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Living with Symptoms: A Qualitative Study of Black Adults with Advanced Cancer Living in Poverty

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In the United States, blacks experience the highest death rate and shortest survival of any racial/ethnic group for most cancers. The reasons of these inequalities are multifactorial and reflect social and economic disparities more than biological differences (American Cancer Society, 2016). Poverty and the associated limited access to resources has been identified as contributing to poor health and well-being (Pickett & Wilkinson, 2015). Blacks are disproportionately represented in the lower socioeconomic strata -- 24% of Blacks live in poverty compared with 9% of whites and 21% Hispanics (Kaiser Family Foundation, 2013).

Cancer is associated with disease-related and treatment-related symptoms. A symptom is a subjective experience reflecting changes in biopsychosocial functioning, sensations, or cognition of an individual (Dodd et al., 2001). Most people diagnosed with cancer experience symptoms at some time in their disease continuum. Common symptoms experienced in advanced cancer include pain, fatigue, reduced appetite, weakness, lack of energy, dry mouth, constipation, early satiety, and dyspnea (Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011; Walsh, Donnelly, & Rybicki, 2000). In a sample of individuals in an ambulatory palliative care service, 98% reported the presence of symptoms and 85% reported at least one severe symptom (≥6 on 0–10-point scale) (Riechelmann, Krzyzanowska, O'Carroll, & Zimmermann, 2007).

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Symptoms rarely occur in isolation. Instead, these frequently emerge in pairs or clusters, even when unrelated to each other (Kirkova & Walsh, 2007; Miaskowski, Aouizerat, Dodd, & Cooper, 2007). The presence of clusters is influenced by primary cancer site, sex, age, and performance status (Jimenez et al., 2011). Different symptom clusters affect quality of life and performance status differently. In a study of individuals with cancer, pain and fatigue were associated with a reduction of physical well-being and performance status, fatigue and insomnia were related to a decline in cognition, and depression and pain were linked to a decrease in social well-being (Ferreira et al., 2008). Cheung, Le, and Zimmerman (2009) found two symptom clusters in their study of individuals with advanced cancer: 1) fatigue, drowsiness, nausea, decreased appetite, and dyspnea, and 2) anxiety and depression. Fan, Hadi, and Chow (2007), in a study of individuals receiving palliative radiation therapy, found three clusters: 1) lack of appetite, nausea, poor general well-being, and pain; 2) fatigue, drowsiness, and shortness of breath; and 3) anxiety and depression. To understand the symptom experience, more information is needed to describe how symptoms occur together and interact.

Despite the disproportionate burden of cancer experienced in the black community, the experience of blacks living with symptoms of cancer has not been adequately addressed in the literature. Most of the research on racial disparities in cancer symptoms has examined pain, and these investigations have elucidated that disparities exist in the assessment and treatment of cancer pain. In studies comparing blacks with other racial/ethnic groups, blacks experience more pain and are more likely to under report pain (Anderson, et al., 2000; Anderson, et al., 2002; Bonham, 2001; Ezenwa, Ameringer, Ward, & Serlin, 2006; Im, et al., 2007). Physicians too often underestimate pain severity and undertreat pain in blacks (Anderson, et al., 2000). In a nationwide study of 4704 cancer survivors experiencing pain, blacks were more likely than whites to experience individual, provider, and system level barriers to pain management (Stein, Alcaraz, Kamson, Fallon, & Smith, 2016). Furthermore, limited research has been conducted to explore cancer symptoms other than pain among the black community.

The objectives of this study were to explore the symptom experience of blacks with advanced cancer by describing the symptoms these individuals experience and how these symptoms affect their day-to-day lives. In addition, this study narrated the experience of black cancer patients living in poverty, a community with a high disease burden, whose perspectives are rarely included in research. Because the symptom experience of black individuals with advanced cancer has been largely unexplored, qualitative methods are most appropriate.

METHODS

A descriptive qualitative approach was used to provide an insider's account of the experience of living with symptoms (Sandelowski, 2010; Sandelowski, 2000). Data collection involved semi-structured interviews with symptomatic individuals with advanced-stage cancer. The goal of using this qualitative approach was to learn about this experience and how symptoms affected day-to-day life directly for poor black individuals with cancer.

Participants

A total of 59 individuals were recruited from oncology clinics of an urban public hospital in a large southeastern city. Eligibility criteria included (a) being 21 years of age or older; (b) being an English speaker; (c) self-identifying as black (African American or other ancestry); (d) living in a personal residence and not in a skilled care facility or hospital; (e) having a diagnosis of advanced cancer, defined as metastatic or locally advanced refractory disease per medical record review; (f) experiencing ≥2 symptoms of moderate severity per the Edmonton Symptom Assessment Scale (ESAS); (g) having minimal financial resources (self-reported personal income below federal poverty level); (h) being determined by a health care provider to be mentally competent and capable of providing informed consent; and (i) being physically able to tolerate a 1–2-hour interview as determined by the individual's health care provider.

