Discussion Guide

Reciprocal Determinism

Individuals are influenced by their environment and can, therefore, influence it and self-regulate their behavior.

- In your opinion, what do couples or families who have survived lung cancer and treatment need most?
- When an individual is diagnosed with lung cancer, when is the best time for families to make changes to live healthier?
 - Is it right after you learn of the diagnosis or later?
 - What about the timing is important?

Outcome Expectations

The belief that individuals hold about the likelihood of the consequences of their behavior

- How would working together as a family to make behavior changes that promote a healthier lifestyle benefit you and your family?
 - Tell us about a time when you worked together to accomplish a goal or complete a project.
 - What are some of the challenges you might encounter while working together to make health behavior changes?
 - What are some of the challenges you might encounter as you plan to increase your physical activity?

Self-Efficacy

An individual's confidence and belief in his or her ability to change behaviors

- How confident are you that you could work together to successfully make changes to live healthier at this time?
 - Describe types of things that boost or increase your confidence about making behavior changes.
 - What types of things decrease your confidence about making behavior changes?

Note. Health behavior questions were asked in reference to separate behaviors (e.g., physical activity, diet, smoking, stress management).

swimming, bicycling, or jogging once weekly. Three participants reported engaging in moderate exercise (e.g., easy swimming, bicycling, dancing), and seven participants reported engaging in at least 15 minutes of mild exercise (e.g., yoga, bowling, easy walking) on a weekly basis (see Table 2).

The following four themes reflected the views of the participants in the focus groups: (a) rethinking recovery and identifying information oversights; (b) needing compassion, hope, and understanding; (c) living longer with lingering symptoms; and (d) being willing and able to compromise and change. Each theme is discussed and illustrated with sample quotations from participants in the following sections.

TABLE 1. Sample Characteristics by Group

Characteristic	Survivors (N = 26)		Family Members (N = 26)	
	\bar{X}	Range	\bar{X}	Range
Age (years)	67	52-86	54	21-70
Characteristic	n		n	
Gender				
Female	18		21	
Male	8		5	
Marital status				
Married	10		12	
Separated	7		2	
Widowed	5		2	
Single	4		10	
Annual income (\$)				
Less than 10,000	4		4	
10,000-19,999	8		4	
20,000-49,999	7		11	
50,000-99,999	2		3	
More than 100,000	1		1	
Declined to answer	4		3	
Employment				
Retired	12		8	
Unable to work	9		2	
Employed	3		13	
Unemployed	1		2	
Homemaker	1		-	
Student	-		1	
Highest level of education				
Middle school	2		-	
Some high school	6		3	
High school graduate	7		6	
Some college	6		10	
College graduate	5		7	
General health status				
Fair/poor	13		5	
Good	10		14	
Very good	3		5	
Excellent	-		2	

Rethinking Recovery and Identifying Information Oversights

Participants reported having difficulty understanding information presented during encounters with oncology care providers and expressed a desire for clearer understanding of their disease process, risk of recurrence, treatment expectations, and symptom management without the use of medical jargon. One family member (dyad 3) said, “Most doctors talk to you like you really understand what they are trying to tell you, but half of us do not. Break it down simple for us to understand. How can we help our loved ones?”

Because of their inexperience with interacting with providers, participants described themselves as unsure of which questions to ask, and survivors wanted their family member to help them communicate with providers. Participants acknowledged that communication is a two-way process, but many felt unprepared to engage providers in a discussion and pose questions that would elicit the necessary answers. One survivor (dyad 7) touched on the possible influence of race in this area: “Black people don’t go to doctors. We don’t ask the right questions to get the answers we need.” Family members in particular wanted additional information if they were unable to attend appointments with the survivor. Adult children expressed uncertainty about how to access information regarding their parents. One survivor’s daughter (dyad 6) said, “I just need[ed] to know what was happening with my mother when I got there. What can I do to help when she comes home? What do I need not to do? I didn’t get any of that information.”

Participants also expressed disappointment with their providers’ communication about strategies for a better quality of life during survivorship. One survivor (dyad 1) described feelings of being alone and abandoned after completing treatment: “I don’t feel like I am getting what I need. I’m fighting this alone. It’s like you were just left out on a deserted island. There are a lot of professionals out there who could be helping us!”

