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12/15/2011

Symptoms and Self-Management in Low Income African Americans  
with Advanced Cancer

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Doctor of Philosophy

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Symptoms and Self-Management in Low Income African Americans  
with Advanced Cancer

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M.S., University of California, San Francisco, 1993  
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An abstract of  
A dissertation submitted to the Faculty of the James T. Laney School of Graduate Studies  
of Emory University  
in partial fulfillment of the requirements for the degree of Doctor of Philosophy  
in Nursing

2012

## Abstract

### Symptoms and Self-Management in Low Income African Americans

with Advanced Cancer

By Katherine Aylward Yeager

#### **Background:**

Little is known about the symptom experience of African Americans with advanced cancer, although many African Americans disproportionately experience advanced cancer. Individuals with advanced cancer must work to manage symptoms in order to function day-to-day and experience a satisfactory quality of life. The challenges of symptom management are amplified in persons with little financial resources.

#### **Purpose:**

This purpose of this study was to explore the symptom experience and symptom self-management practices of low-income African American adults with advanced cancer.

#### **Sample:**

Twenty-seven participants receiving care at Grady Memorial Hospital in Atlanta, Georgia participated in the study by completing an in-depth interview conducted by two research interviewers. The majority of the sample was female (n=18) with a mean age of 57 (range 30 to 79).

#### **Methods:**

Our knowledge regarding symptom experience and self-management practices among low-income African Americans with advanced cancer is limited. The qualitative research paradigm applied in this study allows for an inquiry that considers the perspective of the participants, the so-called insiders' perspective. Data analysis involved the constant comparison method, including axial coding.

#### **Findings:**

Two main themes emerged in terms of the participants' symptom experiences: (1) "being in pain," which included the overwhelming experience of living with pain, both physical and emotional pain and (2) "symptoms associated with functioning in everyday life". Participants frequently used the context of activities in their daily lives to explain symptoms, including the effect of symptoms on the activities of eating, moving/doing, and communicating. The symptom self-management strategies were captured in two main themes: behavioral and spiritual coping. Behavioral coping included using medications and lifestyle changes. Spiritual coping included the use of faith and prayer.

#### **Discussion:**

People with advanced cancer have to negotiate a high frequency of multiple distressful symptoms with severe to moderate severity requiring multiple medications and management strategies. Information gained from this study can help guide research in symptom self-management and provide direction for clinicians working with this minority group.

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## **Chapter One: Introduction**

### **Statement of Problem**

The most recent cancer statistics show that the 5-year survival rate for African American adults is less than that for White adults within each stage of disease for nearly every type of cancer. Moreover, African American men and women experience poorer survival rates due to late stage diagnosis and more limited access to appropriate and timely treatment (American Cancer Society, 2011b). These alarming disparities in the cancer experience of African Americans extend to include the symptom experience. From the limited research on symptoms in African Americans with cancer, we know that African Americans often experience more pain and are more likely to under report pain when compared to other groups (Anderson, Green, & Payne, 2009; Anderson, et al., 2000; Anderson, et al., 2002; Bonham, 2001; Payne, Medina, & Hampton, 2003). African American women with breast cancer are more likely to report unmet needs related to symptom management than women from other ethnic groups (Yoon, et al., 2008). Physicians also often underestimate pain severity and under treat pain in African Americans (Anderson, et al., 2000). Unfortunately, the cancer experience among many African Americans is compounded by a poor economic situation, which in itself is a powerful gauge of health and well-being (Francoeur, 2005).

Cancer, in particular advanced stage cancer, is associated with disease-related and treatment-related symptoms. People with advanced cancer have a high frequency of multiple distressful symptoms with moderate to high severity requiring multiple medications and management strategies (Riechelmann, Krzyzanowska, O'Carroll, & Zimmermann, 2007; Tsai, Wu, Chiu, Hu, & Chen, 2006; Walsh, Donnelly, & Rybicki,

2000). Common symptoms include pain, fatigue, and lack of appetite, all of which can affect a person's ability to perform activities of daily living and their overall quality of life. Symptoms can result in suffering for individuals and families, long-term disability, costly hospital admissions, financial hardship, and social isolation (Sherwood, Donovan, Rosenzweig, Hamilton, & Bender, 2008). In advanced cancer when the focus of care has shifted from cure to improving or maintaining quality of life, symptom management is a top priority. Because symptoms rarely occur in isolation, individuals must learn to evaluate and manage a variety of symptoms as they happen together. The collection of strategies that an individual uses to relieve or control symptoms is referred to as symptom self-management. These actions can be initiated by the individual or prescribed by health care professionals. Unfortunately, many people do not receive the help they need in managing symptoms and report unmet needs (Morasso, et al., 1999; Teno, et al., 2004). Their challenges are amplified when they live in poverty and have minimal financial resources (Hughes, 2005).

High-quality, evidence-based palliative care is a critical component of maintaining an acceptable quality of life. Palliative care includes the relief of distressing symptoms. The symptom experience of poor African Americans with cancer is missing from the literature. As the scope and mission of palliative care is being refined, the needs of this understudied group must be examined. Only then can interventions be implemented to provide evidence based palliative care for poor and underserved African Americans with advanced cancer.

### **Purpose of Study**

The purpose of the study is to explore the symptom experience and symptom self-management practices of low-income African American adults with advanced cancer. A qualitative descriptive approach was used. This study provides information on a specific and understudied population—who face significant health disparities. The information gained from this study provides the groundwork for a larger research program to develop and test culturally sensitive interventions to improve symptom self-management strategies and outcomes among African American men and women.

### **Aims of Study**

Because the symptom experience and symptom self-management practices of low-income African Americans with advanced cancer have been largely unexplored, qualitative methods are most appropriate. The specific aims and associated research questions for this study are as follows:

Aim 1. To explore the symptom experience of low-income African Americans with advanced cancer.

Q1 What symptoms do these individuals experience?

Q2 How do the symptoms affect their day-to-day lives?

Aim 2. To explore the symptom self-management experience of low-income African American individuals with advanced cancer.

Q1 What strategies do they use to manage symptoms?

Q2 What are the facilitators and barriers to their self-management of cancer-related symptoms?

## **Context of Inquiry**

Recently, researchers have recognized the failure of existing models to capture the dynamic nature of symptoms and the experience of multiple symptoms when trying to explain symptom management (Brant, Beck, & Miaskowski, 2010). Few models adequately describe symptom self- management in advanced cancer. Researchers have not adequately explored the experience of minorities with little resources in how they manage their symptoms. Due to the nature of qualitative research as well as the scarcity of the research in the area of interest, this study is not based on a conceptual framework or theory. Although with this qualitative approach, an understanding of the context of the study is essential. The role of race and health disparities, poverty and health, and end-of-life care in advanced cancer will be discussed to describe the contextual background. A description of my background and recognized biases will also be presented as part of this qualitative inquiry.

The sample for this study contains low income African Americans. The history of this vulnerable group is important to consider as well as the current state of health disparities that they experience. Since the time of slavery, African Americans have experienced varying levels of social, economic, and political exclusion that have resulted in poorer health. In 2002 the Institute of Medicine's Report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" found that a consistent body of research demonstrated the existence of disparities by race, even when insurance status, income, age, and severity of conditions were comparable (Smedley, Stith, & Nelson, 2003). African Americans historically have experienced shorter life expectancy and higher rates of cancer, diabetes, heart disease, stroke, substance abuse, infant mortality

and low birth weight than White Americans ("Health Disparities- Closing the Gap," 2008). Research indicates that in the United States (U.S.), racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services (Smedley, et al., 2003). African Americans are more likely to develop and die from cancer than any other racial group. The death rate from cancer among African American males is 33% higher than White males. For females, the African American death rate is 16% higher (American Cancer Society, 2011b). When first diagnosed, African Americans are more likely to be diagnosed with advanced disease ("Health Disparities- Closing the Gap," 2008; Smedley, Stith, & Nelson, 2003). Many have argued that these health disparities are due to genetic differences although researchers now know that the construct of race is socially derived with limited biological basis (Brawley & Berger, 2008; Smedley, et al., 2003; Williams & Mohammed, 2009).

Unfortunately racism, the belief that a group of people is inferior to other groups based on skin color, continues today and has contributed to health disparities (Freeman, 2004; Smedley, et al., 2003; Williams & Mohammed, 2009). Racism contributes to health disparities by operating at three distinct levels: institutionalized policies and practices, individual racial discrimination and biased treatment, and internalized cognitive processes (Smedley, et al., 2003; Williams & Mohammed, 2009). Studies suggest that racial and ethnic discrimination and bias on the part of medical care providers influence the quality of health care delivery (Burgess, Fu, & van Ryn, 2004; Burgess, Freeman, 2004; van Ryn, 2002; van Ryn & Burke, 2000; Williams & Mohammed, 2009). For example, for African Americans experiencing pain, physicians often underestimate pain severity and under-treat pain (Anderson, et al., 2009; Anderson,

et al., 2000). Targets of discrimination are often aware of some of these discriminatory practices resulting in stress for the individual (Benkert, Peters, Tate, & Dinardo, 2008; Williams & Mohammed, 2009). This stress from discrimination has been suggested to contribute to the health disparities (Benkert, Hollie, Nordstrom, Wickson, & Bins-Emerick, 2009; Williams & Mohammed, 2009). The awareness of this discrimination has created a layer of mistrust between African American individuals and the health care system and providers (Benkert, Peters, Tate, & Dinardo, 2008; Corbie-Smith, Thomas, & St George, 2002; Stone & Dula, 2009).

This mistrust spills over into research (Corbie-Smith, et al., 2002; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999) and is rooted in history, specifically the Tuskegee Syphilis Experiment. For forty years, between 1932 and 1972, the U.S. Public Health Service conducted an experiment on black men in the late stages of syphilis (Baker, Brawley, & Marks, 2005). These men, for the most part illiterate sharecroppers from one of the poorest counties in Alabama, were never told what disease they were suffering from or of its seriousness. The data for the experiment was to be collected from autopsies of the men, and they were thus deliberately left to live and die from tertiary syphilis (Jones, 1993; King, 1992). The Tuskegee example, along with current patterns of discrimination, health disparities, and the resulting mistrust, serve as part of the context to this study of African Americans.

An additional area that shapes this project is the role of poverty and health. The consequences of poverty produce significant public health and social problems in the US. Social economic status, more than any other factor, determines health status (Fiscella & Shin, 2005; Fiscella & Williams, 2004; Mechanic & Tanner, 2007). Low SES

contributes to poor health and poor health is related to low SES (Fiscella & Shin, 2005). In addition to poor health, many stereotypes exist about the poor and are often communicated with little hesitancy or shame (Lott, 2002). Descriptors used to describe the poor include: uneducated, lazy, dirty, stupid, immoral, criminal, abusive, and violent (Cozzarelli, Wilkinson, & Tagler, 2001). Health care providers also hold these stereotypes. Physicians see individuals with lower SES having more negative personality characteristics, lower level of intelligence, less likely to be adherent, and less likely to want active lifestyle even when controlling for other demographic factors (van Ryn & Burke, 2000). Not only are these negative feelings regularly communicated about the poor, the poor are often blamed for their condition (Lott, 2002). Although rates of unhealthy behavior, including inadequate physical activity, smoking, and poor diet, are more prevalent among persons of low socioeconomic status, differences in these behaviors explain a relatively small portion of disparities in mortality (Fiscella & Williams, 2004; Lantz, et al., 1998; Lantz, et al., 2001). This pattern of unhealthy behavior likely represents the effect of environmental and social factors (Fiscella & Williams, 2004) and certainly does not justify assigning blame to those who suffer in poverty.

Being poor affects daily routines, human interactions, and communities (Blacksher, 2002; Mechanic & Tanner, 2007). Financial hardship, low literacy, limited access to quality health care, and social marginalization, which are all often part of a poor person's life, is associated with chronic stress (Fiscella & Williams, 2004). Dealing with stereotypes, blame, and stress can result in lower self esteem and lower confidence (Blacksher, 2002; Maliski, Kwan, Krupski, Fink, & Litwin, 2004). Individuals with

limited resources can possess strong survival skills, but lack hope and imagination of a brighter future (Blacksher & Christopher, 2002). Specifically the urban poor with advanced cancer deal with day-to-day concerns, such as housing issues, personal safety, transportation to appointments, limited money for insurance co-pays, delays in diagnosis of advanced cancer, discrimination, and distrust in the health care provider (Hughes, Gudmundsdottir, & Davies, 2007).

