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# Health behavior changes in African American family members facing lung cancer: Tensions and compromises

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ABSTRACT

*Purpose:* Behavioral interventions targeting cancer survivors often fail to address the clustering of unhealthy behaviors among family members and friends, and the impact of close relationships on behavior change. The study's aim was to identify factors associated with receptivity and preferences for lifestyle behavior change among family members of African-American survivors of lung cancer.

*Methods:* Principles of social cognitive theory guided the design. A descriptive, qualitative study recruited 26 African-American family members of lung cancer survivors from two teaching hospitals in the southeastern United States. A 20-item Information Form collected demographic, health status, and health behavior information. Family members participated in one of three semi-structured focus group discussions.

*Results:* Four major themes emerged: family members and survivors both resisted the caregiver role; dramatic changes evoked by the diagnosis of lung cancer were facilitators and barriers to lifestyle choices; leaning on faith was the primary source of support; and these families live with a constant threat of multiple cancers. Findings emphasize the importance of meaningful conversations among health-care providers, survivors, and family members during the time of diagnosis, treatment, and recovery, so that family members are better prepared to cope with anticipated changes.

*Conclusions:* This study highlights the stressors that affect family members and sheds light on their unique needs. The stressors limit their ability to change health behaviors. Family members need basic education, skills training, and support related to the lung cancer diagnosis and other cancers. Current methods to provide these services are limited in their accessibility, availability, and effectiveness.

## 1. Introduction

Patients seldom make important health decisions alone. In part, this is because patients' decisions affect not only themselves but also the health and well-being of others, particularly family members and close friends (Janis and Mann, 1982). Evidence exists that continued unhealthy lifestyle behaviors after a diagnosis of lung cancer can adversely affect the patient's quality of life and prognosis (Campo et al., 2011; McDonnell et al., 2014). Behavioral interventions targeting cancer survivors often fail to address the clustering of unhealthy behaviors among family members and friends, and the impact of close relationships on behavior change (Ozakinci et al., 2010). Yet, the closeness of these relationships may be leveraged to facilitate lifestyle behavior change among patients and their family members alike (Hawkins et al., 2010).

Typically, family members receive no preparation, information, or support to perform their inherited role as a primary caregiver. Family members do not always have a choice in becoming caregivers, and they often have little time to come to terms with the diagnosis while also preparing for their new roles. Family members' responsibilities include providing emotional and practical support, while coping with their own concerns, including the uncertainty surrounding the course of the illness, fear of losing a family member, and the impact of their own health behaviors on the patient. The burden on family members can be

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strenuous, as patients with lung cancer experience long-term unresolved symptoms such as dyspnea and fatigue (Ellis, 2012). Often, family members lack information and guidance from providers about the survivor's long-term needs and experience distress because of all the uncertainty (Given et al., 2012; Kim and Given, 2008; Vijayvergia et al., 2015).

There has been a recent increase in the amount of research exploring the cancer experience within families and the potential influence of that experience on lifestyle behaviors (Cooley et al., 2013; Howell et al., 2016; McDonnell et al., 2014). In a large, primarily Caucasian, and well-educated sample of family members (N = 583), more than half of the participants preferred a family-based approach to behavior change interventions. There was also a large preference for weight management and nutritional education (Howell et al., 2016). Further, Cooley et al. (2013), in a study of primarily Caucasian participants, found that more than 60% of family members each had two lifestyle risk factors for lung cancer, and more than 20% had three risk factors. Most family members were interested in health promotion programming that addressed diet, exercise, stress management, and smoking cessation. Finally, in a small, interventional pilot study conducted immediately after survivors' diagnosis, the dyadic sample (N = 16) was 100% Caucasian. Family members in this study were in concordance that a family-based, multiple-behavior intervention that included smoking cessation, weight management, and physical activity was preferred over a single-behavior intervention for survivors only (McDonnell et al., 2014).

African-American family members have not been well represented in previous research. When coping with a lung cancer diagnosis in the family, African-American family members may face even greater hurdles due to disparity in care and cultural beliefs about tobacco, lung cancer, and treatment options (Alberg et al., 2013). African Americans tend to wait longer to seek treatment and have a higher incidence of lung cancer than their white counterparts (Lathan et al., 2015). These factors may add an additional burden to an African-American family member caring for a lung cancer survivor.