Several survivors described self-initiated efforts to improve their dietary intake by eating fewer fatty

TABLE 2. Frequency of Health Behaviors by Group

Variable	Survivors (N = 26)	Family Members (N = 26)
	n	n
Smoke-free home (i.e., restricts all smoking inside home)	24	23
Daily intake of fruits (e.g., fresh, frozen, canned)	18	12
Daily intake of beans (e.g., refried, baked, black, garbanzo, soy, edamame, tofu)	4	-
Daily intake of dark green vegetables (e.g., broccoli, chard, collard greens, spinach)	7	2
Daily intake of orange vegetables (e.g., carrots, sweet potatoes, pumpkin)	1	2
Intake of other vegetables (e.g., corn, eggplant, peas, lettuce, cabbage, potatoes)	9	6
Never participated in mild exercise (e.g., light walking, bowling, fishing, yoga) for 15 minutes or longer during the past 7 days	17	11
Never/rarely participated in frequent exercise (i.e., regular activity lasting long enough to work up a sweat or rapid heartbeat) during the past 7 days ^a	14	7

^a Response options were often, sometimes, and never/rarely.

foods and snacks and increasing their fruit and vegetable intake; however, most participants reported having a sedentary lifestyle. Among the survivors who had previously smoked cigarettes, most had stopped smoking shortly after being diagnosed with lung cancer. One survivor (dyad 10) described herself as feeling abandoned and without any specific recommendations for her diet or physical activity. Other participants reported specific needs in terms of health education. One survivor (dyad 12) said,

We need to know not just about the chemo[therapy] that we are going to take. We need to know more from the doctor about other things that we can do to help ourselves. We need to learn more about exercise, diet, and therapy.

Similarly, another survivor (dyad 1) said, “Nobody is teaching me to breathe better, exercise, or eat a better diet. They give you a pamphlet or two and leave you alone.”

Other challenges included confusion about contradictory advice, information, and recommendations from providers versus friends, television, or Internet sources. Participants expressed frustration with their providers’ inability to answer questions, which resulted in many survivors having to self-navigate and persist to find answers from a variety of providers or sources.

You get discouraged when they send you from [one] doctor to another doctor. This doctor can’t answer that question, and the other doctor can’t answer that question. It’s exhausting! I push myself to keep going until I get an answer. If you can’t answer my questions, then I’m going somewhere else. (survivor, dyad 2)

Only one dyad reported satisfaction with the level of care and communication they received from their provider. The survivor (dyad 13) was a 58-year-old employed man whose insurance provided a health coach to help him navigate the healthcare system, rehabilitation, and palliative care services. No other survivor reported having access to these types of services.

Needing Compassion, Hope, and Understanding

In addition to medical treatment, participants reported that they needed more compassion, support, and understanding from their providers and each other. Participants expressed the need for greater empathy, with one family member (dyad 15) saying, “Survivors need doctors to show [they are] caring . . . like you’re concerned. . . . As long as they feel like somebody’s in it with them, then I think that kind of helps them out.”

Several participants discussed the stigma of lung cancer as a death sentence and how they needed

optimism and support. One family member (dyad 20) said, “I think everyone needs a little bit more positive counseling on it not being a death sentence. Survivors need to stay engaged with life.” A sense of shame had forced a few survivors to keep their diagnosis a secret from their adult children and friends. One survivor (dyad 1), who kept her diagnosis a secret for years, described selectively surrounding herself with supportive people: “I surround myself with positive people. If you are negative, then this is the last time you and me [will be] together. I do not get with the people who are naysayers.” One family member also described how the family’s social calendar changed dramatically because the survivor no longer wanted to mingle with friends.

Other survivors identified support needs related to care access, such as scheduling medical appointments or having someone to accompany or transport them to healthcare services. Becoming a caregiver created additional stress for some family members, who often faced competing demands on their time. In some cases, this role adjustment affected the finances and health of the entire family. Many family members described their struggles to help their loved ones maintain their independence:

My dad likes to live on his own. He has a professional aide help him during the day. Some aides have been better than others in helping him with his diet and physical activity. I’m not available to supervise the situation. (family member, dyad 17)