In addition, poor African American families face many other challenges. African Americans account for 75% of births to unmarried mothers (Hummer & Hamilton, 2010). The fragile state of families seen in the African American community is related to socio-economical disadvantages and cultural factors. Often the household makeup may not include the father of the children, but may include grandparents who provide care for their grandchildren. Other attributes of the poor African American household may include intermittent employment, time demands of weekend and night jobs, burdensome debt, dependence on public transportation, unstable housing, and neighborhood violence (Hummer & Hamilton, 2010). The negative effects of these factors are compounded when poor health is also part of the picture.

Persons with advanced cancer face distinct challenges. Symptoms impact the quality of life of nearly all individuals with advanced cancer (Higginson & Costantini, 2008). These individuals also struggle with day-to-day challenges such as insurance paperwork and grieving family and friends (Blacksher & Christopher, 2002). Religious, spiritual, and cultural aspects of their lives are prominent while individuals seek hope, meaning, and comfort (Balboni, et al., 2010; Newlin, Knafl, & Melkus, 2002). Unfortunately, individuals' spiritual needs are not always supported by religious



communities and rarely by the medical system (Balboni, et al., 2007). Specifically, racial and ethnic minorities facing advanced illness, place great importance on spiritual beliefs and religion which influences decision making activities (Balboni, et al., 2010; Braun, Beyth, Ford, & McCullough, 2008; Campbell & Ash, 2007; Campbell, Williams, & Orr, 2010; Johnson, Kuchibhatla, & Tulskey, 2009; Phelps, et al., 2009).

Furthermore, cultural factors influence lives of African Americans with advanced cancer. Culture is formed by values, beliefs, norms and practices common to a specific group. Culture guides thinking, doing, and being; it is an expression of a group's identity and is passed down from one generation to the next (Giger, Davidhizar, & Fordham, 2006). Cultural factors strongly influence individuals' reactions to serious illness, specifically at the end of life. Cultural variations exist in attitudes toward truth telling, life-prolonging technology, disclosure and communication of diagnosis and prognosis, and designation of primary decision makers and decision making styles (Kwak & Haley, 2005; Schmid, Allen, Haley, & Decoster, 2010). African Americans at the end of life may be more reluctant to discuss death, want more aggressive care, and be less informed about hospice and underutilize it, and less likely to have or be aware of advance care directives (Braun, et al., 2008; Johnson, et al., 2009; Kwak & Haley, 2005; Phipps, et al., 2003; Rhodes, Teno, & Welch, 2006; Smith, et al., 2008). Feeding tube use, as an example, is significantly more common in Blacks than in Whites in nursing home residents with severely impaired cognitive status (Gessert, Curry, & Robinson, 2001). Multiple reasons have been proposed for these cultural variations. Some recognize that a history of limited access to health care and a resulting mistrust of the health care system may influence health care decisions. In addition, the quality of patient-physician

relationships among terminally ill African-Americans is worse compared to those among Whites (Loggers, et al., 2009; Mack, Paulk, Viswanath, & Prigerson, 2010; Mack, Weeks, Wright, Block, & Prigerson, 2010; Smith, Davis, & Krakauer, 2007; Trice & Prigerson, 2009). Others propose that for African Americans, illness is a test of faith and therefore aggressive treatment is necessary (Campbell, et al., 2010; Delgado-Guay, Parsons, Li, Palmer, & Bruera, 2009; Giger, et al., 2006; Kwak & Haley, 2005; Searight & Gafford, 2005) . Variations within African American groups exist and may be related to demographic characteristics, clinical factors, knowledge, health literacy or level of acculturation (Allen, Allen, Hilgeman, & DeCoster, 2008; Trice & Prigerson, 2009; Volandes, et al., 2008). These characteristics are important to examine as they form the environment within which this study of African Americans with advanced cancer takes place.

### **Author's Biography**

Qualitative researchers acknowledge that the researcher is an integral part of the research process. Researchers cannot assume that their background, bias, and experiences do not affect their research approach. Whereas this also is true in quantitative research, the role of the researcher is more prominent in qualitative inquiries. They must recognize that they bring their own experiences and expectations to the project that inform not only the questions they ask but also influence their ability to hear the answers that may be different from their expectations (Tong, Sainsbury, & Craig, 2007). This process starts with a critical reflection of the researchers own values, beliefs, and cultural heritage in order to understand how those qualities and issues affect others (Douglas, et al., 2009; Kumagai & Lypson, 2009). Reflexivity, or self-reflection about one's

relationship to a project, is necessary to assess a researcher's representation of a phenomenon (Hofman, 2004; Jootun, McGhee, & Marland, 2009).

The process begins with a brief overview of my background. I am a White female who grew up in a single parent household after my father died when I was six years old. After his death, my family moved from the Midwest to a small town in the South. My mother worked as a secretary and raised me and my 2 older siblings with limited resources although I never felt poor or disadvantaged at any time. After attending a Catholic school in a predominately White area of Peoria, Illinois, I was moved to a public school in a small Georgia town shortly after the schools had been integrated. The cultural difference between the Midwest and rural South was evident even to a 10 year old child. By witnessing the poverty and segregation in this small town, I realized that being born with white skin gave me certain privileges that children with dark skin did not have.

My first professional position was as a registered nurse on an oncology unit at a Veterans Administration Medical Center. On that unit, I saw how men of different backgrounds who may not socialize back in their hometown, form special bonds based on their common experience with cancer. Later in San Francisco, I worked with and cared for a very diverse and multi-cultural group. On this bone marrow transplant unit, I began to understand the role of nurses, patients, and families in managing symptoms. I also had a rich experience in my masters program at the University of California and studied attitudes and beliefs about pain in individuals with cancer and their caregivers.

After completing my master's degree, I returned to Atlanta and began my career in research. As a project manager on multiple clinical studies, I learned how individuals manage symptoms and how the different resources of the individual impacted symptom

management. In my research position, I worked with research participants at Emory University (tertiary center with many resources) as well as Grady Hospital (a safety net hospital caring for a predominantly indigent and African American population) and the contrast at times was alarming. I also worked as a research project manager at the Grady HIV clinic and met many individuals with limited resources and many challenges related to their disease. I was especially influenced by the women I met when I was a group facilitator for a study using motivational interviewing to increase medication adherence and risk reduction for HIV positive women. These women shared their lives with me and their courage and compassion showed me how rich life can be despite living with HIV symptoms, treatment challenges, little resources, and stigma.

My commitment and interest in end-of-life issues comes from educational, professional and personal experiences. When I was 8 months pregnant with my second son, my mother died of cancer in my home. I had cared for my mother in my home while working full-time. The challenges of dealing with the medical system, despite the advocacy of me and my physician husband, were very difficult. The choices my mother made about her care and my relationship to her as her daughter and care provider influenced my desire to study symptom self- management. I have always been interested in end-of-life care, but this personal experience was pivotal as well as my experience at the Grady Palliative Care Clinic early on in my doctoral studies. The people I met there taught me how to live, not die. The individuals I met were resilient, determined, smart, caring, and active. Their lives had been full of challenges and this latest challenge was just another bump in the road, a story similar to what I learned from the HIV positive women. They were not dirty, dishonest, dumb, drug addicted, or scary. They came

dressed up to the clinic in their ironed jeans and shiny shoes and stayed busy volunteering at church and caring for their family despite their pain and fatigue.

Regarding issues of faith, I do not consider myself a very religious person. I was raised a Catholic and converted to Judaism as an adult. Religion has not provided me with much support in my life and I instead find comfort in my own spirituality. My spirituality recognizes the presence of a God who has blessed me in many ways. This is a very private part of my life and I rarely share my beliefs publically.

As I entered the doctoral program I learned about the atrocities of health disparities which I had not paid much attention to previously. Since then, I have participated in numerous discussions about race across the Emory and Grady community through my work with the Transforming Community Project and the Gustafson “Reality of Race” Seminar. I have heard many firsthand accounts of how racism still operates today in our community and throughout our society. I continue to think about the privileges I receive due to the color of my skin. My background has shaped my understanding of the world and what matters to me. I hope to use my privileges to tell the story of those that have not had those same advantages.

## **Chapter Two: Literature Review**

This chapter provides a comprehensive review of the literature on symptoms and symptom self-management specifically in individuals with advanced cancer and highlighting issues related to being African American and low income. The significance of the study is also discussed.

### **Advanced Cancer**

Advanced cancer is usually defined as stage IV disease and often involves metastases. A cancer's stage is based on the primary tumor's size and location and whether it has spread to other areas of the body, with stage IV being the most advanced (American Cancer Society, 2011a). Progress in cancer care has extended the length of time people live with advanced stage cancers and some live for many years (Higginson & Costantini, 2008). Kato, Severson, and Schwartz (2001) analyzed data of 217,573 individuals with breast, colorectal, lung, or prostate carcinoma who were newly diagnosed with distant disease. The researchers found that the median survival for participants with advanced cancer at the time of diagnosis was 18 months for breast cancer, 24 months for prostate cancer, four months for lung cancer, and seven months for colorectal cancer. But for those participants who were still alive two years after diagnosis of advanced cancer, the length of time they could expect to live increased significantly. Survival for individuals with breast and prostate cancer increased by 26 months, 13 months for individuals with lung cancer and 16 months for individuals with colorectal cancer.

For the individual living with advanced cancer, the priority of care is often control of tumor growth and almost always symptom management. Management of symptoms

like pain, nausea, and dyspnea is aimed at enhancing the individual's ability to function and improve his or her quality of life (Chang & Ingham, 2003). Despite this symptom burden, individuals with advanced cancer often have full and active lives (DeSanto-Madeya, Bauer-Wu, & Gross, 2007). Individuals often demonstrate great resilience while balancing responsibilities of an active life and managing symptoms on a day-to-day basis (Higginson & Costantini, 2008). Little is known about how individuals manage their symptoms, especially those with advanced cancer.

### **Symptoms**

A symptom is a subjective experience reflecting changes in biopsychosocial functioning, sensations, or cognition of an individual (Dodd, et al., 2001). Symptoms are uncomfortable, unpleasant, and can interfere with comfort and productivity (Giardino & Wolf, 1993). Most people diagnosed with cancer experience symptoms at some time in their disease continuum; these are often related to both the disease and treatments. Common symptoms studied include pain, fatigue, appetite changes, nausea, bowel problems, mucositis, peripheral neuropathy, urinary problems, dyspnea, hair loss, skin irritation, sexual dysfunction, sleeping difficulties, depression, and anxiety (Yarbro, Wujcik, & Gobel, 2011). The quality of life of nearly all individuals with advanced disease is impaired by one or more symptoms (Higginson & Costantini, 2008). In one study, participants with advanced cancer reported a median of 11 symptoms (Tsai, et al., 2006). Other studies have shown a similar profile of symptoms in individuals with stage IV cancer compared to other cancer stages (I-III): commonly pain, fatigue, reduced appetite, dry mouth, and dyspnea (Aranda, et al., 2005; Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011; Riechelmann, et al., 2007; Solano, Gomes, & Higginson,

2006). Additional symptoms reported include nausea, constipation, sleep disturbances, difficulty concentrating, depression, and anxiety (Delgado-Guay, et al., 2009; Hwang, et al., 2004; Labori, Hjermstad, Wester, Buanes, & Loge, 2006). In a sample of individuals in an ambulatory palliative care service, 98% reported presence of symptoms and 85% reported at least one severe symptom ( $\geq 6$  on 0-10 scale). Sixty-eight percent of these participants experienced co-morbidities and took a median number of 6 medicines (Riechelmann, et al., 2007).

### **Symptom pairs and clusters.**

Symptoms rarely occur in isolation. Symptoms often occur in pairs or clusters and they may or may not be related (Cleeland, et al., 2007; Kirkova & Walsh, 2007; Miaskowski, Aouizerat, Dodd, & Cooper, 2007). The presence of clusters is influenced by primary cancer site, gender, 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/fatigue were associated with a reduction of physical well-being and performance status, fatigue/ insomnia were related to a decline in cognition; and depression/ pain were linked to a decrease in social well-being (Ferreira, et al., 2008). Zimmerman, Cheung, and Le (2008) found two clusters in their study of individuals with advanced cancer: 1) fatigue, drowsiness, nausea, and decreased appetite; and 2) anxiety, depression, and poor general well-being. 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 research is needed to describe how symptoms occur together.



### **Symptoms in African Americans with cancer.**

Different racial and ethnic groups may experience symptoms differently.