Symptom severity was assessed with the ESAS, which uses a visual analogue numerical scale of 0 to 10 (0 = no symptom, 10 = worst possible symptom). A score of ≥4 on the ESAS scale was defined as a moderate level of severity (Given et al., 2008) and used to determine eligibility into the study. The ESAS is a valid and reliable instrument to assess symptom severity. Extensive testing (test-retest, content validity, concurrent validity, predictive validity, and sensitivity and specificity), often with individuals with advanced cancer, has been completed (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991; Chang, Hwang, & Feuerman, 2000; Richardson & Jones, 2009). The ESAS measures nine symptoms: pain, fatigue, nausea, anorexia, dyspnea, drowsiness, insomnia, depression, and anxiety. A 10th symptom, "feelings of well-being," and an optional 11th symptom, constipation, also were assessed.

In addition to these criteria we used purposive sampling to capture a diverse sample of individuals managing advanced cancer and to find cases that were information-rich. Specifically we sought to get a mixture of different cancer diagnoses and individuals at different points along the cancer continuum. Since the majority of the participants had been living with cancer for years, a participant was selected later in the study who had just been diagnosed with advanced cancer and was deciding about treatment. Overall, sampling was aimed at interviews that offered a range of experiences and depth of narrative.

Data Collection

The study protocol was approved by the institutional review board at the university and the research committee at the hospital. Participants were recruited over 10 months, from August 2010 through May 2011. Of the 59 recruited participants, a total of 27 individuals gave informed consent and completed the study. Thirteen of the 59 recruited patients were not eligible, three were not interested, and sixteen were scheduled for an interview but did not complete the interview. Reasons for not completing the interview included death (1), hospitalization (2), sickness (1), and lost to follow-up (12).

Audio-recorded interviews were conducted at the clinic or hospital (11) and participants' homes (16). Before beginning the semi-structured part of the interview, the participant completed the ESAS and a demographic survey. All but two interviews were completed with two interviewers present—the principal investigator (a white female nurse researcher) and a black retired female nurse who had worked most recently as an organizer for a residential community. The second interviewer was included with the intention of increasing the level of trust with the interview process as she brought a perspective more grounded in the community. Interviews were audio recorded, transcribed by a professional transcriptionist, and checked for accuracy. Interviews ranged between 22 to 82 minutes, averaging 60 minutes. An interview guide, designed on the basis of a literature review, which included opened-ended questions and suggested phrases to probe for answers (if needed) was used during the interview process. Sample questions were as follows: (1) What symptoms have you had in the last week (last month, last year)?; (2) Tell me about what happens when you experience (symptom).; (3) How do the symptoms affect your day?; and (4) Tell me about what a day is like for you when you are having (symptom).

At the conclusion of the interviews, the participants were thanked and compensated for their input and time; participants were given a $20 gift card for a local grocery store and a coupon for free parking at the clinic or a public transportation token.

Data Analysis

Content analysis (Hsieh & Shannon, 2005) started with open coding in which the researcher read through the transcripts and identified comments that reflected one key thought. Each code was defined and organized in a codebook created by the first author and two additional persons (a clinician in palliative care and a skilled qualitative researcher). Regular meetings between these coders included discussions to reach consensus on the codes. Next comparisons of the codes allowed for examination of how codes were similar and different, eventually resulting in the grouping of codes with similar meaning together to create broader categories. These categories were then used to organize and group data into meaningful clusters or themes. Two additional qualitative experts validated the thematic organization by participating in the analytical decision-making process and reaching consensus when inconsistencies in the interpretation of the data occurred. An audit trail was used to document all processes and collaborations, and data decisions were documented as part of an audit trail.

FINDINGS

The demographic and clinical characteristics of the 27 participants are summarized in Table 1. Many types of cancer were represented in the sample; the most common cancers represented were breast (9) and lung (8). Fourteen of the 27 participants were recruited from the palliative care clinic, and the others were recruited from various oncology clinics. The mean age of the sample was 57 (range 30–79) years.

The Symptom Experience

In addition to the qualitative interviews that allowed the individuals to discuss symptoms in their own terms and context, quantitative symptom data were collected using the ESAS. Participants reported at least two symptoms of moderate severity at study entry. The ESAS was administered to determine eligibility during the screening process and then again before starting the interview. Table 2 shows the ESAS scores at both the screening visit and the interview visit, using a 0 to 10 scale, where 0 equaled the absence of the symptom or the best state and 10 represented the worst symptom or state. The time between the screening assessment and interview varied from participant to participant but the mean severity rating was highest for pain at both time points (6.19 at screening and 5.26 at the interview) followed by tiredness (5.15 at screening and 5.22 at the interview). A paired-samples t-test was conducted to compare the symptom severity at the screening and interview time point. No significant differences between symptom scores at the two time points were noted except for depressive symptoms and drowsiness. Mean severity scores for depressive symptom at screening (M=3.78, SD=4.00) and at the interview (M=1.56, SD=2.75) were significantly different (t(26)=3.80, p = .001). Mean severity scores for drowsiness at screening (M=3.41, SD=3.66) and at the interview (M=2.15, SD=2.92) were significantly different (t(26)=2.55, p = .017).