Living Longer With Lingering Symptoms

Although grateful for life-extending cancer treatment, survivors reported experiencing chronic symptoms—particularly shortness of breath, pain, and fatigue—long after they completed the prescribed treatment regimen. These lingering symptoms affected their quality of life as individuals and as a part of the family. Many participants felt unprepared to cope with ongoing or unresolved symptoms, which was a source of distress for dyads:

I still must deal with pain in my chest because of the scar tissue that is left in my lungs. When the doctor told me that I was cancer-free, he didn’t tell me that all this other stuff was [going to] be left in my lungs. (survivor, dyad 11)

Burdensome symptoms were also described as limiting survivors’ physical and social activity and contributing to the family’s level of stress. One survivor

(dyad 2) said the following: “The fatigue is a big issue for me. I loved to dance. I recently got up to dance at a wedding and had to sit down. I can’t dance anymore. I’m not as much fun.” Another survivor (dyad 6) described a similar experience with chronic symptoms and their influence on the family member: “Sometimes the pain will hit you and you crawl up in bed. My daughter thinks I spend too much time in bed.”

Although the notion of engaging in positive behavioral changes, such as increased physical activity, appealed to many survivors, they reported that lingering symptoms often held them back. In addition, some family members feared the unknown consequences of survivors participating in physical activity without companionship or professional guidance. One family member (dyad 14) said, “When my husband exerts himself, he seems like he is struggling to breathe. That frightens me. He pushes himself too often.” Few survivors reported having received assistance with or a consultation for symptom management. Only two survivors reported receiving referrals for pulmonary rehabilitation and palliative care, and one survivor was unable to afford the co-payment for pulmonary rehabilitation. Survivors and family members were also uninformed about how support services could help them.

In some cases, when survivors could not perform the activities that they had been accustomed to doing prior to diagnosis and treatment, it created stress among family members. Survivors and family members reported having wrongly assumed that the survivor would return to a near-normal level of functioning following treatment. Conflicting perceptions and expectations strained relationships among survivors and family members. One survivor (dyad 5) said, “My sister and daughter do too much for me. I tell them, ‘I’m not an invalid!’ I need to move about.” Another family member (dyad 6) noted her concerns about her mother’s low physical activity level: “I want my mom to walk while shopping, and she wants to take the motorized cart. I tell her that she needs to walk to strengthen her lungs. Her doctor has been telling her to walk, too.”

Being Willing to Compromise and Change

Survivors and their family members described the challenges and successes of working together to change their health behaviors, as well as their willingness to change. Although participants indicated that such changes were challenging, many participants were confident that they would be successful because of their previous experiences with other

major health behavior changes, such as smoking cessation: “I’m very confident that we can change. After 44 years, we know each other well” (family member, dyad 12). One male survivor (dyad 13) said, “If I had to give up smoking, [my wife] had to do it, too. This lady used to smoke two packs a day. That [was] about three years ago.”

Several survivors reported that they stopped smoking immediately following diagnosis and described depending on their faith to help them “go cold turkey.” In one dyad, another family member was recruited to also stop smoking because the survivor knew he could not do it alone. Although the family member was reluctant, the pair ended up being successful together. In other dyads, survivors and family members described their reluctance to change: “My mom lives with my family now. She is more dependent on me and my family. If I’m doing all the cooking, my mom is going to eat it” (family member, dyad 6). One survivor (dyad 14) described feeling “bullied” by well-intentioned family members to stop smoking, change eating habits, and increase physical activity: “Since I got sick, I watch a lot of TV. My wife says, ‘You need to get up and walk around the house.’ She is always on me!”

Participants emphasized that a lung cancer diagnosis influences the lives of everyone in the family and noted that change is very difficult. For some dyads, compromising and setting realistic goals for working together was a successful strategy for coping with the diagnosis and resulting changes. One family member (dyad 2) said, “We do a lot of stuff together. We have a senior group at our church. We keep each other encouraged.” Another family member (dyad 19) described using accountability to be successful: “You get to hold each other accountable. I want to make sure my mom make[s] all her appointments. If I can help her to eat healthy and to do better, then I think that’s my job.”

The general consensus among survivors was that their motivation to modify their health behaviors was greatest immediately following diagnosis; however, a few survivors reported that their emotional reaction would have limited them from making changes at that time. Overall, survivors expressed an eagerness to learn practical strategies to improve their quality of life.