In addition to research gaps due to a lack of racial representation, some existing evidence is conflicting. Several studies have indicated that survivors with cancer are interested in helping their family members in efforts to modify behaviors, such as smoking cigarettes or getting insufficient physical activity (Bottorff et al., 2009; Garces et al., 2011; Schnoll et al., 2013). Yet, many such family members and friends are reluctant or unwilling to participate (Bottorff et al., 2009; Falba and Sindelar, 2008; Robinson et al., 2010). It is unclear whether family members can be directed into healthier lifestyles at the life-changing moment of a cancer diagnosis and, if so, the best strategy for influencing them.

The aim of this study was to identify factors associated with receptivity and preferences for lifestyle behavior change among family members of African-American survivors of lung cancer, and to identify their preferences for lifestyle behavior change. To the authors' knowledge, the current study is the first to examine the preferences and receptivity of African Americans to change their health behaviors following a lung cancer diagnosis in one of their family members.

## 2. Methods

### 2.1. Design

Social cognitive theory (SCT) seeks to explain why and how people change health behaviors, and the social and physical environments that influence them. SCT focuses on individuals' potential to alter their environments using a broad range of approaches to modify diverse behaviors (McAlister et al., 2008). This descriptive, exploratory study used focus group methodologies to elicit sharing of perspectives and experiences from family members of lung cancer survivors. An Interview Guide was developed by the research team to explore key concepts of SCT—namely, reciprocal determinism, outcomes expectation, self-efficacy, and facilitation/behavioral capability.

### 2.2. Participant selection, recruitment, and ethical considerations

For the purposes of this study, a 'family member' included any individual the survivor considered to be a major source of support. Living in the same household as the survivor was not a requirement. Eligibility criteria required that all participants be at least 21 years old, be invited by a survivor to attend, and be able to speak and read English. The primary recruitment method was a mailed invitation (a one-page, culturally sensitive invitation, mailed twice) indicating a toll-free telephone number to RSVP for the study or get more information. Two local IRBs approved the request for a partial waiver of consent so the research team could access contact information of eligible survivors through the cancer registry at two American College of Surgeons–approved cancer programs in the southeastern USA. The invitation was sent to 178 individuals who had been diagnosed with stage I, II, or IIIa lung cancer within a 7-year timeframe (2008–2014). A substantial number of invitations (n = 46, 26%) were returned due to unknown addresses. An equal number of survivors responded to telephone calls as did not respond (n = 66, 37%). Once contact was established, subsequent phone calls were made to speak with family members (Friedman et al., 2012; Stewart et al., 2015). Informed written consent was obtained from all participants. Each participant received a monetary incentive ($50 USD) as a "thank you" gift for participation.

### 2.3. Instruments and data collection

Participants completed a 20-item, self-administered Information Form that collected demographic, household, health status, and technology use information. This form included five items from the 2015 Behavioral Risk Factor Surveillance System Questionnaire, available on the Centers for Disease Control and Prevention website (www.cdc.gov/brfss/questionnaires/index.htm), to measure fruit and vegetable intake and physical activity levels. African-American moderators with experience facilitating focus groups used a scripted, semi-structured Interview Guide with open-ended questions to collect data (see Table 1). Questions probed the following risk behaviors: tobacco use, secondary smoke exposure, poor nutrition, lack of exercise, and stress management. Questions were also posed to evaluate receptivity to and preferences for behavior change.

### 2.4. Data analyses

Descriptive statistics were used to characterize the sample using the Statistical Package for the Social Sciences, version 22.0. A professional service transcribed the digital audio recordings verbatim. The primary author reviewed each audiotape to maximize observations, discussion climate, and recall. Six members of the research team (KKM, SO, DKHM, LW, SH, CC) independently read the transcripts to become familiar with the content of the discussions. Three research team members (KKM, LW, CC) used a six-step, thematic analysis method developed by Braun and Clarke (2006) to review the transcripts. To encourage reflexivity—an acknowledgement of how individual experiences and prior knowledge influence interpretations of the data—the team met to discuss initial thoughts, assumptions, and understandings of key concepts (Dowling, 2006). Initially, using an iterative approach to understand the participants' viewpoints, each reviewer independently coded the full transcripts line by line and began searching for themes. The three reviewers met on several occasions to compare the individually identified codes and themes, as well as to assess how well the themes reflected the discussions. The researchers discussed specific quotes that were representative of the confirmed themes. Upon data saturation, the analysis was considered complete and the themes were finalized.