Eversley and colleagues compared African Americans to other groups and found that African Americans often report greater pain and number of symptoms compared to Whites and persons of Latino ethnicity (Eversley, et al., 2005). Race, specifically being African American, appears to be associated with adverse symptoms and decreased survival among individuals with lung cancer (Tammemagi, Neslund-Dudas, Simoff, & Kvale, 2004). In a study of breast cancer, African American women were more likely to report an unmet need related to symptom management (Yoon, et al., 2008).

Cancer-related pain is the most common symptom, across all cancer stages, described in the literature. Racial disparities have been documented in the assessment and treatment of cancer pain. In studies comparing African Americans to other groups, African Americans often 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; Payne, et al., 2003). Physicians too often underestimate pain severity and under-treat pain in African Americans (Anderson, et al., 2000). The African American cancer pain experience has been described, but with fairly well-educated middle class samples (Im, Lim, Clark, & Chee, 2008; Meghani & Houldin, 2007). In one study describing the meaning of cancer pain in African Americans, 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, et al., 2008). Another qualitative study on the meaning of and attitudes toward cancer pain, African American respondents found that stoicism, faith, and finding meaning in the cancer pain experience

were important in shaping their pain treatment negotiations with providers (Meghani & Houldin, 2007). Vallerand and colleagues examined differences in pain intensity, pain-related distress, functional status, and perception of control over pain between White and African American cancer study participants (Vallerand, Hasenau, Templin, & Collins-Bohler, 2005). After controlling for co-variables of education, marital status, gender, employment and metastasis, African Americans were found to have higher pain intensity, distress, and interferences with function than Whites. When the participant's perception of control over pain was held constant, disparities in distress and function were significantly decreased, and only the difference in intensity remained. This finding may indicate that when individuals feel they can manage their pain, their experience may improve. With the exception of pain, symptoms have essentially not been studied in African Americans with cancer.

### **Symptom Self-Management**

Symptom management strategies are actions used to avoid or defer a negative outcome through interactions with the health care system or from self-care strategies (Dodd, et al., 2001). The process of symptom management is a dynamic process, often requiring changes in strategies over time or in response to the effectiveness of the strategies or the changing state of the symptom experience. Such strategies can be provided by the individual, family members, and health care providers. Symptom self-management activities, the focus of this study, are done by an individual to relieve or control his/her own symptoms.

Most research on cancer symptom management to date has focused on the treatment/post treatment phase and on medical interventions. Individuals with cancer

often manage their symptoms at home without direct health care supervision. The importance of self-management strategies have been recognized, although minimally studied (Dodd & Miaskowski, 2000). The focus of the proposed study is symptom experience and how individuals manage their symptoms. These actions are collectively called “symptom self-management” and have also been described in the literature as self-care strategies, self-care behaviors, self-care measures, self-care activities, and self-care of symptoms (Borthwick, Knowles, McNamara, Dea, & Stroner, 2003; Richardson & Ream, 1997; Williams, et al., 2006). Symptom self-management activities are done by an individual to relieve, or control symptoms and can be initiated by the individual or healthcare provider.

Symptom self-management involves a range of activities such as specific actions, asking for advice, interacting with healthcare professionals, or sometimes doing nothing. A variety of strategies have been described specific to treatment-related symptoms initially using primarily White middle class samples undergoing cancer therapy (Craddock, Adams, Usui, & Mitchell, 1999; Nail, Jones, Greene, Schipper, & Jensen, 1991; Williams, et al., 2006). This work has recently been replicated with Chinese and Filipino cancer participants and found similar findings to the initial work in the Midwestern U.S. sample (Williams, Balabagno, et al., 2010; Williams, Lopez, et al., 2010). Nail and colleagues used a self-care diary to gather information on side effects and self-care activities upon completion of chemotherapy treatment (Nail, et al., 1991). Fatigue, nausea, and change in appetite were the most common symptoms with various strategies used that had moderate efficacy. In a study of fatigue in individuals with lung cancer receiving radiation therapy, self-care strategies to manage symptoms included

resting, sleeping, watching television, reading/listening to music, hobbies, 'socializing,' and walking (Borthwick, et al., 2003). Lundberg and Rattanasuwan (2007) studied Thai Buddhist receiving radiation therapy for cancer and found five categories of self-management for fatigue including social support, religious practices, and meditation, treating physical symptoms (resting, exercise, taking medications, and massage), accepting the situation, and consulting with health care providers (Lundberg & Rattanasuwan, 2007). In a study of Chinese Americans with cancer, the participants experienced multiple symptoms and on average used two self-care strategies per symptom with low to moderate effectiveness (Chou, Dodd, Abrams, & Padilla, 2007).

An additional and related area to self-management of symptoms is the emerging field of integrative or complementary therapies. In studies of individuals with breast cancer and lung cancer, women used these therapies to reduce physical and psychological symptoms and to gain a feeling of control over treatment (Blaes, Kreitzer, Torkelson, & Haddad, 2011; Lengacher, et al., 2006; Wells, et al., 2007). In a study of individuals receiving cancer treatment, the sample used many self-care strategies that could be categorized as complementary therapies. Participants in this study used diet/nutrition/lifestyle change, mind/body control, biologic treatments (e.g. vitamins), herbal treatments (e.g. herbal teas), and ethno (or folk) medicine (e.g. lime juice and garlic) (Williams, et al., 2006). Gross, Liu, and Bauer-Wu (2007) specifically examined women with advanced breast cancer and found 90% of their sample used at least one type of integrative therapy.

### **Symptom self-management in African Americans with cancer.**

Management of symptoms by African Americans with cancer has been minimally studied. Campbell showed African American prostate cancer survivors who reported higher self-efficacy for managing symptoms related to prostate cancer and its treatment also reported better quality of life (Campbell, et al., 2004). A few studies have explored the use of complementary therapies in African Americans, specifically with breast and prostate cancer, and found that participants mainly use spiritual healing although some used herbal treatments (Greenlee, et al., 2009; Jones, et al., 2007; Lee, Chang, Jacobs, & Wrench, 2002). Spirituality has been found to be an important coping strategy for African American women with breast cancer (Ashing-Giwa, Ganz, & Petersen, 1999; Henderson, Gore, Davis, & Condon, 2003; Morgan, Gaston-Johansson, & Mock, 2006; Simon, Crowther, & Higerson, 2007).

Although not specific to cancer, Chou (2004) studied self-care strategies used by individuals with HIV/AIDS to manage their disease-related symptoms and found that racial difference was the predominant predictor for type of symptom self-care strategies used. Non-White participants were two times more likely than White participants to use self-comforting strategies, nearly six times more likely to use help seeking strategies, and five times more likely to use spiritual care strategies. This work, while not with individuals with cancer but with another population with a serious chronic illness, shows that differences across racial groups in symptom self-management exist. Therefore, similar differences may also exist in individual with advanced cancer.

### **Symptoms and symptom self-management in individuals with cancer and low income.**

Little work has been done to describe symptoms and symptom management specifically to individuals with cancer and low financial resources. Research on barriers to cancer pain management for socioeconomically disadvantaged minority participants with cancer have identified the following individual factors: communication barriers, reluctance to report pain, stoicism, and concerns about possible addiction and tolerance to opioid medications (Anderson, et al., 2002). Hughes' qualitative study of the urban poor with advanced cancer highlights their day-to-day concerns, such as housing issues, personal safety, transportation to appointments, limited money for insurance co-pays, and health care systems where they felt unwelcomed (Hughes, et al., 2007). They found that participants described health care system problems, such as discharge from hospital without support, delays in diagnosis of advanced cancer, needing to jump through hoops to get care, long lines, discrimination, and distrust in the health care provider. While enlightening, this study by Hughes was not focused on symptoms and/or symptom management. In a qualitative study of women with metastatic breast cancer, participants were asked about barriers and challenges to optimal symptom management and then the influence of race and income on symptom management was examined (Rosenzweig, Wiehagen, Brufsky, & Arnold, 2009). Symptom management barriers were not well elicited and instead the women described the specific strengths and challenges they faced with living with cancer. Low income African American women reported more severe physical and symptom distress and ineffectual symptom management strategies but no description of symptoms were included. Overall, the limited research with poor

individuals with cancer describes system and individual factors that make the cancer experience more difficult. Gaps in the literature exist in the impact of SES on symptoms and self-management of symptoms in individuals with all stages of cancer, especially with advanced disease.

### **Role of Socioeconomic Status**

SES plays an important role in disparities in cancer across all races, with late-stage diagnoses being associated with lower SES (Byers, et al., 2008; Clegg, et al., 2008). Studies show that Medicaid-insured participants and uninsured participants across all races are more likely to be diagnosed with late stage cancer across multiple cancer sites and have an increased risk of dying when compared to insured participants (American Cancer Society, 2008). Whether underinsured, uninsured, or insured by a government program, many individuals with cancer face barriers to obtaining health care because of their limited financial resources (Arozullah, et al., 2004; Bradley, et al., 2007; Darby, Davis, Likes, & Bell, 2009). These barriers can limit access to treatment and supportive care. Even when these individuals have adequate access to cancer care, they may face the added cost burden resulting from medications, lost wages of the individual and their caregivers, transportation for frequent medical visits, and home health care (Pisu, et al., 2010; Sherwood, et al., 2008). Ell and colleagues' study of low-income women with cancer showed that economic stress was significantly associated with poorer functional and emotional well-being (Ell, et al., 2008). In this study, many women reported negative economic changes precipitated by their cancer diagnosis. They indicated that financial responsibilities of caring for family members as well as for cancer treatments caused hardship; transportations costs alone – getting to doctor visits, tests or therapies –

were a severe stressor for many. African Americans are disproportionately represented in the low socioeconomic group, although socioeconomic factors alone cannot explain the higher percentage of advanced disease (Smedley, et al., 2003). Being poor and having advanced cancer presents a dire situation for many African Americans. Because both racial and economic status affects outcomes in cancer care, the focus of this study is low-income African Americans with advanced cancer.

### **Summary**

In summary, increased attention to the symptoms experienced by African Americans with all types of cancer is needed given that African Americans with cancer experience a greater disease burden (Campbell, et al., 2004). Little is known about the symptom experience of African Americans with advanced cancer, although many African Americans disproportionately experience advanced cancer. The individual with advanced cancer must work to manage symptoms in order to function day-to-day and experience satisfactory quality of life. The challenges of symptom management are amplified in persons with little financial resources. No published research exists that describes the symptom experience and self-management strategies of low-income African Americans with advanced cancer.

### **Significance**

Understanding and correcting disparities has become a priority for many leading research organizations such as the National Cancer Institute (NCI), the National Center on Minority Health and Health Disparities (NCMHD), the National Institute of Nursing Research (NINR), the National Centers for Disease Control and Prevention (CDC), the Institute of Medicine (IOM), Healthy People 2020 of Health and Human Services (HHS),



and the American Cancer Society (ACS). The significance of this study addresses the initiatives of many of these organizations. Specifically the focus of this study addresses two of the four areas of research interest in the 2011 NINR Strategic Plan, improving quality of life by managing symptoms and improving palliative and end-of-life care (NINR, 2011). The experience of symptoms and symptom management strategies as described by low-income African Americans with advanced stage cancer is a story that needs to be told. The gap in the literature in symptom management is worrisome at a time when more African Americans are being diagnosed with advanced cancer. Individuals are being asked to manage symptoms at home with limited resources. Using the individual's perspective as a starting point, this is a first step in learning about symptom self-management in order to develop and test interventions to assist this disadvantaged group of individuals with advanced cancer. The overall goal is to help low-income African Americans with advanced cancer live out their days as fully, productively, and comfortably as possible.

### **Chapter Three: Methodology**

An understanding of the experiences of low-income African Americans living with advanced cancer is virtually absent from the existing literature. Therefore, a descriptive qualitative approach was used in this study to give an insiders' account of the experience of living with advanced cancer and managing related symptoms. The focus of this chapter is on the research design, including the setting, recruitment, participant selection, sample, data collection procedures, and data management and analysis.

#### **Research Design**

The study utilized qualitative methods to explore the experience of living with and managing symptoms at home in a sample of low-income African Americans. The study design included a onetime, in-depth, semi-structured interview of individuals with advanced-stage cancer diagnosis who were experiencing symptoms.