Discussion

Social cognitive theory constructs (reciprocal determinism, outcome expectations, self-efficacy and self-regulation) were used to understand the impact

KNOWLEDGE TRANSLATION

- Nurses can address potential and actual health literacy and communication issues among providers, African American lung cancer survivors, and family members to help mitigate these issues and improve treatment outcomes.
 - Meaningful practical solutions are needed to fill information gaps and enhance survivors’ and family members’ comprehension of strategies to maximize self-management of quality of life.
 - African American lung cancer survivors and their family members are receptive to interventions targeting families, which can facilitate risk-reducing health behavior changes and improve symptom self-management.
-

of a lung cancer diagnosis on the ability of survivors and their family members to change individual and family health behaviors following treatment. Based on the findings of this study, lung cancer survivors and their family members struggle to maximize the quality of their lives for years following diagnosis of and treatment for a serious health threat. Many survivors in this study lived with other family members, so everyone in the household needed to understand and compromise about any recommendations for modifying their lifestyle. Participants unknowingly continued several risky health behaviors, such as low vegetable intake and physical activity. These risky health behaviors demonstrate a need for the development of interventions aimed at improving healthy behaviors, such as diet, physical activity, and smoke-free lifestyles, among those recovering from lung cancer and its treatment. Survivors in this study recognized that a cancer diagnosis is an opportunity for survivors and family members to implement health behavior changes; however, a majority of both groups were unaware of the specific behavioral changes and strategies that might benefit them the most. Survivors tended to focus on their diet and made simple changes regarding beverage and food choices.

A recurring theme across all three focus groups was the overwhelming need for comprehensible information and improved, compassionate communication from providers. All participants reported knowledge gaps related to the disease process and management, long-term expectations, symptom management, and recommendations and implementation strategies for diet and physical activity. This lack of clear communication created confusion, tension, and disappointment for participants, which is consistent with previous research (McDonnell et al., 2019; Song

et al., 2012; Thorne et al., 2014; Webb & McDonnell, 2018). Song et al. (2012) explored the perspectives of older African American breast and prostate cancer survivors (N = 15 and 13, respectively) about their communication patterns with physicians; a lack of communication about cancer-related information was the most commonly reported pattern, followed by communication of shared decision making, empathy, understanding, and respect. Similarly, Thorne et al. (2014) examined the communication needs of 125 cancer survivors to better understand their perceptions of poor communication throughout the cancer care trajectory and identified the following three types of poor communication that conceptualized the issue: ordinary misses, systematic misunderstandings, and repeat offenders.

In the current study, participants recommended that providers speak in simple, easy-to-understand terms and engage family members in discussions. This recommendation to bridge serious communication gaps aligns with national efforts from the Institute of Medicine (2004) to improve health literacy. Limited health literacy among American adults has been associated with poor health outcomes and failure to engage in preventive behaviors and to perform self-management regimens for acute or chronic issues. According to Osborn et al. (2011), African Americans with compromised health status are likely to experience low health literacy, which can compound difficulty understanding information and experiencing dissatisfaction with communication from providers (Gabrijel et al., 2008; Morse et al., 2008; Nelson et al., 2011). Most participants in the current study expressed dissatisfaction and felt that their communication with providers negatively influenced their self-confidence with and understanding of the importance of changing behaviors. According to the participants in this study, communication with providers needed improvement.

In a 2006 report, the Institute of Medicine recommended that every survivor receive a comprehensive care summary and follow-up care plan. This individualized survivorship care plan should include recommendations from providers for monitoring and maintaining one's health over time (Institute of Medicine, 2006). In an integrative review of survivorship care plans, Mayer et al. (2015) found that their use is sporadic, and evidence of improved outcomes is limited. Although a commentary by Nekhlyudov et al. (2017) described progress since the Institute of Medicine's 2006 report, they agreed that additional work needs to be done to develop new strategies that

can measure and improve outcomes. None of the survivors in the current study reported receiving a written follow-up care plan following the completion of treatment, which may explain the confusion related to enhancing quality-of-life strategies that participants reported experiencing.