As demonstrated by both the ESAS assessments and the qualitative interviews, study participants experienced multiple symptoms. ESAS includes assessment of pain, fatigue, nausea, anorexia, dyspnea, drowsiness, insomnia, depression, anxiety, and constipation. The findings of the ESAS were sometimes referred to in the interview to initiate the discussion. The interviewers did not specifically ask about any symptoms not assessed by ESAS. Once the discussions were initiated, we found that participants spoke of many other symptoms not included in the ESAS, including balance disturbances, cognitive changes, cough, diarrhea, dizziness, fear, flatus, hair loss, hoarseness, loss of libido, respiratory congestion, skin sores, sleep difficulties, sore throat, swallowing difficulties, swollen extremities, changes in taste and smell, tingling, burning, numbness in extremities, difficulties urinating, visual changes, vomiting, and worry. During the interviews participants discussed an average of ten different symptoms with a range of five to fifteen. Participants' descriptions included current as well as past symptom experiences. Participants described changing intensity and quality of the symptoms over the course of their illness experience. In addition, multiple symptoms often co-existed, thereby contributing to greater distress. The analysis of the interviews found two main themes that described the symptom experience: 1) living in pain and 2) symptoms associated with functioning in everyday life. The primary symptom theme described was pain. Most descriptions of pain were physical, however, emotional pain was also noted. All participants, except one, spoke about pain and stated that they began to experience it around the time of their cancer diagnosis. The second theme, symptoms associated with functioning in everyday life, explained how symptoms changed the way participants ate, moved, and communicated. Before they started experiencing cancer symptoms, basic activities such as eating a meal with their families, walking to the bus stop, or meeting deadlines at work were taken for granted. Participants often compared their current experience to life before symptoms. Participants now experienced symptoms daily, which altered their everyday activities. Pseudonyms of participants (e.g. Ms. G) are used in the following discussion of the findings.

Living with Pain

Many participants described that they first learned they had cancer because of the onset of physical pain, and others related that they knew their cancer had returned because of the recurrence of pain. Cancer treatments also caused pain for many. Most participants experienced pain during the study interview. Most experienced a variety of pains over time associated with different causes. The descriptions of physical pain related to diagnosis, treatment, or just day-to-day life. Often participants spoke of emotional pain that related to the physical pain.

Many participants spoke of severe pain related to treatment. Participants described a full body achiness that occurred after chemotherapy. One person reported that “every bone in your body is aching” and another said “even my toenails hurt.” Three women spoke of the pain from skin burns that they received from radiation treatment for their cancers (lung, breast, or cervical), and each speculated that they had received too much radiation. Ms. C said the burn felt like having hot grease thrown on her skin. Ms. G described this pain when asked about the location of her pain:

> *All the way through my back, they burnt my whole chest up, I don’t know if you see two different colors up here or not. It was burnt. It’s just like a scratch and you been burnt with a hot iron and you know if you scratch it, it blister up. When I scratched it all my skin came off in my hand from the radiation. I didn’t even know I was burnt like that. It was burnt on the inside and the outside, all the way through to my back.*

In contrast with pain known to be caused by treatment, the source of most pain was unclear and was accepted as part of the cancer experience. The characteristics of the pain changed over time and sometimes consumed their lives. Some said the pain from their cancer hurt more than anything they experienced in their past, and they worried about what the pain foreboded; others expected to experience some pain related to their advanced cancers. Mr. T, who before his cancer diagnosis would ride his bicycle all over town, now walked with a cane because of the discomfort from the large tumor on his left thigh. He wished for a day without pain and shared a description of the location and quality of his pain.

> *If I could just have one day of just, just no, just no pain, you know, just one day like it used to be without the pain, it would be so wonderful. So now since they did the radiation, I don’t have as much severe pain as I use to have, but I still have pain. I mean a lot of pain and the pain ranges from my thigh, to my knee, to my ankle, and it is a very aggravating, sharp pain that make you wish you didn’t have it.*

Participants spoke of physical pains with different qualities, in different locations, and occurring in different patterns. Some participants reported multiple types of pain co-occurring in different locations, from arthritis or neuropathy, and at different anatomical sites, such as the back, nipple, or leg. Some said pain was worse in the morning when first waking up; others said it was worst at night after a day of activity. Participants reported that physical pain regularly interacted with other symptoms and sometimes limited activities. One participant said he could not eat, sleep, or walk when he had pain.