#### **Setting.**

The setting for the study was the Georgia Cancer Center, which is part of the Grady Health System, a network that manages the care of many indigent patients within its target area. Most of its revenue comes from Medicare and Medicaid reimbursement. For individuals to receive free care at Grady, they must be residents of Georgia's Fulton or DeKalb counties and make 200% or lower than the federal poverty level. In August 2010, recruitment of study participants began at the Palliative Care Clinic at the Georgia Cancer Center. The Palliative Care Clinic serves individuals on an outpatient basis and meets once a week. About 90% of the individuals treated at the clinic are African American. Individuals are referred to the clinic if they have stage IV cancer and/or are experiencing significant and uncontrolled symptoms, or require help with end-of-life

planning. Referrals come primarily from the oncology clinic, but also from the inpatient medicine service, the radiation service, the gynecologic oncology service, and the emergency clinic. Despite the symptom burden, individuals seen at the palliative care clinic are relatively active and are able to travel to the clinic for appointments. When their health begins to deteriorate, they are referred to home or to inpatient hospice services.

Due to a slower than expected recruitment rate for the first four months, additional recruitment sites from the Georgia Cancer Center were added halfway through the study. These included the Radiation Oncology Clinic, the Breast Oncology Clinic, a general oncology clinic, the Gynecology Oncology Clinic and the Lung Cancer Clinic. For each of these clinics, we worked with a key provider, most often a nurse practitioner at that clinic, to identify potential participants.

### **Recruitment.**

Recruitment for this sample of poor urban African Americans with advanced cancer required a clinic based culturally appropriate approach (Smith, et al., 2007). We sought to build relationships in the Grady community as part of the research process. Therefore, the first step of this study was to form a community advisory board (CAB) in order to facilitate a community-engaged study (Corbie-Smith, Moody-Ayers, & Thrasher, 2004; Corbie-Smith, et al., 1999; NIMH Multisite HIV STD Prevent Trial Group, 2008). The CAB members included a breast cancer survivor and former patient at the Grady Cancer Center, a pharmacist with the oncology team, the palliative care social worker, a palliative care nurse practitioner, an American Cancer Society patient resource navigator and a radiation therapist. The one former patient on the board, a breast cancer survivor, volunteered in the breast clinic and was helpful in orienting me to the flow of the clinic

when recruitment began there. Prior to starting the study, I met with the board to review the recruitment plan, recruitment material, consent process, incentive plan and the interview process. I received valuable advice on recruitment strategies and the incentive plan. Suggestions included revisions of the recruitment flyer and incentive amounts. Throughout the study, I also contacted board members individually to determine additional recruitment possibilities. A follow-up meeting is planned with the CAB to discuss the study findings and determine the best way to report the study findings back to the larger community.

Prior to recruitment of participants, I completed all regulatory processes and obtained approval for initiating the study from the Institutional Review Board (IRB) of Emory University, the Grady Clinical Oncology Research Committee, and the Research Oversight Committee of Grady Health System. IRB-approved flyers that included brief information about the study, eligibility criteria and contact information were distributed to key providers in the targeted clinics.

I regularly attended the pre-clinic morning meeting at the Palliative Care Clinic to remind the staff of the study and to identify potential participants and then stayed until clinic was finished. Since the palliative care staff was part of my recruitment team, I routinely gave clinic staff updates about who had completed the study during the meeting but did not actively participate in discussions about the patients. I was also available on days when the other oncology clinics met to speak with interested potential participants throughout the day. At the radiation therapy clinic, the social worker invited me to come at the end of the support group meeting to introduce the study, although no individuals were recruited by that method.

At each clinic, the health care provider introduced the study to the potential participant and determined if the person was interested in the study, competent to give consent and able to physically tolerate the interview. If the individual was potentially eligible and interested, the practitioner would either introduce me to the individual in person or obtain permission for me to contact the individual by phone. After meeting with the individual and explaining the study in detail, with permission from the individual, I would then review the clinic chart to determine further eligibility. All participants were initially contacted in person except a participant from the radiation oncology clinic who was initially contacted by phone.

### **Participant Selection.**

Potential participants were screened for eligibility through a study screening form (see Appendix A) and completion of the Edmonton Symptom Assessment Scale / ESAS (see Appendix B), a commonly used symptom assessment tool for advanced cancer and palliative care participants (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991). The inclusion criteria included: being 21 years or older; self-identification as African American or Black ; living at home; English-speaking; primary diagnosis of advanced cancer per medical record review; experiencing at least two symptoms of moderate severity (per the ESAS); income level at or below 200% of the Federal poverty level per self report; mentally competent to give informed consent; and physically able to tolerate a one-to two-hour interview as determined by the individual's health care provider. Providers often would screen participants and determine individuals were not eligible without my assistance. Advanced cancer was defined as metastatic or locally advanced refractory disease.

Moderate symptom severity was determined by a score of 4 or higher for at least two symptoms on the ESAS. The ESAS has been thoroughly tested, mostly in individuals with advanced cancer (test-retest, content validity, concurrent validity, predictive validity and sensitivity and/or specificity), and found to be both valid and reliable in the assessment of symptoms in cancer (Bruera, et al., 1991; Nekolaichuk, Watanabe, & Beaumont, 2008; Richardson & Jones, 2009). The overall Cronbach alpha for the ESAS was .79 in a sample of individuals with cancer (Chang, Hwang, & Feuerman, 2000). The ESAS measures nine symptoms: pain, fatigue, nausea, anorexia, dyspnea, drowsiness, insomnia, depression and anxiety. A tenth item, 'feelings of well-being', and an optional 11<sup>th</sup> item are also included on the ESAS. For the palliative care clinic, the additional item was listed as 'constipation'. The severity of each symptom is rated on a visual analogue numerical scale of 0 to 10 (0=no symptom, 10=worst possible symptom). The score of 4 as a minimum cutoff is based on research indicating that a 4 on a 0 to 10 scale is most often equivalent to moderate severity across multiple symptoms (Given, et al., 2008).

A total of 59 individuals were screened for study entry. Twenty-seven individuals completed the study. A total of 16 were referred by a provider and determined to be ineligible by me due to the following reasons: not interested (3); cancer not advanced (2); did not meet symptom criteria (9); not African American (1); and unable to talk (1). An additional 16 individuals were scheduled for an interview but did not complete it. One person died prior to the scheduled appointment, two people were admitted to the hospital prior to the scheduled interview, and one individual was too sick to be interviewed at the scheduled time of the interview. The remaining individuals were lost to follow up despite multiple attempts to contact them.

One additional interview was started but ended approximately ten minutes after initiation because the interviewers realized the individual was confused and unable to answer the questions. When we arrived at his home, the individual was able to answer routine questions and seemed to understand the consent process. Once he was engaged in dialogue, however, he was unable to string thoughts together in an understandable manner. The interview was then discontinued. The individual was thanked and given his gift card. We then left the participant with his wife and immediately followed up with his health care provider to communicate our concern. A few days later he was seen in the clinic where his pain medications were adjusted.

We used purposive sampling to capture a diverse sample of individuals managing advanced cancer and to find cases that were information-rich (Creswell, 2007; Miles & Huberman, 1994). The study sought equal numbers of male and female participants, since gender-specific differences in how people experience and manage symptoms have been extensively documented (Fillingim, King, Ribeiro-Dasilva, Rahim-Williams, & Riley Iii, 2009; Miaskowski, 2004; Walsh, et al., 2000). As the study progressed, theoretical sampling was used to include participants with different symptom experiences and for a deeper exploration of some of the emerging themes. For example, the primary symptom experienced by most participants was pain that required management of complex medication regimens. A participant who was not experiencing pain but had other symptoms was selected towards the end of the study, in order to assess strategies of symptom management and the role of medications in the absence of pain. Participants were intentionally selected 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 (Higginbottom, 2004).

Once the participant was screened and determined as eligible for the study, the time and location for the interview were decided, based on the participant's preference and my availability. The participant chose the interview location, either at his/her home or in a private conference room in the hospital building, near the clinic. We requested that all interviews be with the participant alone, i.e., without family members, caregivers or other people present yet stated that exceptions could be made if the participant so desired. We made reminder calls to the participants prior to each interview, and interviews were rescheduled as needed in cases where the participant was not feeling well. Informed consent was obtained prior to starting each interview. A sample of 9 male and 18 female individuals attending the Grady Cancer Center were enrolled in the study and were interviewed.

#### **Data Collection Procedures.**

As determined by the participants, 10 interviews were conducted at the clinic, 16 interviews were conducted at the participants' home, and one interview was conducted at another hospital where the participant was receiving outpatient treatment. All interviews were completed in a single session, though prior to each interview I gave the participant the option of splitting the interview into two sessions. Except for two, all interviews were completed with me and an additional interviewer, an African American retired nurse who had worked most recently as an organizer for a residential community. Both interviewers went through training in qualitative interviewing prior to study interviews and then



practiced interviewing volunteers who agreed to be taped for educational purposes. The practice interview tapes as well as the study tapes were reviewed by both interviewers in order to critique the interviewing techniques. The two interviewers exchanged feedback throughout the study in order to improve the interviewing techniques.

At the interview appointment, we first reviewed the informed consent procedures with the participant. The entire consent and Health Insurance Portability and Accountability Act (HIPAA) Authorization Form were read out loud (See Appendix C and D). Then the interviewer verbally confirmed that the participant fully understood the procedures and purpose of the study and was still willing to participate. After introducing myself and the other interviewer, I verbally administered the demographic questionnaire (see Appendix E) and the ESAS. This second administration of the ESAS was used to evaluate the current symptom state and to serve as reference for the interview. After the paperwork and instruments were completed, the interview began and the recording started. The recorded interviews lasted approximately 60 minutes on average with a range of 22 to 82 minutes. An interview guide, based on a literature review, served as a template during the interview process. All interviews were audio-taped, two recorders being used simultaneously as a preventive measure against the possibility of data loss.

Both interviewers shared the responsibilities of the interview. In general, both interviewers focused on the participant, actively listening while asking questions and probing for more information as needed. I usually began the interview while the interviewer documented procedural details, such as a description of the environment and the appearance of the participant, including clothes, body language and any signs of

discomfort or distress. These notes were later used to remind me of the context of the interview and provided detail to the transcripts.

The interview guide was intended to orient the participant's narrative towards detailed symptom description, including how symptoms significantly influence daily life. This study viewed individuals with cancer as experts with regard to their own care and individual symptom management. While the strategies delineated in the interview guide could be either prescribed by health care professionals or initiated by the individuals themselves, the study acknowledged the individual with cancer as the authority on the implementation of those strategies in his /her own unique situation. Study participants also gave detailed accounts of situation-specific elements that either obstructed or enhanced symptom self-management.

There were only two instances of deviation from the study protocol. Two interviews were completed without the second interviewer. These interviews took place toward the end of the study and the quality and content of the interview did not differ from that of the other interviews. All interviews took place alone with the participant except for one conducted in the participant's home, with a friend/roommate seated on the couch next to the participant for most of the interview, massaging the woman's legs.

At the conclusion of the interviews, we thanked the participants for their time and willingness to share their experience and compensated the participants for their input and time. As recommended by the CAB, the incentive included a \$20 gift card from a local grocery store and a coupon for free parking at the clinic or a coupon redeemable for two rides on public transportation.

Overall, the approach to the recruitment and the interview processes accommodated the needs of the participants and acknowledged that they were the experts with regard to their own care. It is well documented that as a research methodology the use of qualitative interviews with individuals with advanced cancer experiencing symptoms requires special attention and facilitation to ensure that no harm is caused (Koenig, Back, & Crawley, 2003). At the conclusion of each interview the participant was asked about the interview experience; most responded that it had been enjoyable. No one gave a negative response; the least positive response was that “it was OK”. No participants said the interviews caused distress of any kind. Some participants expressed appreciation for the chance to talk freely and share a deeply personal experience. Studies that have examined terminally ill individuals’ experience of participating in qualitative research similarly report positive feedback (Emanuel, Fairclough, Wolfe, & Emanuel, 2004; Gysels, Shipman, & Higginson, 2008).