**Table 1**
Focus group discussion topics and questions based on social cognitive theory.

| Topic | SCT[a] Construct | Questions |
|---|---|---|
| Impact of lung cancer diagnosis | Reciprocal determinism | How did the diagnosis of lung cancer and its treatment impact you and your family? |
| Changes in family lifestyle since the diagnosis of lung cancer to reduce cancer risk | Outcome expectation | ▪ As an example, the American Cancer Society recommends that everyone avoid being inactive and exercise at least 150 min per week. Knowing your own level of physical activity now, is that a good recommendation for you? Why or why not?<br>▪ The National Cancer Institute recommends that everyone stop smoking or using tobacco and protect themselves from other people's cigarette smoke. Would that be a major lifestyle change for you and your family members? Why or why not?<br>▪ Research suggests that food choices may affect risks of additional cancers and survival from cancer. The American Cancer Society recommends limiting red meat like beef and processed meats like bacon, hot dogs, and luncheon meats; and eating about 2½ cups of fruits and vegetables (plant foods) every day. Knowing the foods you eat every day, is this a good recommendation for you? Why or why not? |
| Managing stress | Outcome expectation | ▪ As a family member, how did you manage the stress that comes along with a serious illness?<br>▪ What effect did that stress have on your family? |
| Advice received from providers | Facilitation/behavioral capability | ▪ As a family member of a survivor of cancer, what type of advice have you received about living healthier?<br>▪ Who spoke with you about it? Was it a physician, nurse, dietician, social worker, another survivor, a friend, or family member? |
| Confidence and preferred timing for lifestyle changes | Self-efficacy | ▪ How confident are you that you can make a change to live healthier at this time?<br>▪ In your opinion, when a person is diagnosed with lung cancer, when is a good time to make changes to live healthier?<br>▪ Is it best immediately after you learn of the diagnosis, or is it later? |

[a] SCT = social cognitive theory.

## 3. Results

### 3.1. Participant profile

A total of 26 African-American family members were recruited. Some participants (n = 6, 23%) were related to long-term survivors, defined as those diagnosed before 2010. A majority (n = 16, 62%) were related to survivors diagnosed since 2012. In terms of family relationship type, there were equal numbers of spouses, siblings, and daughters. Five participants (19%) were male and included 2 spouses, 1 brother, 1 son, and 1 close friend, all of whom lived in the same household as their associated survivor. Family members' mean age was 54 years old (Table 2). Nearly half (n = 12, 46%) were married. Most participants were high school graduates who had completed some college coursework (n = 16, 62%). Almost half (n = 12, 46%) were employed, and nearly a third were retired (n = 8, 31%). A majority (n = 19, 73%) reported a household income of less than $50,000. Of the 26 participants, 21 (81%) described their health as good to excellent.

### 3.2. Lifestyle behaviors

Only 2 participants (8%) described themselves as current smokers (Table 3). The majority (n = 22, 84%) lived in smoke-free homes. More than half (n = 14, 56%) reported not eating one serving of fresh, frozen, or canned fruit daily. Consumption of cooked or canned beans and vegetables was less frequent than fruit. No one reported daily consumption of beans, dark green, or orange vegetables. A dozen (46%) reported eating 1–3 servings of beans, such as black beans, garbanzo beans, soybeans, edamame, or lentils, daily; roughly half reported weekly consumption of dark green (n = 15, 58%); orange-colored (n = 11, 42%); and other types of vegetables such as tomatoes, corn, peas, lettuce, cabbage, or white potatoes (n = 13, 50%).

Almost half (n = 11, 42%) reported never or rarely participating in exercise that required minimal effort, such as easy walking for more than 15 min. Few reported participating in strenuous exercise (like running, jogging, vigorous swimming, or skating) for more than 15 min weekly. Only 2 (8%) reported doing so three times a week. Half (n = 13) reported mild exercise for more than 15 min several times per week, including bowling or easy walking. During weekly leisure-time activities, 19 family members (73%) reported engaging in regular activities long enough to work up a sweat.

**Table 2**
Sample characteristics.

| Characteristic | n (%)[a] |
|---|---|
| Annual income (USD) | |
| 4999 or less | 4 (15%) |
| 10,000–19,999 | 4 (15%) |
| 20,000–49,000. | 11 (42%) |
| 50,000–99,000. | 3 (12%) |
| 100,000 or more | 2 (8%) |
| Refused to answer | 2 (8%) |
| Employment | |
| Employed for wages | 12 (46%) |
| Self-employed | 1 (4%) |
| Retired | 8 (31%) |
| Unable to work | 2 (8%) |
| Out of work > 1 year | 2 (8%) |
| Student | 1 (4%) |
| Homemaker | 0 |
| Highest educational level | |
| Some high school | 3 (12%) |
| High school graduate | 6 (23%) |
| Some college | 10 (38%) |
| College graduate | 7 (27%) |
| General health | |
| Poor | 1 (4%) |
| Fair | 4 (15%) |
| Good | 14 (54%) |
| Very good | 5 (19%) |
| Excellent | 2 (8%) |
| Marital status | |
| Married | 12 (46%) |
| Single | 10 (38%) |
| Separated | 2 (8%) |
| Widow | 2 (8%) |

*Note.* N = 26; mean age = 54 yr (range: 21–70).
[a] Percentages in column may not sum to 100% due to rounding.