Neuropathic pain, a common side effect of some chemotherapeutic agents, was reported as burning, tingling, and numbness by many participants. They described this pain vividly as if “someone was sticking pins in the end of them (toes)” or “thunder and lightning in my legs”. The story of Ms. D illustrated how her life changed because of neuropathic pain. She described having to quit the job she loved. Her job required her to drive long distances, and because of the numbness and discomfort in her feet, she had to quit.

> *The chemo tore up the nerves in my leg and my feet. And my right foot, you know you drive with your right foot. My right foot, it feels like, a bunch of sand is up under here, and my toes feel like they was swollen, and I hit on the brakes, actually it didn't feel like I was stepping on the brakes.*

Participants who reported an inability to sleep attributed it to being in pain; others reported being awakened because of pain. Others described trouble sleeping because their cough was worse at night than during the day and that the cough aggravated their pain. Individuals with lung cancer and breast cancer who had metastatic disease in their lungs were most likely to recount the co-occurring symptoms of pain, coughing, and poor sleep. Other individuals told of drowsiness or excessive sleepiness, often explaining that this feeling was a side effect of the pain medication they were taking. Because their pain was so distressful, they had no choice but to take the medicine and deal with the drowsiness.

Constipation resulting from taking pain medication caused pain. Many participants talked about the need to take pain medicine that then caused constipation, which resulted in additional pain. Ms. L said the pain pills made her constipation worse, and then, when she had a bowel movement, she experienced severe pain that extended all the way down her legs. When asked if she was still taking the pain medicine, she told us that the pain was "so overwhelming" that she had to take the pain medication. If she did not take the pain medication, her pain kept her from sleeping.

Emotional pain—Pain was not only expressed as a physical symptom but also as an emotional one that included depressed mood, worry, anxiety, and fear. These emotional states often occurred along with physical pain. Ms. G spoke of the toil of not having control of the situation. She said,

> *The kind of pain you mostly have, that wor-ration, that worry is what kill people too… so much pain from dealing with what you're going through, and it adds on to what you can't do nothing about, and then it becomes a problem, an agony.*

Among the participants who spoke about worry and a depressed mood, some related it to unrelieved pain, whereas others referenced an underlying psychiatric disorder. Their inability to control the pain seemed to make their emotional pain worse, which contrasted with others who had experienced pain yet had found relief. Ms. K expressed being tired of the pain and tired of taking medication. She hurt throughout the interview. Her roommate sat next to her during the interview and massaged her legs. She spoke of giving up.

> *Sometimes I just feel real depressed. I'll say, my God you ready for me? Come and get me now. A lot of times I'll be in pain, and I'll tell [friend's name] and my mama and them, I say I'm so tired, so tired of being in pain. God can come and take me.*

Ms. M, who routinely saw a psychiatrist for her diagnosis of schizophrenia, spoke of the severe pain and giving up.

> *But it can get to a point that it shatters your mind. It was like your mind just shot. The pain can be so excruciating. And I said to myself… I can understand why some people just give up and die instead of go through it.*

Both of these women expressed sadness and hopelessness over the inability to control their pain.

In interviews, about half of the women and half of the men in the sample talked of feeling depressed, although the men did not speak about it in depth. Ms. L, who was under the care of a psychiatrist for her depression, spoke of her depression coming from her inability to clean her apartment and do the things she used to do. She expressed her lack of control in the situation in her list of questions, “Will I ever get rid of this? Is I’m ever going to stop hurting? Why do I feel so weak? Why am I so tired?” Some participants reported that feelings came from losses: loss of control, comfort, and function. Other participants stated that their depressed mood came after learning they had severe cancer and faced the prospect of death. Others related the feeling of depressed mood to stressful relationships with family members. Ms. W and Ms. E worried about who would care for their children when they died, and related their depressed mood to the uncertainty of the future. These two participants also mentioned financial concerns that caused anxiety.

Anxiety and depressed mood often were reported together. The participants who discussed anxiety attributed this feeling to their treatments. One person thought that one of her medicines made her nervous, and another described becoming anxious before undergoing a stressful radiation treatment that required her to place her head in a helmet fastened to a table. Participants also discussed fear related to the uncertainly and lack of control related to the diagnosis of cancer, symptoms, and death.

Symptoms associated with functioning in everyday life—Besides pain, participants spoke of symptoms that interrupted their usual daily activities, including their ability to take care of themselves, their family, and their jobs. Before cancer, these daily activities were taken for granted, but now warranted special attention. Symptoms were grouped around the activities of eating, moving and doing, and communicating. Participants often measured the intensity and distress of these symptoms on the basis of how much the symptoms disturbed their day-to-day activities.

Eating, an everyday activity of life, provides nutrition as well as sensory stimulation and often social interaction. The act of eating changed for many study participants who experienced symptoms of anorexia, changes in taste and smell, nausea, vomiting, sore throat and mouth, and swallowing difficulties. Most of these symptoms co-occurred and together disrupted the act of eating. Anorexia or the loss of the desire to eat was the most common symptom and was devastating. Participants did not desire food for many reasons: they could not taste or smell it, the food tasted different, or their stomach was upset. Some related these symptoms to chemotherapy, but not everyone who had problems received chemotherapy. Mr. S spoke about his inability to eat.