Evidence on the lingering consequences of lung cancer has important implications in clinical settings for the delivery of post-treatment follow-up care. Confusion and knowledge gaps exist among survivors regarding symptom management, smoking cessation, nutrition, physical activity, and stress management, which may impede the ability of survivors to fully recover from treatment and make important health behavior changes. The experience of chronic symptoms negatively influenced survivors' interest and confidence in changing their behaviors in this study, and few participants realized that resources were available to help them. In terms of self-confidence, participants seemed reluctant to insist on improved communication and access to resources from providers. Informational, skills-boosting, and support-building interventions can improve knowledge and quality of life (Northouse et al., 2007).

Participants described the need for compassion, hope, and understanding from their providers and each other. The belief that lung cancer is a self-inflicted, smoking-related disease with a typically poor prognosis can result in fear of discrimination, shame, and guilt for survivors. Stigma can negatively influence self-confidence, physical and psychological symptoms of lung cancer, and health-seeking behaviors (Carter-Harris et al., 2014). African Americans who fear being stigmatized may distance themselves and refuse to disclose their illness to others, which can result in social isolation and loneliness (Chambers et al., 2015; Hamilton et al., 2010; Webb & McDonnell, 2018). Additional research is needed to better understand how the impact of stigma can be lessened for lung cancer survivors.

When patients are motivated to change their behaviors, family members and friends can potentially act as barriers to success (Shin et al., 2014). Although health behaviors tend to cluster in families and social networks (Wells et al., 2017), most health behavior-related interventions focus on individual behaviors (Noonan et al., 2019). Dyadic interventions exploring the effects of family members (and their behaviors) on each other when a family member is diagnosed with a serious illness have increased and have been shown to hold promise (Badr et al., 2019; Badr & Krebs, 2013; Given, 2019; Hu et al., 2019). It is believed

that when a survivor and a family member are treated simultaneously, the well-being of each improves more so than when the survivor is treated alone (Badr & Krebs, 2013). When family members' needs are not addressed, they are at risk for impaired health. Dyads in the current study were receptive to interventions that targeted entire families, indicating that greater emphasis is needed on dyadic interventions.

Limitations

The relatively small convenience sample may not represent all African American lung cancer survivors and family members from the United States or worldwide. For the purposes of this study, a family member was defined as a supportive relative or close friend; therefore, the sample included a diverse selection of family members of early-stage survivors. A more homogeneous group of family members, more recently diagnosed or younger survivors, or survivors with more advanced disease and their family members may have reported different experiences and opinions. The focus groups were conducted in an urban setting in the southeastern United States, and most participants reported a lower socioeconomic status; survivors living in a different locale with a higher socioeconomic status may have more resources available (e.g., educational attainment, access to information sources or computers, financial stability). Although the focus groups were conducted by a trained African American facilitator, were digitally recorded, and were professionally transcribed, some variation among the groups may have occurred. Recruiting participants from two acute care settings may have also added to the potential for variation.

Implications for Nursing

Nurses need to recognize that effective communication is an essential and complex aspect of providing patient-centered care to African American lung cancer survivors and their family members. Survivors and their families may need assistance from providers to properly express their needs and understand available resources and recommendations. Although evidence suggests that making positive health behavior changes improves survival, self-management of symptoms, and quality of life following a lung cancer diagnosis (Krebs et al., 2012), lung cancer survivors and their family members may lack access to this information. Additional research is needed to better understand ways to improve communication among providers, survivors, and family members.

Conclusion

This study provides insight into the receptivity of and preferences for health behavior changes in an underrepresented population of localized lung cancer survivors and their family members (dyads). The findings of the current study suggest that African American survivors and their family members are receptive to behavior changes, with a strong preference for improving communication with their providers and each other. It is essential for providers to understand these findings so that they can better serve families in the African American community by providing the information, support, and training needed to implement health behavior changes and increase overall quality of life. Developing and testing family-focused, culturally sensitive interventions for this vulnerable and historically underserved population can improve health outcomes for all.