### 3.3. Technology accessibility

Availability and use of technology were assessed for future intervention delivery. All family members had a working television in their home; most used cable services (n = 23, 89%) and watched health programming (n = 23, 89%). More than half had a working computer (n = 15, 58%); fewer had a working tablet (n = 10, 39%), had a

**Table 3**
Lifestyle behaviors of family members.

| Lifestyle Behavior | n (%)[a] |
|---|---|
| What is your smoking status? | |
| Never a smoker | 18 (69%) |
| Former smoker | 5 (19%) |
| Current smoker | 2 (8%) |
| Declined to answer | 1 (4%) |
| Do you restrict all smoking in your home? | |
| Yes | 22 (85%) |
| No | 4 (15%) |
| In the past month, how many fresh, frozen, or canned **fruit** servings did you eat daily/weekly? | |
| Not daily | 14 (54%) |
| Daily: 1–2 servings | 11 (42%) |
| Daily: 3 + servings | 1 (4%) |
| Not weekly | 17 (65%) |
| Weekly: 1–2 servings | 1 (4%) |
| Weekly: 3 + servings | 8 (31%) |
| In the past month, how many cooked or canned **beans** servings did you eat daily/weekly? | |
| Not daily | 26 (100%) |
| Not weekly | 14 (54%) |
| Weekly: 1–2 servings | 6 (23%) |
| Weekly: 3 + servings | 6 (23%) |
| In the past month, how many **dark green vegetables** servings did you eat daily/weekly? | |
| Not daily | 24 (92%) |
| Daily: 1 serving | 2 (8%) |
| Not weekly | 11 (42%) |
| Weekly: 1–2 servings | 5 (20%) |
| Weekly: 3+ | 10 (38%) |
| In the past month, how many **orange vegetables** servings did you eat daily/monthly? | |
| Not daily | 24 (92%) |
| Daily: 1 serving | 2 (8%) |
| Not weekly | 15 (58%) |
| Weekly: 1–2 servings | 4 (16%) |
| Weekly: 3+ | 7 (26%) |
| In the past month, how many **other vegetables** servings did you eat daily/monthly? | |
| Not daily | 20 (77%) |
| Daily: 1 serving | 5 (19%) |
| Daily: 3 servings | 1 (4%) |
| Not weekly | 13 (50%) |
| Weekly: 1–2 servings | 4 (12%) |
| Weekly: 3 + servings | 9 (38%) |
| In the past 7 days, how often did you engage in **mild exercise** for > 15 min? | |
| No mild exercise | 11 (42%) |
| 2–3 times | 7 (27%) |
| 4–5 times | 4 (16%) |
| 7 times | 4 (16%) |
| In the past 7 days, how often did you engage in **moderate exercise** for > 15 min? | |
| No moderate exercise | 12 (46%) |
| 2–3 times | 7 (27%) |
| 4–5 times | 5 (19) |
| 7 times | 2 (8%) |
| In the past 7 days, how often did you engage in **strenuous exercise** for > 15 min? | |
| No strenuous exercise | 21 (81%) |
| 2–3 times | 5 (19%) |
| In the past 7 days, how often did you engage in any regular activity long enough to **work up a sweat** (heart beats rapidly)? | |
| Never | 7 (27%) |
| Sometimes | 12 (46%) |
| Often | 7 (27%) |

[a] Percentages in categories may not sum to 100% due to rounding. The number of total responses to each question varied across the survey because the survey did not require that respondents answer all questions. Some participants left select questions blank, thus altering the number of responses per question. In addition, for some questions, more than one answer choice could be selected.

working smartphone (n = 14, 54%), or used text messaging for communication (n = 13, 50%). Participants described no preferences for intervention delivery method.

### 3.4. Focus group themes

Four major themes emerged: family members and survivors both resisted the caregiver role; dramatic changes created by the diagnosis of lung cancer were facilitators and barriers to lifestyle choices; leaning on faith was the primary source of support; and these families live with a constant threat of multiple cancers. Each theme is described with representative quotations in the following sections.