***Interview Guide.*** The main instrument for this research project was an in-depth semi-structured interview guide (see Appendix F). The guide enabled the interviewers to facilitate and focus the interaction with the participant. Only minor revisions were needed throughout the study because the guide was developed with a menu of different situations. An example of a question that was added was “Tell me about any people in your life who have helped you deal with your (symptom)?” because we were having difficulty getting information about social support. Using the same (or similar) interview guide for the entire process allowed comparisons to be made across the study sample (Bernard & Ryan, 2010). Interview topics included symptom description, effects of symptoms on day-to-day life, self-management strategies used for symptoms, and

facilitators of barriers to symptom self-management. In order to establish rapport with the participants, the first questions were broad and allowed the participant to freely describe him/herself and the experience of cancer (Kvale & Brinkmann, 2009). The guide opened with a general question such as “Tell me about how cancer has affected your life in the last year”. The questions were designed to promote an open discussion of the participant’s experience with symptoms. As the interview progressed, the questions became increasingly focused on how the symptoms interacted and impacted day-to-day activities. The conversational nature of the semi-structured interview guide allowed the interviewers and participant to have a back and forth exchange so that the questions and responses were understood by both the interviewer and interviewee. Also, the interview guide provided a menu of questions under each topic to allow the interviewers to vary the questions in relation to the participant’s response. Communication strategies such as using open-ended questions, reflective listening, reframing, summarizing, along with positive acknowledgement and empathetic listening, were used to create a climate in which the subjects became comfortable enough to talk in depth and detail about their symptoms and the challenges of symptom management. Probing questions were used when needed to encourage participants to talk about their experience and management activities. Examples include questions, such as “Can you give me an example?” or “Tell me more about that activity”. Often the most successful technique was to allow silence after an exchange, which offered the participant time to reflect on the conversation and add additional information. Since many participants were eager to talk and often moved from one topic to another, the interviewers found themselves using specific techniques to redirect the speakers back to the original question.

**Data Sources.**

*Interviews.* The primary source of data was the transcripts of the interviews. The audio-taped interviews were first de-identified and assigned a unique identifier. The tapes were then transcribed verbatim into an electronic Word document by an experienced research transcriptionist. Either I or the interviewer then carefully listened to the entire transcript of each interview while reading the typed text, to verify the accuracy of transcription. Minor edits were made as needed. All electronic and paper copies of the transcripts were secured at all times.

*Field notes.* Two types of field notes – procedural and analytical – constituted additional data for the study. During the interview, both interviewers took notes but one person was responsible for documenting specifics about the interview like description of the interview location, presence of any additional persons at the interview (family member or friend, etc) as well as the appearance of the participant – his/her dress, body language, and outward signs of emotion and mood.

After each interview, the interviewer and co-interviewer meet to discuss procedural issues, first impressions of the data, interview techniques that worked well or those that needed improvement. This debriefing happened the same day of the interview to allow for a supportive exchange and review. Also, the interviewers documented analytical notes with regard to the core themes of the interview. Between interviews, the interviewer took notes to document beginning ideas on codes choices, definitions, and patterns seen in the data. By reflecting and writing about the interviews, the analysis phase began a cyclic process including data collection, coding, note taking, and revisions for the next interviews. The notes were mainly used to document ideas pertaining to new

themes or themes which had been introduced in earlier interviews which needed to be reviewed in light of the current interview. Interviewers also wrote comments to share with the other interviewer to facilitate the debriefing session.

In qualitative analysis, the researcher engages with the data on two different levels. First, the researcher must think through how the analytic decisions are made and how these drive the interpretation of the data. Second, the researcher must consider how the data engage him/her emotionally. The research design of this study incorporated a post-interview debriefing process, discussion, and note-taking to allow the researchers to document both cognitive and affective reactions to the data and to observe how these reactions begin to shape the interpretation of the data.

A major strength of this study was using two interviewers. The interviewer was an African American retired public health nurse in her 70s, who had been involved personally with the Grady community her entire life. The researcher, a middle-aged White woman, had been exposed to the Grady community throughout her career but mainly on a professional basis as an oncology nurse and researcher. The two interviewers approached the study with different biases and experiences and were able to freely discuss with each other how that background influenced the interview process as well as the analysis. The interviewers asked questions differently, picked up on different important topics, and connected with the participant in different ways. This sharing of the interviewing process with a community 'insider' and the extension of the process into detailed post-interview discussions allowed me to reflect on how my values, beliefs, experiences influenced her approach to the study.

**Data Management.**

When the data had been collected, all identifiers were removed and replaced with a study identification number (ID). Documents with identifiers (consent forms and locator information) were kept in a locked cabinet different from the locked cabinets where the rest of the data were stored. All potential identifiers (such as names of individuals and specific institutions) were removed from the transcripts. The digital recordings of the interviews, transcriptions and field notes were saved on a password-protected computer.

The qualitative data management program NVivo, developed by QSR International (QSR, 2008), was used for organizing the transcriptions. The transcripts were imported into NVivo and then coded. The properties of NVivo allowed me to create, delete, merge and move codes as needed to build the coding framework. All field notes were dated, given a descriptive title and entered into NVivo, enabling their classification and easy retrieval.

**Data Analysis**

As described by Miles and Huberman (1994), the purpose of qualitative analysis is three-fold: data reduction, data display, and conclusion-drawing and verification. All activities are simultaneous and involve analytical choices. For this qualitative study with low-income African Americans with advanced cancer, I hoped to gather information on their experience of living with multiple symptoms and the details (who, what and where) of the strategies of self-management. The goal of using the descriptive qualitative approach was to obtain the facts as described by the individuals and to carefully document the meaning the participants give to the facts (Sandelowski, 2000).

Data analysis was an ongoing process throughout the study, within the frame of four time points: 1) interview; 2) first cycle; 3) second cycle; and 4) saturation. Although these time points are recognized and explained separately, the processes occurred over time in a cyclic and iterative process to allow the data to reveal its richness and complexity (Bernard & Ryan, 2010).

As stated earlier, data analysis began with the first interview. Each interview was reviewed soon after it was conducted. I listened carefully to the audio-tapes, read and re-read the transcripts, checked the transcription against the audio-tape, and used field notes to add context to the participants' statements.

The first cycle of coding, which included construction of the code book, was an initial attempt to organize the data into groups for classification purposes. The code book included a code name, description, and a brief data example and was structured so that the framework included the categories of symptoms, strategies, day-to-day changes, facilitators, and barriers. This framework was based on the research question and the interview guide, and all subsequent coding was listed under these categories. I coded all interviews using the codebook schema. In general, the coding was very detailed and included all mentions of symptoms and strategies to manage symptoms. In order to evaluate and enhance reliability, interviews were coded by two additional persons early in the process of data analysis. The first coder, a clinician in palliative care, helped me to develop and revise the codebook. Using the first ten interviews, multiple codes were developed using the initial framework of categories. The two coders worked closely discussing the interviews, this effort resulting in a very detailed, multilayered codebook. Throughout the process, coders reviewed each other's coding and resolved discrepancies.



The second coder, a skilled qualitative researcher, coded an additional nine interviews using the codebook to further establish interrater reliability. The second coder and I obtained an average kappa of .84 across the nine interviews.

During the next cycle of coding, themes emerged as I stepped back to examine the bigger picture. This phase of sequential analysis included many versions and revisions and required frequent consultation with my advisor and the committee member who served as the qualitative expert.

The constant comparison method looks for similarities and differences in the data and makes comparisons across units of data. This method asks what this passage is about and how is it similar or different to the preceding or following text (Bernard & Ryan, 2010). Originally developed in the grounded theory methodology of Glaser and Strauss, the constant comparison method is discovery-oriented and involves taking one piece of data and comparing it with all others that may be similar or different in order to develop conceptualizations of the possible relations among various pieces of data (Corbin & Strauss, 1990). Using this method, I moved iteratively between code and text in order to derive themes related to symptoms and symptom strategies.

More analytical coding or interpretive coding (Richards & Morse, 2007) was applied in the second cycle, resulting in a thematic organization taken from the first cycle. The first-cycle codes were reorganized and reconfigured to develop a smaller and more select list of broader categories. As these developed, the process of axial coding was used to make connections among and within them. This was achieved by exploring the conditions, context, action, interactions and consequences which influence the topic being studied (Corbin & Morse, 2003). For example, the effect of the *severe tiredness*

was explored in this manner. When reading and rereading the context and conditions of tiredness, individuals made changes in their activities, their schedule, and slowed down the speed of their day. I noticed that the participants did not describe how it felt yet instead talked about the how tiredness impacted how they functioned. I was then able to connect the other symptoms to functioning in everyday life. In this way, more abstract concepts were identified through sequential analysis. I repeatedly examined the data closely but also stepped back to see look for redundancy and overall fit (Richards & Morse, 2007). Throughout, I called on qualitative experts to corroborate findings and to discuss the analytical decision-making process.

### **Saturation.**

Final sample size was determined during the data analysis. Data gathering continued until the saturation was reached, i.e., when findings from new interviews consistently replicated findings that had been documented in earlier ones (Adler & Adler, 1998). The interviewer and I agreed after in-depth discussion that the information given by participants seemed to be getting repetitive, a pattern confirmed by data analysis. I also consulted my advisor and my committee member who served as the qualitative expert and determined the sample to be of sufficient size and data to be rich enough to answer the research questions. Recruitment ceased as the data approached saturation. Since the initial goal was to recruit equal numbers of men and women, the data from the males was examined and determined to be sufficient. The final sample size of 27 participants was similar to the sample sizes in other qualitative work with similar populations (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007; Hamilton, Powe, Pollard, Lee, & Felton, 2007; Hughes, et al., 2007; Sherwood, et al., 2008).

**Validity.**

Validity refers to the truth, the correctness or strength of a statement. Kvale and Brinman (2009) describe validation not as a separate stage of a study rather as a continual process. For this study, validity was examined at two levels—procedures and analysis. We ensured procedural validity through transparency in each phase of the study. All processes and collaborations were meticulously documented. The careful documentation of all processes and the archiving of items such as the screening form and the interview note page, along with additional field notes, and documentation of any deviations from the study design, helped confirm our adherence to the prescribed procedures.

Prior to conducting the study, a protocol manual was created. The manual also described the activities of each phase of the study. For example, a recruitment section outlined the procedure to be followed for recruitment and included study recruitment material, correspondence with providers describing the study, and a screening form to document the eligibility status of all potential participants. Data collection procedures outlined in the manual were similarly open to scrutiny. The instructions for the interview were documented, as well as how to handle any unusual circumstances, such as that of a participant wishing to split the session into two meetings or that of a participant who might feel ill during the interview and be unable to complete it. Transparency was also ensured through the audio-taped interview material being rigorously checked against the transcripts.

Transparency in the analysis phase allows others to follow what you have done. This enables the research findings to be tracked and corroborated each step of the way.

Close attention to documentation in the coding manual as well as in the field allowed an ongoing review of the process and showed reliable interpretations based on links between the data and interpretation (Green & Thorogood, 2004). Early drafts of themes emerging from the data, and subsequent revisions of these drafts along with enough descriptive context to establish credibility were provided to my advisor.

The documentation collected throughout the study was all part of an audit trail and its purpose was to assess the trustworthiness of the data (Tobin & Begley, 2004). The audit trail documents the data analysis procedures in a logical and traceable manner. Credibility or internal validity of the data was checked frequently in discussions with my advisor and qualitative expert.

### **Methodological Issues**

A high level of sensitivity and ethical consideration are required when researching an underserved and underprivileged population with multiple social vulnerabilities and a high disease burden. The study was also based on the awareness that respect for the autonomy of vulnerable participants was crucial and was to be continually maintained, even if the participant had a set of values and goals that differed from mine. The informed consent process, requiring special attention in the case of participants who were poor, possibly uneducated and sick with advanced cancer, was closely monitored throughout the study. I was confident that the participants completely understood the scope and requirements of the study and that he /she had the right to terminate the interview at any time. I consulted the interviewer and coders and regularly consulted with her advisor and qualitative expert to ensure flexible and transparent data collection, detailed and consistent documentation and trustworthy data analysis.

## **Chapter 4: Findings**

### **Introduction**

Individuals with advanced cancer experience multiple symptoms that affect their daily activities. For many of the participants of this study, these symptom experiences dominated their lives. It was typical for them to monitor their symptoms as well as seek ways to find relief. The findings from this study are presented in three parts, the sample description, the symptom experience, and the coping strategies used to deal with the symptoms. An overview of the findings related to symptoms is illustrated in Figure 1. Figure 1 shows that the symptoms experienced can be described by two themes. The first theme was “being in pain” and included the overwhelming experience of living with pain, both physical and emotional. The second theme was “symptoms associated with functioning in everyday life”. Participants frequently used the context of their daily activities to explain symptoms, including the effect of symptoms on the activities of eating, moving/doing, and communicating. Figure 2 outlines how this sample managed their symptoms or how they coped with them. The symptom self- management strategies could be described by two approaches, behavioral and spiritual coping. Behavioral coping included using medications and lifestyle changes. Spiritual coping included the use of faith and prayer. The following descriptions will provide information about the sample followed by more elaboration of these themes.