Karen Kane McDonnell, PhD, RN, is an associate professor in the College of Nursing; **Otis L. Owens, MPH, PhD**, is an assistant professor in the College of Social Work and core faculty in the Statewide Cancer Prevention and Control Program in the Arnold School of Public Health; **DeAnne K. Hilfinger Messias, PhD, RN, FAAN**, is an Emily Myrtle Smith Professor of Nursing Emerita in the College of Nursing; **Daniela B. Friedman, PhD**, is a professor and chair of the Department of Health Promotion, Education, and Behavior and core faculty in the Cancer Prevention and Control Program in the Arnold School of Public Health; **Brandi R. Newsome, MD**, is a clinical assistant professor in the Division of Pulmonary and Critical Care in the School of Medicine; **Callie Campbell King, BA**, is a research specialist in the College of Nursing; and **Coretta Jenerette, PhD, RN, AOCN®, CNE, FAAN**, is a professor and associate dean of diversity, equity, and inclusivity in the College of Nursing, all at the University of South Carolina in Columbia; and **Lisa A. Webb, PhD, RN, CEN**, is a nurse scientist for the VA Nursing Academic Partnership at the Ralph H. Johnson VA Medical Center in Charleston, SC. McDonnell can be reached at karenkm@mailbox.sc.edu, with copy to ONFEditor@ons.org. (Submitted August 2019. Accepted November 28, 2019.)

This study was funded by an institutional research grant from the American Cancer Society to the College of Pharmacy at the University of South Carolina. During the writing of this article, McDonnell was supported by a mentored research scholar grant (#MMSG-17-152-01) from the American Cancer Society.

McDonnell, Messias, and Friedman contributed to the conceptualization and design. McDonnell, Owens, King, and Webb completed the data collection. McDonnell provided statistical

support. McDonnell, Owens, Messias, and Webb provided the analysis. All authors contributed to the manuscript preparation.

REFERENCES

- American Cancer Society. (2019a). *Cancer facts and figures for African Americans, 2019–2021*. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf>
- American Cancer Society. (2019b). *Cancer facts and figures, 2019*. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2019/cancer-facts-and-figures-2019.pdf>
- Badr, H., Bakhshai, J., & Chhabria, K. (2019). Dyadic interventions for cancer survivors and caregivers: State of the science and new directions. *Seminars in Oncology Nursing, 35*(4), 337–341. <https://doi.org/10.1016/j.soncn.2019.06.004>
- Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-Oncology, 22*(8), 1688–1704. <https://doi.org/10.1002/pon.3200>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Campo, R.A., Rowland, J.H., Irwin, M.L., Nathan, P.C., Griz, E.R., & Kinney, A.Y. (2011). Cancer prevention after cancer: Changing the paradigm—A report from the American Society of Preventive Oncology. *Cancer Epidemiology, Biomarkers, and Prevention, 20*(10), 2317–2324. <https://doi.org/10.1158/1055-9965.EPI-11-0728>
- Carter-Harris, L., Hermann, C.P., Schreiber, J., Weaver, M.T., & Rawl, S.M. (2014). Lung cancer stigma predicts timing of medical-help seeking behavior. *Oncology Nursing Forum, 41*(3), E203–E210. <https://doi.org/10.1188/14.ONF.E203-E210>
- Chambers, S.K., Baade, P., Youl, P., Aitken, J., Occhipinti, S., Vinod, S., . . . O'Connell, D.L. (2015). Psychological distress and quality of life in lung cancer: The role of health-related stigma, illness appraisals and social constraints. *Psycho-Oncology, 24*(11), 1569–1577. <https://doi.org/10.1002/pon.3829>