#### 3.4.1. Resisting caregiving

Caregiving and care receiving are demanding. Family members described reluctance and discomfort with their new roles as caregiver, decision maker, and medical care manager. Some family members had taken on caregiving responsibilities, but others acted only in a supportive role to the survivor. A daughter stated, 'After thoracic surgery, my mom moved in with me. I stayed away from home as much as possible, to be honest.' Many family members described caregiving as being a difficult issue. Some family members were reluctant to become caregivers, and others described survivors as being resistant to caregiving because they were worried about being a burden or losing their independence. One family member said, 'My mom is supposed to wear oxygen. She resists it. Do you know how hard it is to tell your sixty-something-year-old mom that she needs to wear oxygen while dodging something she is throwing at you?' This reluctance on the part of the family member, coupled with the survivor's resistance, created tensions.

Many family members dealt with the burden of shared decision making about treatment after the cancer diagnosis. This was intimidating and new to family members, who had become accustomed to the survivor being independent or in an authoritative role (e.g., as a parent or spouse). One daughter said:

> I was shocked. My dad went in for a physical and they discovered a spot on his lung. The next thing I know, we are in a surgeon's office. I guess that is one decision I regret. I didn't seek a second opinion. I was so shocked I agreed to the surgery. I think I made the wrong decision.

Some family members shied away from the decision-making role because they perceived it to be an overwhelming responsibility. One family member had advised her dad to have thoracic surgery, not fully realizing the complications that could and did arise afterward. Since then, she had felt the burden of guilt for pushing him into treatment and thus now resisted giving advice because she did not want to make the wrong decision.

Some family members felt daunted by the responsibilities of managing medical equipment, prescriptions, and doctor's appointments for the patient. A middle-aged niece caring for her elderly aunt with lung cancer was frightened when the provider prescribed oxygen and her aunt required oxygen tanks to be stored at the niece's house. She said, 'I never seen so much oxygen. They brought all this oxygen to my house and I says, "Lord, have mercy." I really didn't want to deal with it.' The niece was afraid of something going wrong with the tanks while she was responsible for them and felt stressed by maintaining and learning to use the equipment. She eventually had the equipment removed from the home and the aunt was forced to manage without oxygen.

Despite the resistance to caregiver responsibilities, social support helped many family members feel better about their new roles. One spouse described how a life coach, provided through their health insurance, dramatically helped her get through the struggles of her husband's diagnosis and treatment. The wife said, 'My husband kept his concerns to himself to protect me. I was afraid. I needed someone to talk to who had some answers. This coach helped me to be a better support.' This coaching service was provided over the telephone and available around the clock. Health-care providers and insurance companies did not offer any of the other 25 family members the services of a health coach or similar support.

*3.4.2. Dramatic changes complicate lifestyle choices*

Lives were transformed for all families after the lung cancer diagnosis. Along with being asked to modify their own lifestyle to support the survivor (i.e., through diet restrictions, exercise, smoking habits), family members also dealt with their own emotions, as well as unexpected reductions to the survivor's capacity to accomplish routine activities. Adopting new behaviors was difficult for many. One family member described feeling as if she had received a divine ultimatum: 'God came into my heart and said, "I'm not pleased with your lifestyle."' Not all family members were willing to change a behavior completely, but many were willing to compromise. They worked to make lifestyle changes that were in their control. Family members most often described simple diet changes (e.g., increasing water intake, switching to some whole grain foods) to move toward a healthier lifestyle with the survivor. Most family members, even those who were still smoking, insisted on creating a smoke-free home to help the survivor.

Other family members made lifestyle changes because the survivor was no longer physically able to perform former activities. Family members described how survivors continued to have problems with unresolved symptoms. One said, 'It still hurts me when she can't breathe sometimes, because she's got two half-lungs.' Another family member said:

> I regret that my cousin can no longer take long walks with me. She no longer has the stamina and often needs to use oxygen. The lung cancer has changed both of our lives. I don't like to walk alone.

Some family members described the impact of the lung cancer diagnosis on their social networks. They distanced themselves from negative people who made the survivor feel awkward in public, or from smokers or others who didn't support a healthy lifestyle, as they tried to keep the survivor in a positive mood. Some family members indicated that they felt they needed to stay strong for the survivor and other family members, and therefore withheld their own emotions—something that was very stressful for them.