### **Sample Characteristics**

A sample of 9 male and 18 female individuals attending the Grady Cancer Center were enrolled in the study and were interviewed. Table 1 provides demographic information about these 27 participants. The mean age of the sample was 57 with a range

from 30 to 79. Only three of the participants were married whereas 78% were either single or divorced/separated. Over half lived in their own home or apartment, and the others lived in homes of family members or friends. One quarter of the participants lived alone while two lived in a large household of 9 or 10. All but two participants were born in the U.S. Most participants reported that their current financial status was not adequate (“I go without/ I barely have enough to get by”) although only one-third described their family’s financial status when they were a child in the same manner. Years of education varied greatly, ranging from 3 years of elementary school to two years of graduate school with 74% having no more than a high school degree. A majority received medical care through Medicaid.

Table 2 provides information on the participants’ clinical characteristics. Participants’ cancer diagnoses varied considerably. The most common cancers represented were breast (9) and lung (8). Most participants were recruited from the palliative care clinic, and the others came from various oncology clinics. One of the participants recruited from the lung cancer clinic had also received care from the palliative care clinic. About half of the sample had received palliative care support. Participants reported a variety of co-morbidities. Over half reported hypertension. To better describe the sample, pseudonyms were given to all 27 participants. See Table 3 for a description of each individual, including information on age, cancer type, education, marital status, living arrangement, financial situation, co-morbidities, treatments, and palliative care services.

## **The Symptom Experience**

As part of the eligibility criteria, all participants reported at least two symptoms of moderate severity at study entry. The ESAS was administered to determine eligibility as part of the screening process and then again before starting the interview. Table 4 shows both the ESAS scores for the screening visit and the interview visit. As illustrated in this table, study participants experienced multiple symptoms which varied between two time points. The findings of the ESAS were sometimes referred to in the interview in order to initiate discussion. The interviewers did not specifically ask about any symptoms except those on the ESAS which included pain, fatigue, nausea, anorexia, dyspnea, drowsiness, insomnia, depression, anxiety, and constipation. Once the discussions began, the participants spoke of many other symptoms, and all the symptoms discussed during the interview are listed in Table 5. Participants experienced multiple symptoms; their descriptions included symptoms they currently experienced as well as symptoms that occurred in the past. The intensity and quality of the symptoms changed over the course of disease progression. 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, being in pain and symptoms associated with functioning in everyday life.

The primary symptom group dealt with pain that was both physical and emotional. Although all participants were not experiencing pain at the time of the interview, all participants, except one, spoke of having pain since being diagnosed with cancer. The other theme, symptoms associated with functioning in everyday life, explained how symptoms changed the way participants ate, moved and communicated.

Prior to experiencing 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 daily activities.

### **Being in pain.**

Many participants first learned they had cancer because of the onset of physical pain and others knew their cancer had reoccurred because of pain. Cancer treatments also caused pain for many. The majority of the participants experienced pain during the study interview. Pain in this sample occurred across cancer types, gender, and in all ages. The pain experience was similar for those who lived alone as those who lived with family or friends. Often participants spoke of emotional pain that related to the physical pain. Here are the descriptions of pain across the sample.

*Physical pain.* The stories of pain were often related to diagnosis, treatment, or just day-to-day life. Most experienced a variety of pain over time due to different causes. Ms. Smith described the pain associated with her ovarian cancer, perhaps from the pressure of a tumor she did not know was growing in her body.

*My stomach was hurting so bad, I would just lay on the floor and just about cry. I would, I couldn't sleep in a bed. I would have to sleep on the floor and that was the most comfortable for me.*

Surgery to treat her cancer caused her most recent pain. Similar to Ms. Smith's pain from surgery, 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". Ms.



Green, Ms. Cochran, and Ms. Lee spoke of the pain from skin burns. They received radiation treatment for their cancers (lung, breast, and cervical, respectively) and each speculated that they had received too much radiation. Ms. Green described the burn when asked about her 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 I 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, had me burnt on the inside and the outside, all the way through to my back.*

Ms. Cochran said the burn felt like having hot grease thrown on her skin. In contrast to the pain known to be caused by treatment, the cause of most pain was unclear and was accepted as part of the cancer experience.

The pain changed overtime and sometimes consumed their lives. Some said the pain from their cancer hurt more than anything they experienced in the past. Others experienced severe pain for the first time. Ms. Cochran spoke of never experiencing pain before and said *“ain't never had pains until I went through this, all this, this stuff I'm going through now. Now, I been getting pains, all different kind of pains.”* For some, pain lurked at the back of their mind even when they were not experiencing it.

While some worried about what the pain signaled, others expected to experience some pain related to their advanced cancers. Others looked back at life before cancer. Mr. Thomas, who prior to his 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 use to be without the pain, it would be so wonderful. So now since they did the radiation, I don't have as uh, as much severe pain as I use to have, but I still have pain. I mean a lot of pain and uh the pain range from my thigh, to my knee, to my ankle and it is a very aggravating, uh, 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. Participants spoke of different types of pain, from arthritis or neuropathy, and pain at different locations like the back, nipple, and leg. Some said pain was worse in the morning when first waking up; other said it was worst at night after a day of activity. This 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.

A common side effect of some chemotherapeutic agents is neuropathic pain, described 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. Carter illustrated how her life changed because of neuropathic pain. She described having to quit the job she loved. She worked at a car rental agency prior to her diagnosis and needed to drive long distances for her job. She

felt she had no choice but to stop working because of the numbness and discomfort in her feet.

*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 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.*

Her job was a social outlet and she missed seeing her co-workers. Now, she spent her days caring for her adolescent grandson. Her son, the boy's father, visited her daily, cooked for her, and drove her as needed. He also forced her to stop driving. She was appreciative of her son's assistance and love, yet was frustrated that he took away her independence.

Participants who reported an inability to sleep attributed it to being in pain, including 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 like to recount the co-occurring symptoms of pain, coughing, and poor sleep. Other individuals, who reported changes in their sleep, told of drowsiness or excessive sleepiness, often explaining they expected this to be a side effect of the pain medication they were taking. Since their pain was so distressful, they had no choice but to take the medicine and deal with the drowsiness.

Pain medications were the cause of another bothersome symptom, constipation. Participants rarely discussed constipation as it related to other symptoms associated with the gastrointestinal tract, but instead linked it to presence of pain. Sometimes participants

spoke of pain caused by constipation. Often they talked about the need to take pain medicine which caused constipation. Ms. Lewis 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. A few people reported excessive abdominal bloating that also caused pain.

***Emotional pain.*** Pain was not only expressed as a physical symptom but also as an emotional one, including a depressed mood, worry, anxiety, and fear. These emotional states often occurred together along with physical pain. Ms. Green changed the focus of the interview when asked a follow-up question about her pain from skin burns.

She said:

*The kind of pain you mostly have, that wor-ration, that worry is what kill people too. It ain't so much, so much pain, 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. Cooke 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. Clark, 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 shooo, just shot. The pain can be so excruciating. And I said to myself...I could see why some people...when they have pain or cancer or whatever, cause I understood, people use to tell me cancer can be very painful. 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.

Ms. Lewis, 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?*” For all these women, these feelings came from losses: loss of control, comfort, and function. For other individuals, their depressed mood came after learning they had cancer and now faced the prospect of death. Others related depressed mood to stressful relationships with family members. Ms. Washington and Ms. Evans worried about who would care for their children when they died, and related their depressed mood to the uncertainty of the future. These women also mentioned financial concerns that caused

anxiety. Of note, 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.

Anxiety and depressed mood often occurred together. Participants who discussed anxiety related it to treatments. One person thought that one of her medicines made her nervous while another described becoming anxious prior to going to her radiation treatment where she had to place her head in a helmet which was fastened to a table. Participants also discussed fear related to the uncertainty 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. Before cancer these 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 based on how much they disturbed these activities.

***Eating.*** 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/mouth, and swallowing difficulties. Most of the symptoms occurred and together disrupted the act of eating.

Anorexia or the loss of the desire to eat was the most common symptom in this group. Since eating is a universal experience, not wanting to eat 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 had received chemotherapy. Mr. Scott, 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 make me sick on the stomach. I throw it up.*

When these individuals could not taste their food, some still tried to eat and some did not. Some forced themselves to eat food that had no taste, making it an unfulfilling experience. Ms. Washington 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, such as Ensure. Many participants who could not taste, also could not smell, which made it even more difficult to eat. A few spoke about taste changes. Often food tasted like metal which resulted in decreased eating.

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.

A subgroup of participants was unable to eat despite their desire to eat. Their sore mouths and throats or swallowing problems made it difficult to eat although they were hungry. They gauged the severity of these symptoms by their nutritional input. For instance, one person described that her mouth felt so sore she could not eat spicy food and gave specific examples of how her diet had changed. Ms. Robinson, who had been

through brain radiation, chemotherapy, and two craniotomies felt frustration because she could not eat due to swallowing problems possibly related to her recent surgery. She tried different foods but was then warned by a caregiver she should not eat because it might “*slip down her lungs*”. As she waited for swallowing tests to be completed, she fed herself through her gastrostomy tube and longed to eat again.

The story of Ms. Hall illustrates the life changes brought about because of this group of symptoms. Ms. Hall, along with other women in the study, spoke of being the cook of the family but because they no longer could taste their 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. Hall worked as a cook for many of her 79 years. 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. And I can’t – and I’ll be cooking. They said, Momma, that sure smells good; but I can’t smell it.*” Instead of eating, she mainly drank Ensure because the doctor had told her to, one can three times a day. 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 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 when she taught her



grandson who lived with her how to cook. This group of symptoms had changed how she functioned in her everyday life.

***Moving/doing.*** Being active and mobile is another important but basic part of life for most people. Restrictions on movement 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 and impacted the ability 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 impacted the ability to walk and take out the garbage for Ms. Miller 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 to stand or walk. Weakness made it difficult for individuals to shower and cook. Ms. Lewis spoke of how tiredness impacted 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. Patrick, a former hotel concierge, could no longer participate in her favorite hobby, roller skating.

*But I like to roller-skate. I have a pair of roller skates sitting in the backseat like a child and I look at those things, and I sometimes sit in the truck and I weep. And I weep because I can't get on those puppies any more. I tried and [Participant name] gets real tired. It really does, it muscles out, tires out the legs I guess.*

Shortness of breath, also described by breathlessness and being winded, impacted the ability 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 interchanged the two. Ms. Washington 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"*.

Although not co-existing with other symptoms, cancer impacted the ability to urinate. A few participants experienced difficulty urinating as an initial sign of their cancer while others attributed it to their cancer treatment. Ms. Carter experienced a change in the normal clues to urinate, she felt pain instead of bladder fullness. She related this to damage from her surgery and expressed frustration over this change that impacted her throughout the day.

One woman and one man mentioned that the cancer experience negatively affected their libido. Mr. Scott said *"Something else went with my strength, my ah, my nature. It decreased my sex drive. It decreased, it decreased tremendously."* Ms. Patrick talked about becoming celibate during her cancer experience. She reflected on her priorities and said *"The mental state of how you feel, as a woman first. The only thing*

*you're thinking about, I'm human. Of course you know you're a lady but all that goes. You're trying to survive".*

**Communicating.** Although not as frequently mentioned as other symptoms, a group of symptoms affected the ability to communicate, due to cognitive changes, visual disturbances and talking challenges.

Cognitive changes caused distress and impacted the way participants communicated. Most associated this as a side effect of chemotherapy while some speculated that anesthesia or pain medication could have been the cause. Speech problems were the main difficulty as illustrated by Ms. Miller who only had completed five years of elementary school. *"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. Lee, a former social worker who completed her master's degree, spoke of difficulties in conversations where it took time to come up with the correct word. She also described not being able to type as fast as she used to when she was writing grants under a tight timeline. Ms. Patrick 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. Wilson 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.*

The cancer process impacted the ability to communicate and perceive their surroundings for two other participants. Mr. King woke up one morning and could not see out of one of his eyes. He immediately went to the hospital and soon found out his cancer had spread to his brain. Fortunately after treatment, both chemotherapy and radiation, he reported that his vision was almost back to baseline. Mr. Coleman spoke in a very hoarse whisper due to his vocal cord cancer. This inability to communicate easily frustrated him. His social interactions had decreased and he seemed quite isolated. He had recently been diagnosed and had not started treatment. He was reluctant to start treatment due to the potential side effects he had heard about from others. Although his fear kept him from starting treatment, he started to plan for a future when he might not be able to talk. He said, *“If I’m just losing my voice and that’s what’s going to happen, I can live. I take some school. I can take some sign language. I’ll be all right.”*

### **Summary**

The symptom experience produced distress. In addition, the ongoing changes in the day-to-day lives of the participants forced ongoing adjustments. Many were forced to stop working. Personal hygiene, household chores, daily schedules, exercise, sleep, and social outings were also impacted. 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. Strategies to manage symptoms became a new part of their lives.