> *I got so sick, I couldn’t eat nothing. I lost my appetite, lost my taste, my smell. I couldn’t even eat the food the lady would bring there, to give me. And the doctor*

> *said, you got to eat. I said I can't eat, it just won't go down. I said, I told him I try to eat it and it makes me sick on the stomach. I throw it up.*

For the individuals who could not taste their food, some tried to eat and some did not. Some forced themselves to eat the food they could no longer taste, making it an unfulfilling experience. Ms. Y described the experience of eating but not tasting the food. "I don't even have taste no more, in my mouth. I can't taste. I just eat it and remember what the taste tastes like." Others who rarely ate food instead relied on liquid nutritional supplements. Many participants who could not taste also could not smell, which made eating more difficult. A few spoke about taste changes. Often food tasted like metal, which lead to them decreasing their consumption. Chemotherapy, changes in medications, or pain medications caused nausea and vomiting. Nausea frequently would lead to vomiting after smelling food. At times, the experience of vomiting produced fear that it would reoccur, which resulted in participants not wanting to eat.

The story of Ms. H illustrates the life changes brought about by this group of symptoms. Ms. H, along with other women in the study, spoke of being the cook of the family, but because they no longer could taste food, they stopped cooking or changed how they cooked. At meal times, they only ate small portions. Sometimes after cooking their family a full meal, they ate something else they could tolerate, like soup. Others stopped eating. Ms. H, a 79-year-old woman, worked as a cook for much of her life. Food and food preparation had been a focus of her life. At the time of the study interview, she weighed 147 pounds but said a year ago she had weighed 235 pounds. She could not taste her food or smell her food. "If I could just taste it, you know, I probably could eat, but I can't taste it..… I'll be cooking. They said, momma, that sure smells good; but I can't smell it." Instead of eating, she mainly drank nutritional supplements because of the urging by her doctor. Sometimes she tried to eat but became disappointed.

> *Well, I can't eat. I've tried. I like to eat, too, but I can't. I eat a bite or two, and then like I just get full. I can't and if I keep trying to eat it and chew it up, like it will just swell up and I can't swallow it.*

She also shared her frustration. "That's the hardest thing I've had to go through. I can't eat. And now I don't even like to fix food." She used her skills as a cook as she taught her grandson who lived with her how to cook. This group of symptoms had changed how she functioned in her everyday life and affected her quality of life.

Moving and doing—Being active and mobile is another important but basic part of life for most people. Restrictions on movement might limit one's opportunities to participate in basic self-care, as well as caring for others. This group of symptoms included balance problems, dizziness, weakness, tiredness, and shortness of breath that altered the ability of individuals to move and be active. Also included in this group was the inability to urinate and the loss of libido.

Participants often gauged the severity of these symptoms by what they could do or how long they could tolerate an activity. Specifically, the extent to which they were able to walk was used to assess the severity of many of these symptoms. Balance problems can interfere with an individual's ability to walk and complete household chores like take out the garbage, as it did for Ms. O, who lived alone.

> *I take my garbage out, but I be walking like I'm staggering, and I'm like, something is wrong with me. I can't even walk normal. Listen I'm staggering, like I'm drunk when you walking, I be like, when I'm outside walking, I'm about to hit the fence, or about to fall on this end. I can't keep my balance*.

Symptoms such as dizziness and swollen extremities affected the ability of some to stand or walk. Weakness made it difficult for some individuals to shower and cook. Ms. L spoke of how tiredness interfered with her basic self-care. "I wake up so tired I can't even wash my face. I sit in my little chair by my bed, and I just sit there for a while, just huffing and puffing." Ms. P, a former hotel concierge, could no longer participate in her favorite hobby, roller skating.

Shortness of breath, also described as breathlessness and being winded, changed the ability of some to participate in activities. One man said, "Sometimes I think I run out of breath just talking." Shortness of breath made it difficult to walk short distances, climb stairs, or walk up inclines. Participants often spoke of shortness of breath and tiredness together, and sometimes, they interchanged the two. Ms. W distinguished the difference between tiredness and shortness of breath this way: "The tiredness is mostly when I'm cleaning up or something. The shortness of breath happen to me when I'm sitting down. It seem like I just can't catch my breath."

A few participants experienced difficulty urinating as an initial sign of their cancer, and others attributed it to their cancer treatment. Ms. C experienced a change in the normal clues to urinate; she felt pain instead of bladder fullness. She related this change in sensation to damage from her surgery and expressed frustration over this change that affected her throughout the day. One woman and one man mentioned that the cancer experience negatively affected their libido. Mr. S said, "Something else went with my strength, my ah, my nature. It decreased my sex drive. It decreased, it decreased tremendously."