*3.4.3. Facilitators and barriers to lifestyle change*

*3.4.3.1. Facilitators*. Family members identified facilitators to change, including family support, positive communication, and smoke-free environments. They frequently discussed children and grandchildren as motivators to change. Pleas by these younger people to lead a healthier lifestyle had a persuasive effect on the adults to change their unhealthy behaviors. One family member shared, 'We have two kids, and they would say, "Daddy, you're killing us. You're killing both of us, Daddy. Please stop smoking."' A few family members were willing to make lifestyle changes in solidarity with the survivor. One family member (a spouse) was very reluctant to stop smoking. She said of her husband (the survivor):

> He was not gonna quit smoking if he saw me smoking. It took much longer for me to be successful. I had to work alongside him and sacrifice for him. It was very difficult for me to stop smoking. But, I did it.

Most (though not all) family members understood that the survivor needed support to make major lifestyle changes, and that those changes could help prevent others from developing lung cancer. Some family members made lifestyle adjustments alongside the survivor to support the survivor's challenging behavior changes. For instance, one wife agreed to go to the gym with her husband to support him exercising. She did not exercise while there, but she felt that by at least going, her husband would be more motivated to go and exercise. Another family member, a daughter-in-law who did most of the cooking for the family, agreed to cook brown rice instead of white rice and to omit fried foods from the menu. It was difficult for the daughter-in-law to make these subtle changes, but she did it anyway for the good of the survivor and the family.

Many family members said they were more receptive to changing their lifestyles when they received advice as suggestions instead of as demands. A daughter said, 'Quality of communication was an important factor in determining my receptivity to change.' Demands felt too cumbersome and created tension, while suggestions felt achievable.

Family members appreciated smoke-free environments like restaurants and other facilities. Participants discussed establishing a smoke-free home, with a few even putting up signs to indicate to guests that no smoking was allowed in or around their homes. One said, 'I had to put up a sign that oxygen was in use to stop some friends from smoking in our home. Smoking inside our home was a difficult routine to stop.' Family members expressed feeling discouraged when others were reluctant to honor their no-smoking restrictions while visiting in their homes.

*3.4.3.2. Barriers*. Three barriers to behavior change were time demands, finances, and survivor attitudes. Lack of time was identified as a major barrier to implementing lifestyle changes. Many family members said they lacked the time to take basic care of themselves, so making personal lifestyle changes presented an additional challenge. One family member said, 'You do stuff you have to do for the sick people, but when you get back, you ain't really got time to do it for yourself.' Family members' new responsibilities as a caregiver, and as (in many cases) the one and only means of transportation for the survivor as well as other family members, further infringed upon their time economy. New responsibilities were added to existing ones, which included full-time employment, attending college, and/or caring for their own children.

Family members also discussed finances as a barrier to making lifestyle changes. Gym memberships, smoking cessation medications, and healthy foods were cost prohibitive to many participants. One said:

> It's hard when you choose whether to feed your family healthy or to put the roof over their head, you know? I buy blueberries. They are healthy for me. Blueberries are expensive, but it beats getting sick and going to the doctor, which costs a $60 co-pay. I try to find discounted food to buy.

The moods of survivors and family members were also a barrier to making lifestyle changes. Survivors would become agitated, abrasive, and hard to work with, while family members would feel discouraged, depressed, and defeated. One family member said:

> After a while, it's hard to get along with them. My mom became nasty and mean, taking her bad mood out on other people. So, when we try to control her diet [she says], 'You can't tell me what to do, I'm your momma.' So, we just deal with that.

Another family member said, 'I'm not going to argue with you. You my mama, but we eat vegetables every day. If you live with us, so do you.' One family member worried that her 'encouragement to increase her physical activity or follow a healthier diet came across as bullying.' Many family members felt that they were not fully informed on what changes they should be making with survivors. They also felt that they were getting conflicting or confusing advice from other family members and friends. One said:

> Several friends at church advised us to stay home from services because being around other people might increase my sister's (survivor) risk of a serious infection. The doctor told me that my sister's immune system was not at risk at that time. Isolating her from church was a bigger problem.

*3.4.4. Leaning on faith*

Coping and finding resiliency were important to family members. When overwhelmed with feelings of stress, worry, helplessness, underappreciation, and fatigue, many family members turned to their faith to help them cope. One family member said, 'Help when you can, walk away when you can't.' Many turned to prayer. 'Pray for patience with

the patient' was one family member's mantra. Many described strong reliance on their faith in God: 'I cried and prayed and turned it over to God,' one family member stated. One family member described the faith her husband's illness prompted in her:

> He survived leukemia. He is a determined man with a strong will to live. He doesn't share a lot with me about his lung cancer because he doesn't want me to worry. I do a lot of praying for the both of us. My faith in the Lord is my strength.