- Chiolero, A., Wietlisbach, V., Ruffieux, C., Paccaud, F., & Cornuz, J. (2006). Clustering of risk behaviors with cigarette consumption: A population-based survey. *Preventive Medicine, 42*(5), 348–353. <https://doi.org/10.1016/j.ypmed.2006.01.011>
- Cooley, M.E., Finn, K.T., Wang, Q., Roper, K., Morones, S., Shi, L., . . . Hayman, L.L. (2013). Health behaviors, readiness to change, and interest in health promotion programs among smokers with lung cancer and their family members: A pilot study. *Cancer Nursing, 36*(2), 145–154. <https://doi.org/10.1097/NCC.0b013e31825e4359>
- Cypress, B.S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing, 36*(4), 253–263. <https://doi.org/10.1097/DCC.0000000000000253>
- Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher, 13*(3), 7–21.
- Evangelista, L.S., Sarna, L., Brecht, M.L., Padilla, G., & Chen, J. (2003). Health perceptions and risk behaviors of lung cancer survivors. *Heart and Lung, 32*(2), 131–139. <https://doi.org/10.1067/mhl.2003.12>
- Gabrijel, S., Grize, L., Helfenstein, E., Brutsche, M., Grossman, P., Tamm, M., & Kiss, A. (2008). Receiving the diagnosis of lung cancer: Patient recall of information and satisfaction with physician communication. *Journal of Clinical Oncology, 26*(2), 297–302. <https://doi.org/10.1200/JCO.2007.13.0609>
- Given, C.W. (2019). Family caregiving for cancer patients: The state of the literature and a direction for research to link the informal and formal care systems to improve quality and outcomes. *Seminars in Oncology Nursing, 35*(4), 389–394. <https://doi.org/10.1016/j.soncn.2019.06.014>
- Hamilton, J.B., Moore, C.E., Powe, B.D., Agarwal, M., & Martin, P. (2010). Perceptions of support among older African American cancer survivors. *Oncology Nursing Forum, 37*(4), 484–493. <https://doi.org/10.1188/10.ONF.484-493>
- Hawkins, N.A., Smith, T., Zhao, L., Rodriguez, J., Berkowitz, Z., & Stein, K.D. (2010). Health-related behavior change after cancer: Results of the American Cancer Society's studies of cancer survivors (SCS). *Journal of Cancer Survivorship, 4*, 20–32. <https://doi.org/10.1007/s11764-009-0104-3>
- Hu, Y., Liu, T., & Li, F. (2019). Association between dyadic interventions and outcomes in cancer patients: A meta-analysis. *Supportive Care in Cancer, 27*(3), 745–761. <https://doi.org/10.1007/s00520-018-4556-8>
- Humpel, N., Magee, C., & Jones, S.C. (2007). The impact of a cancer diagnosis on the health behaviors of cancer survivors and their family and friends. *Supportive Care in Cancer, 15*(6), 621–630. <https://doi.org/10.1007/s00520-006-0207-6>
- Institute of Medicine. (2004). *Health literacy: A prescription to end confusion*. National Academies Press.
- Institute of Medicine. (2006). *From cancer patient to cancer survivor: Lost in transition*. National Academies Press.
- Krebs, P., Coups, E.J., Feinstein, M.B., Burkhalter, J.E., Steingart, R.M., Logue, A., . . . Ostroff, J.S. (2012). Health behaviors of early-stage non-small cell lung cancer survivors. *Journal of Cancer Survivorship, 6*, 37–44. <https://doi.org/10.1007/s11764-011-0191-9>
- Marshall, C., & Rossman, G.B. (2011). *Designing qualitative research* (5th ed.). Sage.
- Mayer, D.K., Birken, S.A., Check, D.K., & Chen, R.C. (2015). Summing it up: An integrative review of studies of cancer survivorship care plans (2006–2013). *Cancer, 121*(7), 978–996. <https://doi.org/10.1002/cncr.28884>
- Mazanec, S.R., Flocke, S.A., & Daly, B.J. (2015). Health behaviors in family members of patients completing cancer treatment.