Communicating—Although not as frequently mentioned as other symptoms, a group of symptoms (cognitive changes, visual disturbances, and problems talking) affected the ability of some to communicate. Cognitive changes caused distress and affected the way participants communicated. Most believed the cognitive changes were a side effect of chemotherapy, and some speculated that anesthesia or pain medication could have been the cause. Ms. N blamed chemotherapy on her difficulty communicating. "Chemo is dead. My brain, like it deaden it. One side, it ain't working like it should. I can't say the words I want to say, and like, my speech is messing up." Ms. F, a former social worker with a master's degree, spoke of difficulties in conversations in which it took time to come up with the correct word. She also described not being able to type as fast as she could when she was writing grants under a tight timeline. Ms. P proudly described her former job as a hotel concierge when she interacted with many types of people and had to juggle multiple tasks at once. But during her treatment, she experienced distressful cognitive changes. "I couldn't keep a sentence, going one way, it would scatter everywhere. It almost felt like I was going through Alzheimer's." Mr. V described a change in his decision-making skills.

> *I was making decisions that weren't right. So I would check with my wife and say if I'm going to make a decision, you have to be there. We have to talk it over because I make wrong decisions. I noticed that. I think it's related to, I think maybe the pain tablets, and maybe the chemotherapy.*

Overall, the symptom experience produced distress. In addition, the ongoing changes in symptoms forced ongoing adjustments in the day-to-day lives of the participants. Many were forced to stop working. The ability to complete personal hygiene or household chores, to exercise, to sleep, and to go on social outings were also affected. Participants could no longer engage in activities they previously considered normal parts of their day, like bending over to pick up something off of the floor, having a restful night of sleep, eating a big hearty meal, or roller skating in the park.

DISCUSSION

The purpose of this study was to explore the symptom experience of black adults with advanced cancer who were poor. The findings presented here include information on the experience of co-existing symptoms. Symptoms often overlapped and had a substantial impact on each other. This interaction and synergy was demonstrated by participants who spoke of the experience of sleep disturbance, pain, and cough that co-occurred and exacerbated each other. These descriptions of co-existing symptoms reveal the difficulty of dealing with symptom clusters day to day. Studies of symptom clusters in advanced cancer have used different methodological approaches and described different varieties of clusters (Nguyen, et al., 2011; Tsai, Wu, Chiu, & Chen, 2010; Walsh & Rybicki, 2006; Wang, Tsai, Chen, Lin, & Lin, 2008). The qualitiative description of the interaction of symptoms gives an additional persective; additional qualitative work across the cancer continuim could improve the quality of symptom cluster research (Barsevick, 2016). Futhermore, to build on these findings that describe the experience of blacks with cancer, additional research is needed to examine ethnic differences in the symptom cluster experience.

Pain, as described in the literature, is the most common symptom across all cancer types and stages. Pain was also a major part of the symptom experience for the sample described here. "Living in pain" was discussed by almost the entire sample. Study participants described the experience of pain as both physical and emotional. Many individuals spoke of substantial distress from pain caused by treatments. Participants described multiple types of pain occurring over time and sometimes concurrently. Depression, often described as emotional pain, was related to participants' perception of their inability to control their pain. The cancer pain experience has been described in previous qualitative work with black samples. In one study of 11 black cancer patients who participated in an online forum, cancer was viewed as a challenge to be fought. Participants said they were reluctant to express pain and seek help because they were raised to be strong (Im, Lim, Clark, & Chee, 2008). Another qualitative study on the meaning of and attitudes toward cancer pain, black respondents found that stoicism, faith, and finding meaning in the cancer pain experience were important in shaping their pain treatment decisions with providers (Meghani & Houldin, 2007). In contrast, in the current study participants did not discuss the need to be stoic or fight pain, rather they were working to find ways to cope with the pain. The current study adds important information about the pain experince by showing the interaction between pain and other symptoms plus how additional symptoms affected their daily activities.

In the findings presented here, we found that symptoms clustered by how they affected the participant's functional status. Symptoms changed normal day to a day routines and required adjustments in schedules, rest times, diet, and medications. Participants replaced their regular activities (i.e., employment and entertainment) with daily naps and watching television. Symptoms also interfered with the ability to complete basic personal and social functions such as eating and communicating. The level of impairment—e.g., what the patient could eat, how far or how easily he or she could walk or speak—became an index for gauging the severity of symptoms. In prior research with individuals having diagnoses of advanced cancer, functional status has been related to symptom experience (Doorenbos, Given, Given, & Verbitsky, 2006; Hwang, Chang, Fairclough, Cogswell, & Kasimis, 2003; Walsh, et al., 2000). In a sample of 1000 individuals with advanced cancer, participants with a poor performance function (measured by the Eastern Cooperative Oncology Group performance scores) were more likely to have ten or more symptoms (Walsh, et al., 2000). In another study, Hwang and colleagues (2003) examined symptoms and functional status using the Karnofsky Performance Status (KPS) and found that changes in KPS often followed changes in quality of life and symptoms. Doorenbos and colleagues (2006) examined symptom experiences at the end of life among individuals with cancer and found that their symptom experience was significantly associated with the ability to participate in activities of daily living. Our findings enhance this understanding of the relationship between symptoms and physical functioning in patients with advanced cancer by providing accounts of how daily activities changed because of symptoms and how symptom severity was related to the degree of changes that were needed.