#### 3.4.5. Living with the specter of cancer

Compounding the situation, some family members were supporting multiple people with cancer or other serious illnesses, or were supporting a survivor with multiple cancers. One said:

> Cancer runs in our family. My older sister started with colon cancer, cervical, ovarian, and then I think it spread to her pancreas. My sister with lung cancer kept it a secret from me. She didn't want to share any more bad news.

Other family members shared similar stories about a variety of family members with cancer. The threat of cancer, along with the associated fears of cancer appearing in someone else, was a concern among most participants. One said, 'My father died with it, my aunt died with it, and so, it's like, when we hear the news, you kinda get upset in a sense, but then you say, we gotta work through this too.'

Loss, fear, and stress accompanied the day-to-day responsibilities and sacrifices of caring for someone with lung cancer. Many survivors also had multiple comorbidities like chronic obstructive pulmonary disease (COPD) that led to additional life-limiting consequences. One described the constant worry after a diagnosis of cancer: 'Having that diagnosis, there's always that sword over your head. You wonder, when is it gonna come back?'

## 4. Discussion

Social cognitive theory was used in this study to understand the impact of a lung cancer diagnosis on a family member's ability to change his or her own health behaviors. SCT recognizes the importance of family influences on lifestyle behavior modification (McAlister et al., 2008). Support that family members gave to the survivor with respect to lifestyle behavior changes had positive and negative influences. The positive influences illuminate the potentially substantial changes family members can inspire in a survivor. The negative influences reveal the notable relationship and communication tensions associated with family caregiving (Mosher et al., 2013; Wittenberg et al., 2017).

### 4.1. Lack of access to resources

Notably, only one employed survivor and family member were offered the services of a 'life coach' by their health insurance company. Others really liked this idea but were not offered it. The service was free, convenient, and easy to access to the one family who received it, and the coaching assisted with the day-to-day management of the complex role of caregiving.

Some family members recognized the importance of changing behaviors and were agreeable to doing so along with the survivor, but cited cost as an impediment. Smoking cessation medications, gym memberships, senior programs, healthy living programs, consultations with a nutritionist, and access to cooking classes sounded attractive but cost prohibitive. One family member suggested that access to a psychiatrist or counselor for the family member and survivor during the diagnosis period would have helped them manage challenging decisions upfront.

### 4.2. Culturally different motivations

Contrary to previous research involving family members with mostly Caucasian backgrounds (Cooley et al., 2013; Howell et al., 2016; Mazanec et al., 2015; McDonnell et al., 2014) these results emphasized that family members had more of a desire to improve or make health behavior changes in support of the survivors, as opposed to being motivated predominantly by the (perceived) lessening of their own risk of cancer or other diseases like heart disease and diabetes. In this study, participants describe their health as good to excellent, but their health behaviors needed improvement. Only half reported eating one serving of fresh, frozen, or canned fruit daily; and dark green or orange vegetables were consumed less frequently than fruit. Almost half (42%) reported no physical activity, whereas most of the other participants (50%) reported mild activity like easy walking or bowling for more than 15 min several times a week. Family members were interested in learning about lifestyle behavior change and willing to facilitate change in support of another person. They described having no preferences for future intervention delivery formats (e.g., face-to-face, home-based, or mobile app) but were receptive to receiving information and counseling.

In the three studies of family members with mostly Caucasian backgrounds, most participants were receptive to participation in a lifestyle management program, and some preferred a family-based approach (Cooley et al., 2013; Howell et al., 2016; McDonnell et al., 2014). In this study, family members described experiencing gaps in information about the survivor's condition, long-term health-care and support needs, and clear recommendations about lifestyle changes. The lack of clear guidance negatively impacted family members' confidence about managing behavior change. The consensus among family members was that lifestyle changes were important to make for the survivor's sake, but these changes took a lower priority because they were so busy coping with the numerous changes brought about by this diagnosis of lung cancer and other life-threatening illness(es) in the family. The caregiver's resulting lack of attention to their own needs (diets low in fruits and vegetables, lack of exercise) has been observed in many caregiving situations among individuals (Northouse et al., 2012a, 2012b).

### 4.3. Engaged family members

In this study, women described their responsibilities as caregiving for multiple family members. African-American households, in general, are more likely than Caucasian households to contain multiple generations; to be led by females; to have extensive social networks composed of both nuclear and extended family members, non-kin, and church family; and to have children being raised by extended kin, such as aunts, uncles, and grandparents (Warren-Findlow and Prohaska, 2008). Traditional African-American cultural values include women taking on the central role within the family. While African-American women who lead households are perceived as strong caregivers, many have considerable intergenerational caregiving responsibilities (Moras et al., 2018). This has an impact on family dynamics and the home environment that affects the ability to regulate health behaviors.