- Oncology Nursing Forum*, 42(1), 54–62. <https://doi.org/10.1188/15.ONF.54-62>
- McAlister, A.L., Perry, C.L., & Parcel, G.S. (2008). How individuals, environments, and health behaviors interact: Social cognitive theory. In K. Glanz, B.K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 169–188). Jossey-Bass.
- McBride, C.M., Emmons, K.M., & Lipkus, I.M. (2003). Understanding the potential of teachable moments: The case of smoking cessation. *Health Education and Research*, 18(2), 156–170. <https://doi.org/10.1093/her/18.2.156>
- McBride, C.M., Pollak, K.I., Garst, J., Keefe, F., Lyna, P., Fish, L., & Hood, L. (2003). Distress and motivation for smoking cessation among lung cancer patients' relatives who smoke. *Journal of Cancer Education*, 18(3), 150–156.
- McDonnell, K.K., Hollen, P.J., Heath, J., & Andrews, J.O. (2016). Recruiting family dyads facing thoracic cancer surgery: Challenges and lessons learned from a smoking cessation intervention. *European Journal of Oncology Nursing*, 20, 199–206. <https://doi.org/10.1016/j.ejon.2015.08.006>
- McDonnell, K.K., Owens, O.L., Messias, D.K.H., Heiney, S.P., Friedman, D.B., Campbell, C., & Webb, L.A. (2019). Health behavior changes in African American family members facing lung cancer: Tensions and compromises. *European Journal of Oncology Nursing*, 38, 57–64. <https://doi.org/10.1016/j.ejon.2018.12.002>
- Morse, D.S., Edwardsen, E.A., & Gordon, H.S. (2008). Missed opportunities for interval empathy in lung cancer communication. *Archives of Internal Medicine*, 168(17), 1853–1858. <https://doi.org/10.1001/archinte.168.17.1853>
- Nekhlyudov, L., Ganz, P.A., Arora, N.K., & Rowland, J.H. (2017). Going beyond being lost in transition: A decade of progress in cancer survivorship. *Journal of Clinical Oncology*, 35(18), 1978–1981. <https://doi.org/10.1200/jco.2016.72.1373>
- Nelson, J.E., Gay, E.B., Berman, A.R., Powell, C.A., Salazar-Schicchi, J., & Wisnivesky, J.P. (2011). Patients rate physician communication about lung cancer. *Cancer*, 117(22), 5212–5220. <https://doi.org/10.1002/cncr.26152>
- Noonan, M.C., Wingham, J., Dalal, H.M., & Taylor, R.S. (2019). Involving caregivers in self-management interventions for patients with heart failure and chronic obstructive pulmonary disease. A systematic review and meta-analysis. *Journal of Advanced Nursing*, 75(12), 3331–3345. <https://doi.org/10.1111/jan.14172>
- Northouse, L.L., Mood, D.W., Schafenacker A., Montie, J.E., Sandler, H.M., Forman, J.D., . . . Kershaw, T. (2007). Randomized clinical trial of a family intervention for prostate cancer patients and their spouses. *Cancer*, 110(12), 2809–2818. <https://doi.org/10.1002/cncr.23114>
- Osborn, C.Y., Paasche-Orlow, M.K., Bailey, S.C., & Wolf, M.S. (2011). The mechanisms linking health literacy to behavior and health status. *American Journal of Health Behavior*, 35(1), 118–128. <https://doi.org/10.5993/AJHB.35.1.11>
- Park, E.R., Japuntich, S.J., Rigotti, N.A., Traeger, L., He, Y., Wallace, R.B., . . . Keating, N.L. (2012). A snapshot of smokers after lung and colorectal cancer diagnosis. *Cancer*, 118(12), 3153–3164. <https://doi.org/10.1002/cncr.26545>
- Shin, D.W., Park, J.H., Kim, S.Y., Park, E. W., Yang, H.K., Ahn, E., . . . Seo, H.G. (2014). Guilt, censure, and concealment of active smoking status among cancer patients and family members after diagnosis: A nationwide study. *Psycho-Oncology*, 23(5), 585–591. <https://doi.org/10.1002/pon.3460>
- Song, L., Hamilton, J.B., & Moore, A.D. (2012). Patient–healthcare provider communication: Perspectives of African American cancer patients. *Health Psychology*, 31(5), 539–547. <https://doi.org/10.1037/a0025334>
- Stewart, D.W., & Shamdasani, P.N. (1990). *Focus groups: Theory and practice*. Sage.
- Thorne, S., Hislop, G., Kim-Sing, C., Oglov, V., Oliffe, J.L., & Stajduhar, K.I. (2014). Changing communication needs and preferences across the cancer care trajectory: Insights from the patient perspective. *Supportive Care in Cancer*, 22(4), 1009–1015. <https://doi.org/10.1007/s00520-013-2056-4>
- Vijayvergia, N., Shah, P.C., & Denlinger, C.S. (2015). Survivorship in non–small cell lung cancer: Challenges faced and steps forward. *Journal of the National Comprehensive Cancer Network*, 13(9), 1151–1161. <https://doi.org/10.6004/jccn.2015.0140>
- Webb, L.A., & McDonnell, K.K. (2018). Not a death sentence: Perspectives of African American women living with lung cancer. *Oncology Nursing Forum*, 45(1), 46–54. <https://doi.org/10.1188/18.ONF.46-54>
- Wells, M., Aitchison, P., Harris, F., Ozakinci, G., Radley, A., Bauld, L., . . . Williams, B. (2017). Barriers and facilitators to smoking cessation in a cancer context: A qualitative study of patient, family and professional views. *BMC Cancer*, 17(1), 348. <https://doi.org/10.1186/s12885-017-3344-z>