An important concept that was illustrated in the patient's experience with pain was control. Patients' perceived control over pain seemed to relate not only to distress from pain but also to anxiety, a depressed mood, and the ability to complete activities. Vallerand and colleagues (2007) found that having perceived control over functional status was affected by distress from symptoms. A patient often reacts to pain by feeling distressed and altering their behaviors to reduce the pain, thus altering their functional status. If the individual perceives control over the pain, the person's distress decreases, and functional status improves. Additional work by Vallerand and colleagues (2005) explain the role of control and the relationship between symptoms and functional status, specifically looking at differences between white and black individuals with cancer pain (Vallerand, Hasenau, Templin, & Collins-Bohler, 2005). After controlling for co-variates of education, marital status, sex, employment, and metastasis, blacks were found to have higher pain intensity, distress, and interferences with function than whites. When participants' perception of control over pain was held constant, the racial disparities with distress and function were significantly decreased, and only the difference in intensity remained. This finding might indicate that when individuals feel they can manage their pain, their experience improves. Recent work with a primarily poor black sample demonstrated a significant relationship between perceived control over pain and functional status (Vallerand, Crawley, Pieper, & Templin, 2016). Future work must consider factors such as perceived control over pain and other symptoms and the relationship between function and distress, especially among minority populations.

In the current study, many individuals experienced distress from symptoms that affected both their capacity to eat and their digestion. Anorexia was a daily struggle for several participants. Many in the sample spoke about changes in their ability to taste and smell that were often, but not always, caused by chemotherapy and described how the loss of these abilities changed their desire to cook and eat certain foods. Few previous studies have described how individuals with cancer experience anorexia and taste and smell sensory changes. Hawkins (2000) conducted a survey of 145 hospice and hospital inpatients and homecare patients referred to a palliative care service and found that 36% reported anxiety associated with anorexia. In contrast, the findings presented here showed that the participants were frustrated but not anxious because of their anorexia. In another study of individuals receiving chemotherapy, nearly one-third of the sample of 518 participants who experienced taste and smell changes reported high levels of distress (Bernhardson, Tishelman, & Rutqvist, 2008). Similarly, individuals in the current study described the sense of resignation they lived with after acknowledging that cancer had robbed them of their pleasure in cooking and eating and of the social enjoyment of sharing meals with others. Some hoped that eating would return to baseline and worked to find foods that would stimulate their appetites or be easier to swallow, and others learned to accept a new normal. This new normal included eating food that was tasteless or drinking liquid nutrients from a can.

The major symptoms mentioned related to mobility were tiredness, weakness, and fatigue. Fatigue, a word used by only one study participant, is well studied in the cancer population and was experienced by almost the entire sample. It is a subjective sensation with physical, cognitive, and affective dimensions (Barnes & Bruera, 2002), and the study participants spoke of how it dominated all parts of their day. They had no choice to stop whatever they were doing and rest, and many spoke of the frustration of not being able to participate in the same activities they did before cancer. Again, their normal day had been transformed into a day ruled by symptoms.

The key symptom affecting communication was cognitive changes. Multiple factors contribute to cognitive changes in individuals with cancer. Pain medications, unrelieved pain, different types of chemotherapeutic agents, and other drugs might all directly contribute to cognitive dysfunction or might indirectly make individuals more vulnerable to the effects of opioids, slowing their mental processing or reducing their alertness (Kurita, Lundorff, Pimenta, & Sjogren, 2009; Morrison et al., 2003). In a descriptive phenomenological study, memory impairment and difficulty concentrating were emotionally disturbing, particularly, as it worsened over the course of receiving chemotherapeutic regimens (Mitchell & Turton, 2011). In the current sample, individuals discussed their experiences with cognitive changes and the resulting distress without being prompted. Because symptomatic cancer patients face multiple factors that can cause distressing cognitive changes, more information is needed to help individuals cope with this symptom.