Family members (of both genders) described being deeply engaged in the life of the survivor, which did not allow them the time to address their own health and adopt health-changing behaviors. Family members were providing an array of social support and direct help (housing arrangements, transportation, shopping, cooking assistance). The family members' emotional, social, financial, and practical needs were often unrecognized and unmet. The women, regardless of relationship (mother, daughter, daughter-in-law, sister), resisted or struggled to cope with the changes imposed by their new and unexpected role of 'caregiver' or 'support person.' These disruptions in role or lifestyle led to communication challenges and conflict with the survivor of lung cancer. The care of the survivors left the family members unable to

identify and attend to their own daily needs. It also hindered family members' ability to seek support from outside the family—which, in turn, led to social isolation.

### 4.4. Faith in god will enable change

Religious faith in God was the most common source of support and strategy for stress management for family members. Some described a strong relationship between their faith and their belief in the ability to make health decisions and lifestyle changes. Family members felt responsible for improving their own health and that implementing a healthier lifestyle was possible with God's help (Ammerman et al., 2002). Evidence exists that faith-based organizations may be receptive to providing enhanced health-related or support services to survivors of cancer and their family members. More research is needed to better understand how faith-based organizations might integrate cancer support services into their established outreach efforts to promote spiritual health and physical well-being (Leyva et al., 2017).

### 4.5. Recommended strategy

Family members recommended strategies to relieve some of the burden and stress of caregiving, as well as help them make personal lifestyle changes. As a priority, they expressed the need for more tailored information and education about survivors' prognosis and plan of care. In this study, none of the family members received a written plan of care or survivorship care plan (SCP) after treatment was completed. More than a decade ago, the National Research Council (NRC) and Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* recommended that every survivor with cancer receive a comprehensive care summary and follow-up plan (IOM and NRC, 2006). This individualized SCP should include recommendations for monitoring and maintaining one's health over time. Originally, it was assumed by the IOM committee that the SCP's benefits would be so obvious that providers would rapidly adopt the use of SCPs. However, an integrative review of SCP research found that use of the plans remains sporadic, and the evidence of improved outcomes is very limited (Rowland et al., 2006). SCPs are challenging to implement for a variety of reasons (Birken and Mayer, 2017). More research is needed to facilitate implementation as well as involve survivors and their family members in the SCP conversation.

## 5. Limitations

Focus group methodology has several limitations. Primarily, focus groups use a relatively small convenience sample and are not meant to be representative of all African-American family members of lung cancer survivors from within the United States or worldwide. Our sample included a variety of types of family members of long-term survivors diagnosed with localized lung cancer between 2008 and 2014. More-recently diagnosed survivors, or those with more advanced disease, and their family members may have different experiences and opinions.

Although the focus groups were conducted with an Interview Guide by trained African-American facilitators and scribes, and were digitally recorded and transcribed professionally, some variation among the groups may have occurred. Using two acute care settings may have added to the potential for variation.

## 6. Conclusion

This study provided valuable insights about the need to develop lifestyle behavior interventions with a vulnerable population of African Americans—family members of survivors of lung cancer. A key strength of this study was the sample, which captured a population historically underrepresented in similar studies. Participants were very open to discussing the informational gaps not resolved by providers, their own fears, and obstacles that they had (or were working to) overcome as they managed the burdens of a serious illness in one or more family members. Primarily, understudied issues were targeted to enhance understanding of receptivity and preferences for behavior change on the part of family members related to the growing population of African-American survivors of localized lung cancer. Secondly, this study targeted African-American lung cancer survivors—a group about which there is a huge gap in the literature regarding lifestyle behavior change. This study may be used as a guide for the development, testing, or adaptation of future support programs aimed at filling information gaps, creating materials that are understandable to the target audience, skills training, and support needs related to lung cancer diagnoses.

Caring for a survivor with lung cancer can be an emotionally and physically draining experience. Without adequate support, family members are at risk for psychological distress and medical problems that can adversely affect their own health as well as the survivors' outcomes. Interventions are needed to support family members. Spirituality was the most common source of support identified by family members. Building or expanding relationships with faith communities to enhance health or cancer ministries devoted to assisting those dealing with lung cancer to develop programs that are free, convenient, and easy to access is justified. Guided by the four emergent themes, training programs can be developed that relate more effectively to family members caring for lung cancer survivors, thus helping to facilitate lifestyle changes. Such programs would help manage stress, enhance social support, and effect positive lifestyle behavior changes in both survivors and their family members.

## Declarations of interest

None.

## Conflicts of interest

None.

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