### **Strategies**

As the previous discussion described, symptoms caused significant distress. Study participants utilized coping strategies to deal with these stressful symptoms; the two types

of coping included behavioral coping and spiritual coping. The behavioral strategies were approaches they incorporated into their daily activities, making adjustments in medications and their lifestyle. Spiritual strategies included the use of faith and prayer and impacted all dimensions of their lives. See Table 6 for an overview of what strategies were used by which individuals.

**Behavioral coping.**

Caring for symptoms required adjustments to day-to-day activities. Participants found ways to get relief and took charge. The symptom signaled that something needed to be done. Participants made changes in how they cared for themselves, ate, and moved. To make these adjustments, participants demonstrated many skills such as listening to their bodies, taking action, gathering assistance from others, and continual evaluation. Family and friends helped participants with activities. They often provided transportation, did shopping, and helped with household chores. A few had a nurse's aide visit them at home and provide assistance. But, overall, the participants were in charge. Behavioral strategies included medication modifications and lifestyle modifications.

***Medication modifications.*** Participants with symptoms often self-administered medications to provide symptom relief. For prescribed medications, the doctors wrote the order but the participants held the responsibility for taking the medications and often adjusting the medications to suit their needs. The adjustments included choosing the type, dose, and timing of the medication. For the purposes of this analysis, medicines discussed were administered by participants to decrease symptoms and included prescribed medications and over-the-counter medications. During the interviews, almost

all of the participants discussed the challenges of taking prescribed medications.

Participants took medications for pain, cough, sleep, anorexia, wheezing, insomnia, constipation, nausea, high blood pressure, neuropathy, blood clots, depression, and anxiety. Participants self-administered chemotherapeutic agents used to control cancer and referred to them as my “*cancer pill*”. All of these medications required knowledge that health care providers supplied. But, for multiple reasons, the participants took the medications based on their own assessments of need and benefit, sometimes disregarding the instructions.

For many, this current illness was the first time they needed to take medication. Ms. Hill, a recent double amputee who lived alone, reported that the only medication she had taken prior to being sick was an aspirin. She commented on the change that took place.

They tell me take pills, somebody who ain't never took no pills. I'm popping pills like crazy. It's no sense in coming here if I'm not gonna do what was said. The Lord wouldn't have sent me here, if it wasn't needed. So I just go ahead and just, every morning, takes all my pills, drink some water and go on. That's how it is.

Participants described taking numerous types of medications that required an understanding of the purpose of the medication and the dosing instructions. Many participants recited a long list of medications they took. Mr. Taylor, who also lived by himself, said:

*I take like 12 pills a day, you know, just my pills, a day. So I take bowel movement pills. I take blood pressure pills. I take cancer pills, two sets of cancer pills and water pills and I can't think of the rest of em. And you know for my nerves. And*

*uh for my, you know, feeling depressed. I have a pill for that.*

During the interview, he also discussed his pain medication in detail but did not include it in the list. No doubt, the medication regimens that most of the participants took were complex but with the addition of pain medication, usually opiate therapy, the complexity increased even higher. Participants often referred to the principals of administering opiate medications when they spoke of long versus short acting medications as well as around the clock dosing and as needed dosing. Ms. Nelson describes the different types of pain medication she took.

*And I have to take other pills you know, in between, I have ah , my , ah , short , my other pills that I can take in between my long acting pills , if there is breakthrough pain. So I do have pain if I do a lot of walking, working around the house, or doing normal activities. I'll, you know, take my medicine, and I'll rest, I'll sit down for a while.*

She monitored her pain and her activity to decide what to take. Making decisions about which drug to take, how much to take, and the timing was a common activity. These decisions were not always based on the doctor's original prescription. Some participants took less and some took more as they adjusted the dose based on the symptom intensity. Ms. Cooke was not receiving relief from her pain and spoke of increasing the dose but with some trepidation.

*I just hurt , I hurt all the time , they done gave me all kinds of pain pills, now I'm on oxycodone, And they say take one every six hours, but I have to take more than one. I take two. Sometimes I get scared to take three. I be wanting to take three, but I'm just scared, but oxycodone help. They give me the long ones and the short*

*ones.*

Participants recognized the need to listen to their bodies and base the medication intake on the intensity of their symptoms. Mr. Williams said this:

*I felt myself how the pain was doing me. I felt how, it was coming on, my body was telling me, letting me know when that pain was coming up or whatever, you know, and that's when I start taking them. And then I see the schedule they have me on, well that's what they wanted me to do, take it when I don't have pain, and ah , I didn't want to take it if I didn't have pain.*

Like Mr. Williams, many study participants did not take the pain medication as ordered rather when they felt they needed it.

Participants also titrated the dose of pain medication based on the side effect of the medications, specifically drowsiness, and constipation. Ms. Smith spoke of her cognitive ability and being able to negotiate the bus while on pain medication.

*So I still take pain medication for that (pain). But I try not to take it too often, because then you can't be, you know, bright enough to ride the bus. You're too tired. You're too, you know, you just don't feel like it and I don't wanna be like that.*

Ms. Washington, who lived alone with her three school age children, felt conflicted about driving and taking her medications. *“I mostly don't try to take my medication, cause I don't have nobody to drive for me. But I'm always going to have to take medication because I'm always in pain.”*

Like Ms. Washington, many participants expressed reluctance about taking medications for a variety of reasons including dislike of medication and addiction



concerns. Individuals spoke of not liking to take pills yet when they experienced pain, they had no choice. A few participants spoke of the concern of taking pain medication and addiction. These individuals spoke of how they carefully limited their dose, sometimes resulting in suffering. Ms. Evans mentioned that many of her family members were alcoholic and that she drank heavily in the past. She spoke about her pain medication.

*So I will suffer sometimes not to be dependent on it. I don't want to have to say, you know, it's three hours gone by; I've got to take this pain medication. I'll let it go another three and just deal with it. I don't want - - I just am determined I'm not going to be addicted to anything.*

Ms. Green spoke about being overwhelmed with all her medication and reported that she only took some of her prescribed medications because “*that's just too much medicine for anybody to take.*” When asked how she decided what to take, she said:

*Whatever I think the problem is. If I think my throat needs, seeing after today, I take my gargle, that gargle wash, that antibiotic for my throat. And I take steroids, cause it's suppose to be for my brain and so that's all I been taking right now, and I take a high blood pressure pill, every, not every day, every once in a while if I feel I might need one along the way, sometime with them children.*

Overall the participants reported that the medications were effective at reducing symptoms but many described a personal debate; they did not want to take the medication but knew they needed to take it.

The act of titrating doses of medications was also mentioned in regard to anti-depressants and stool softeners. One participant reported that she only took her stool

softeners once a day although the doctors ordered it twice a day. She assessed the consistency of her bowel movements and realized she needed to take the prescribed amount. Whether large doses of opiates or stool softeners, these adjustments required the participant to monitor their symptoms and make independent decisions.

Although the participants often did not follow the exact medication instructions, they did go to the doctor for information. The participants spoke of the messages received from the doctors as well as their requests for information from their doctors. Mr. Wilson spoke of doing a thorough assessment of his situation and the need to consult with the doctor. He astutely summarized the assessment of his pain and his concern he planned to discuss with his doctor.

*The pain medicine, now that I've increased it, it's helping a lot now. Like right now, I took the last one at 10, and now it's 1 and I'm starting to have a little pain now so I'm getting concerned that that 6 hour window that I usually use is getting shorter. So that I'm going to discuss with the doctor and ask him you know, if he can maybe change that medicine, 'cause I'm worried now that that medicine can cause liver, liver problems in taking it too often.*

Most participants felt the need to call on their doctor to get information about their medicines.

Also, participants heard the doctors encourage them to take their medication. Ms. Cooke said her doctor told her “*don't wait until I get in pain, take the pills, cause they have to dissolve and get inside me, so he said don't wait until I start hurting, take the medication.*” Many participants needed repeated encouragement due to their reluctance to take the medications.

A few participants mentioned the use of over-the-counter medications. Specifically, participants used Goody Powders and ibuprofen for pain as well as over-the-counter suppositories, Maalox, and Milk of Magnesium for constipation. The most common category of over-the-counter medications was topical ointments and liniments such as Watkins camphor, sports creams, Icy Hot ointment, and green rubbing alcohol. Ms. Clark had incorporated the application of a topical analgesic called Icy Hot into her daily schedule.

*But then I have to rub it down like with Icy Hot, some ointment. It helps a lot. I was doing that this morning. I said, let me get up and rub myself down. So when they come at least I'll be ready, give myself about an hour, especially if I'm not going anywhere. Do what I have to do. Just rub myself down with something.*

Medications for symptoms, whether prescribed by a physician or not, in addition to medications to treat co-morbidities, created a complex management activity for many participants.

***Lifestyle modifications.*** To cope with their symptoms, study participants made changes to their lifestyle, primarily related to activities and diet. What a person does, when the person does it and the speed of the activity changes when someone is living with distressful symptoms. As with adjusting medications, participants adjusted their activities based on symptoms. Ms. Nelson discussed the need to listen to her body and the consequence if she did not.

*I listen to my body, because if you don't, you're putting stress on your body, you're putting stress on yourself. You have to listen to your body. When your body start aching, it meaning it's time for you to sit down and relax, and to get*

*yourself together, because it's only going to get worse, meaning the pain because I have pain if I'm standing up for a long period of time, walking. It's, you know, whatever I'm doing, I have a time limit because my body tells me.*

Life slowed down for many of the study participants. The need to rest resulted in a new pattern or schedule for the day. It affected the amount of work they completed and impacted the ability to care for themselves, do household chores, and navigate hospital visits. Individuals said they had no choice but to curtail activities because of symptoms, mostly pain and extreme tiredness. The tiredness often overwhelmed many of these participants who described a busy life prior to cancer. Ms. Carter adjusted her activity, made time for a brief respite but still faced the tasks that had to be done. Her words describe the unrelenting nature of fatigue.

*I get in this chair and sit down when I get tired and lean back for a few minutes, and then I get up and do what I got to do, before it comes over me again, and it does come, all day long.*

The need to rest meant that schedules had to be rearranged and tasks took longer to complete. A person with tiredness, pain, or shortness of breath only had a limited amount of energy or breath before the body made them stop and rest. Ms. Evans described her life before cancer as very busy and active; she often balanced two jobs and managed a family. Now with pain and shortness of breath she said she could only do a little bit at a time and then had to rest. She summed it up by saying “*I recognize I've got a physical condition that makes me sit down.*” Her symptoms gave her no choice but to slow down and rest. Ms. Robinson, whose shaved head exposed one recent surgical incision and one healed surgical scar from two craniotomies for brain metastases in the past 18 months,

expressed her desire to complete her tasks despite her tiredness. *“I mean, if I want to do something or go somewhere, want to clean up the house, I clean up the house. I might sit around and rest in between, but I get the job done.”*

All of the study participants needed to visit the hospital or clinic for treatment, routine assessments, or problems. Most of the sample recently completed or currently received cancer treatment. Radiation therapy required daily weekday visits for weeks. Chemotherapy treatments required weekly or monthly visits. Many participants experienced co-morbidities which required additional visits (Coumadin clinic, dental clinic, and cardiologist appointments). These trips created new challenges for a person who felt tired, short of breath, or in pain. Participants changed the way they navigated their visits because of their symptoms. Ms. Washington spoke about her difficulty in getting to her appointments.

*I mean, when I go to the hospital, and park in a parking space, by the time I get half way up there, I be wanting to sit down, but see they done moved the chairs.*

*They done moved it and I be like, why'd they move these chairs, I can barely make it. I get me some water and then I go on up, and sit down. I be like whew, I made it. But it's terrible Honey you be out of energy, you don't have no energy.*

Mr. Johnson experienced unrelieved pain and spoke of not going to his clinic visit because he felt too bad. Besides his pain keeping him from going to his appointment, he told us his financial difficulties made it difficult to pay the co-payments required for each clinic visit.

Despite not feeling well, participants needed to continue to care for themselves and their family but they needed to slow down. Participants who had children to care for

needed to plan out their day. They needed more time to get things done and then time to rest. The 42 year old mother was the sole caregiver for her 4 children and she experienced constant pain. She explained how she managed her household chores.