The findings of this study should be interpreted in light of the following limitations. Similar to most qualitative work, the sample was small from one hospital system in one city in the Southeast. In addition, the participants we interviewed were quite active and engaged in their care, which could have been a result of selection bias. Clinical staff assisted with study recruitment and could have unintentionally selected individuals who they thought were more outgoing, energetic, and likely to participate. Interestingly, the sample in this study were poor; study eligibility include self-reported personal income below federal poverty level. Lack of resources or money did not come up in the discussion of symptoms except when two participants discussed anxiety related to financial concerns. Many participants described previous employment that no longer was possible due to the challenges of cancer and symptoms. No interview questions addressed the relationship between being poor and the symptom experience; failing to address this topic during the interview was a lost opportunity to learn about being poor and living with symptoms. Nevertheless, this study sheds light on the experience of an understudied group whose symptom experience potentially could be exacerbated by financial challenges such as funds for transportation, limited resources for housekeeping assistance, or cost of nutritional supplements. The impact of symptoms on daily functioning in everyday life for individuals with limited financial resources can result in significant life and health challenges that may require special attention from health care providers. Finally, significant time has passed since this data was collected in 2010 and 2011. Despite this time lag, the cancer symptom experience has not significantly changed for individuals living with advanced cancer. This analysis is a first step to describe how symptoms interact via qualitative methods paving the way for future empirical symptom cluster analysis (Barsevick, 2016).

Implications

The findings of this study direct providers to assess how patients experience symptoms as part of their day-to-day lives. Using a patient-centered approach, health care providers need to expand their assessments to include not only qualitative assessments of symptoms but also their effect on day to day function and how symptoms interact. When caring for individuals with limited financial resources who are experiencing symptoms, additional resources may be needed when seeking symptom relief and determining ways to help individuals stay active. Providers must form partnerships with patients and families to identify methods to reduce the suffering from symptoms related to advanced cancer. Quality of life for these patients is related to their functional status as well as their distress from multiple symptoms.

These findings reveal additional research areas that should be pursued. First of all, research on individuals with cancer must include adequate representation of different ethnicities, especially blacks because they carry an increased burden of suffering due to cancer (American Cancer Society, 2016). In addition, financial toxicity is now recognized as a side effect of cancer treatment experienced by many. Greater financial strain among people with cancer is associated with greater symptom burden and decreased quality of life (Lathan, Cronin, Tucker-Seele, Zafar, Ayanian , & Schrag, 2016). As researchers learn more about financial toxicity, those individuals living in poverty must be included to understand the interactions between this stressor and the symptom experience.

In summary, this study provided detailed information on how symptoms of advanced cancer, especially pain, affected day-to-day life and functioning. Though symptoms substantially altered the fundamental structure of each patient's day, study participants worked to meet their basic needs in ways that differed from their lives before cancer. Understanding the experience from the patient perspective is the first step to assisting individuals to find relief. Evidence-based supportive care is a critical component of maintaining an acceptable quality of life and especially important to vulnerable groups such as minorities with few financial resources.

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Table 1

Demographic and clinical characteristics (n=27)

Variable	**n**	**%**
Sex		
Female	18	63
Male	9	37
Marital Status		
Single	14	52
Divorced/separated/ Widowed	9	33
Married/ In a committed relationship	4	15
Present financial status		
I go without/ I have barely enough to get by	16	59
I feel secure most of the time	6	22
I am very comfortable	3	11
No Answer	2	7
Family’s financial status when growing up		
We went without/ We barely had enough to get by	8	30
We felt secure most of the time	14	52
We got everything we wanted	4	15
No Answer	1	4
Education		
Less than high school	10	37
High school graduate	10	37
At least some college	7	26
Cancer Diagnosis		
Breast	9	33
Lung	8	30
Prostate	3	11
Ovarian	3	11
Other (one each of Cervical, Leiomyosarcoma, Renal Cell, Vocal Cord)	4	15
Co-morbidities per self-report		
None	8	30
Hypertension	15	56
Respiratory Disease	5	19
Diabetes	3	11
Cardiac Disease	3	11

Table 2

Symptom Severity per Edmonton Symptom Assessment Scale (n=27) (0 to 10 scale, 0=absence of symptom or best state, 10=worst symptom or state)

Symptom	Time Point	Mean Severity (Standard Deviation)	Range
Pain	Screening	6.19 (3.14)	0–10
	Pre interview	5.26 (3.12)	0–9
Tired	Screening	5.15 (3.42)	0–10
	Pre interview	5.22 (3.49)	0–10
Well being	Screening	4.41 (2.90)	0–10
	Pre interview	4.15 (3.05)	0–10
Depressed	Screening	3.78 (4.00)	0–10
	Pre interview	1.56 (2.75)	0–9
Appetite	Screening	3.52 (3.80)	0–10
	Pre interview	4.50 (3.67)	0–10
Drowsy	Screening	3.41 (3.66)	0–10
	Pre interview	2.15 (2.92)	0–9
Shortness of Breath	Screening	3.00 (3.51)	0–9
	Pre interview	2.63 (3.40)	0–10
Anxious	Screening	2.93 (3.58)	0–10
	Pre interview	1.52 (2.59)	0–8
Constipation	Screening	2.74 (3.60)	0–10
	Pre interview	2.23 (3.42)	0–10
Nausea	Screening	2.19 (3.62)	0–10
	Pre interview	1.07 (2.45)	0–9