*I try to get up early so I can have it done. Most of the time it takes me 2-3 hours to do what I have to do. I just take my time and do it. I don't try to get myself in no hurry 'cause I know how I am, I get short of breath.*

Similar to others, her balance of activity and rest was not really a choice, but a necessity. She listened to her body and slowed down to avoid the distress of not being able to breathe. People accepted this new pace of life and still felt they could be productive and do what needed to be done. They adjusted their daily schedule to include rest stops.

Cognitive changes required a slower pace, as described by Ms. Lee. She spoke of her inability to recall words in a conversation. Before cancer, she wrote grants and worked under time constraints. Now she did not have work deadlines, and she accepted that she needed more time to communicate.

*It's only disturbing if it's hampering me. Let's say hampering me against a deadline – ah – otherwise, we just wait for whatever information it is to circle around back to track, fall in to place. That name will come back, look at people or just, just say like an actor, and you know their name, and you say ahhh and tomorrow at 12 noon, you say, yeah, that's so and so, but I mean, that type of stuff is not important. But if I had to work against a deadline, I would probably be stressed”.*

Participants also needed to make changes in the activities they participated in, sometimes eliminating activities and, at other times substituting activities. At times the

presence of symptoms meant an activity could no longer be completed, at any speed, which often produced sadness and frustration. Activities impacted included self-care, housekeeping, and travel. Mr. Taylor, who lived alone, could no longer bend over or get on his knees which made it difficult to pick things up off of the floor. This gentleman prided himself on being able to care for himself and spoke of cleaning his apartment and cooking healthy meals but his mobility limitation frustrated him. Many spoke of not being able to drive or take the bus because of pain or weakness. Mr. Johnson's pain kept him from driving long distances which meant he could not visit his mother who lived in another town. Ms. Hall's shortness of breath and pain meant she could not participate in church activities and even walk to the elevator at her apartment complex.

Some of the activities individuals participated in provided comfort or distraction. For comfort, many participants used heat applied to a painful area. A few applied pressure either by getting a friend to rub their back or tightly applying gauze wraps around their sore legs. Ms. Nelson liked to smell scents as a way to calm herself when she experienced anxiety or stress. She also used a simple breathing exercise of inhaling and exhaling when she needed to calm herself.

Others spoke of participating in activities to distract themselves as a way to decrease pain and depressed mood. Activities mentioned included watching television, talking to friends or family, playing with their children, listening to music, singing, exercise, and doing puzzles. Ms. Cooke who had unrelieved pain and shortness of breath that severely limited her activity spoke of doing puzzles to distract herself from the pain.

*When I'm concentrating on the word I'm looking for I don't think about ah pain and stuff. I still have them. I know I have them, but just like it ease it up or I know that's something I can do.*

Mr. Taylor who had metastases in his spine recognized that he could not lie in bed. He needed to get up and cook and clean his apartment. He lived alone and spoke of how the activity of ironing his pants helped his pain. After noting that his motivation came from the high prices at the dry cleaners, he said:

*Starch don't cost but a dollar a can and I don't have to pay no electricity bill so then that give me strength, you know, to stand up for a little while, see I can stand up about 30 minutes or maybe 40 minutes, ironing those pants. But I be kind of tired when I get through ironing them though, you know, But I have my mind on them pants and I don't feel no pain or nothing till I get through.*

One person expressed a variation of this theme. Due to family obligations, Ms. Cochran felt she could not slow down. She expressed anger throughout the interview for the lack of concern her family showed her. Although she reported severe pain, nausea, and tiredness, her daughter depended on her to provide childcare. Ms. Cochran described her experience this way, *"I can't get tired. If I get tired, who gonna watch the boys? Or who gonna fix me something to eat? Who gonna fix them boys something to eat?"*

Most participants spoke of adjusting their diet in order to manage their symptoms. The act of eating often now focused on how they could relieve symptoms such as anorexia, constipation, nausea, pain, and tiredness. Many also intentionally made changes in their diet with the hope of fighting the cancer or improving their health in general. Mr. Scott spoke at length about the distress he experienced because he could not



taste his food. He described the process of trying different type of foods hoping to find something that would wake up his taste buds. He ate different things at room temperature and, when that did not work, he tried the same food after heating it. He longed to taste again, and worked at different approaches like moving a piece of cheese from his tongue, where he could not taste, to the side of his mouth where he could taste it a bit. He also tried different flavors and found that he could detect the sweet taste of pineapple. His sense of taste was returning which pleased him, although he still could not smell.

Many adjusted their eating habits in terms of both food selection and quantity, as they tried to treat their constipation. Mr. Williams spoke of eating more vegetables and fruits as well as eating lighter. Although he loved eating a “*hearty*” meal of pork chops and rice, he concluded that foods like that may be contributing to his constipation. Ms. Nelson eliminated beef and pork from her diet because they exacerbated her constipation. Ms. Moore, originally from Africa, increased her intake of fruits and vegetables and prepared them by “*juicing*” them as a way to treat her constipation. In addition, she drank herbal teas and green teas to help this symptom. She spoke at length of how she had changed her diet in reaction to her cancer diagnosis. When she discovered her cancer had spread, she decided to increase the amount of carrots she juiced each day from 6 to 8 ounces, making adjustments in the carrot juice similar to how others titrated pain medicine. Drinking hot coffee helped another participant treat her constipation while others intentionally increased their water input.

Participants also adjusted their diets hoping to decrease their pain. Ms. Cochran spoke of using the condiment, mustard, to treat pain caused by abdominal bloating, advice she had received from her mother.

*Take a spoonful or about two or three spoonful of it cause we ain't got no Tums and all that. Can't go to the store. My mom use to say go in there and get some mustard. And so I guess the mustard push it down or pull it up or whatever it doing. My mom, we got that from. My mom was a nurse.*

Mr. Wilson carefully evaluated his diet and determined that sugary foods and drinks increased his pain. He cut out sodas and lemonade and cookies from his diet. He experimented with other drinks and found that apple juice worsened his pain but fresh orange juice did not. Ms. Nelson eliminated caffeine because she found out that it made her pain worse. Ms. Green who suffered from a sore throat and tried various soft foods, like eggs and grits, since swallowing was painful. Ms. Washington, who had a sore tongue from mucositis, only ate bland foods like baked potato instead of her once favorite hot wings. Ms. Smith reported that ice cream was a good remedy for her anxiety. She said:

*I love ice cream. So I eat a lot of ice cream. That's like, well, pacifier for me, honestly. I ate a half a gallon of ice cream last week. So this time I just got a half a gallon, some, some ice cream popsicles, chocolate popsicles, those chocolate popsicles. I got those and that's a pacifier for me. I feel good after I ate em because it calms me down for one, helps me sleep.*

Others made adjustments in their diet to decrease nausea. Participants use ginger teas, ginger ale, and peppermint tea as effective treatments for nausea. Decreasing the size of the portions reduced nausea for some. Some participants used liquid nutritional supplements such as Ensure to increase their caloric input either by mouth or by a feeding tube. Overall this group recognized the relationship between their diet to symptoms as

well as their general health. Although not questioned about it, many described a general overhaul of their diet to improve their health and fight cancer by increased intake of fruits, vegetables and organic foods and a decreased intake of meats, sugars, and processed foods. Participants identified that the main barrier to implementing dietary changes was financial, noting that organic and fresh foods were expensive.

### **Spiritual Coping.**

Almost all of the persons interviewed used spirituality to cope with symptoms. The primary manifestation of spirituality in this group of advanced cancer participants was religious faith. Participants possessed a strong belief and trust in a higher power which provided comfort. Private religiosity helped many participants to cope with symptoms. Most individuals participated in private religious practices such as praying, reading the bible, and listening to religious programs. Participants used prayer as a strategy to solve personal problems and decrease symptoms. Some described the interaction between faith and the medical community. Acts of public religiosity such as attending church services was discussed only minimally.

***Faith.*** Individuals used spirituality as an anchor in their lives. Cancer and the distress of symptoms had taken over their lives but faith brought reassurance and comfort. For some, their expressions of faith changed with the diagnosis of cancer, for others, it did not. Even when suffering with pain, their faith was present. Ms. Cochran described her faith as she suffered with pain. This 57 year old women with a three year history of breast cancer had been treated with surgery, radiation, and chemotherapy. She had recently completed palliative radiation treatment for metastases, lytic lesions in her spine. When we spoke she reported unrelieved pain. She cried at times during the

interview. She expressed anger at her family for not being available to help her and at her doctors for not explaining what was going on but she still recognized her faith. *“God is good and God is good to me all the time. Um, and I’m not gonna say He ain’t good to me with these pains, but He’s still, I’m still here.”*

For others, the diagnosis of cancer and the presence of symptoms served as a turning point. Many reconnected to the spiritual dimension of their lives before they could take care of themselves. The diagnosis of cancer increased their faith and made their beliefs stronger. Ms. Nelson often advocated for herself in the health care system but she could do this only after addressing her spiritual relationships. She said, *“I had to guide myself back to my Father up above. Once I got a close relationship with God, that got me stronger, and to speak up for myself and my health.”* Others spoke about rediscovering their faith or how the cancer changed the way they used their faith.

Many participants felt hopeful that the future held the promise for a better situation. Their faith could heal them, perhaps cure them. Many used their faith to find meaning in their lives and expressed appreciation for their lives thus far. Ms. Evans lived with and cared for her disabled adult son. She described her cancer as currently *“in an ugly state.”* Her past treatment included surgery and multiple types of chemotherapy. At the time of the interview, she was not receiving any chemotherapy because Medicare or Medicaid did not cover the one drug the doctor thought would be most effective. Despite her situation, she seemed at peace and spoke about her faith and support from her family and friends. She experienced pain and shortness of breath and used oxygen treatment at home as needed. She described her faith and how it made her feel better.

*Sometimes I let my mind go and get off my religion, and then it hits me. What in*

*the world are you thinking about? You know God is in control, and that's what He's there for, to help us, you know. So I start dwelling on Him, and I'll even get my Bible and read Him and what have you. And it's, maybe it's in my mind, but I start to feel better.*

On numerous occasions, participants explained the power of their faith and its control on their lives. Cancer robbed them of control but their faith took over making them feel positive and strong. Often these individuals spoke about how doctors would explain the severity of their advanced cancer. The participants responded to the doctors by describing their faith in their personal God. Ms. Hall lived with cancer for many years. Initially diagnosed in 1993, she survived a reoccurrence in 2000 and again in 2006. Despite the metastasis in her chest wall, she reported no pain but experienced tiredness, shortness of breath, and anorexia. She did not get upset when the doctors told her about her cancer. She responded *"I won't be gone until God gets ready to get me. Ain't no sense in me worrying about that. So I don't."* Ms. Nelson reported many symptoms including pain. She required high doses of morphine to manage her pain. She spoke about how her faith could heal.

*When, you know, things were down, depressed and thought my life was going to end because of cancer, he (God) told me 'no, you're not dying, you're still living, you just have cancer, but you can overcome that, just have faith and believe you can be healed', so I believe that tremendously, you know.*

In contrast to other participants' feelings of hope and confidence, Ms. Lewis did not have control over her symptoms and pleaded for help. She felt badly when we visited her home. She reported constant pain and nausea and barely ate anything. She felt that

her condition had worsened recently. She planned to speak with her doctor that week before her chemotherapy appointment, “*for them just to see is anything else wrong*” because she felt “*so bad.*” She turned not only to her doctor but also to her faith, pleading for help.

*I pray, I ask him to take this away. I plead the blood of Jesus, just, Lord I know you died on the cross for all my sins and transgressions, so I done been all there, I just put it in his hands. I put it in his hands. I mean it ain't nothing else I can do with it, ain't nothing else I can do with it.*

Many spoke of unwavering faith, but Ms. Washington spoke about her doubts and fears. Of note, she had a tattoo on the side of her neck that said “faith”. She lived alone with her 4 young children and currently experienced multiple symptoms. She cried when she spoke about her children. Ms. Washington worried about who would care for her them after her death. The father of her children had experienced a stroke and was unable to care for the children. She tried to believe that her faith could cure her but she also considered how to prepare her family for her death.

*I tell myself it's going to get better. I think once chemo do its job, help clean, help remove this from my body. I know I have that much faith in the Lord that it's going to get better. But you also got something in the back of you that's saying it's not you know, but I keep going and saying it's going to get better and chemo got a lot to do with it, of me getting better.*

Participants spoke about their faith as a counter measure to fear. But fear represented more than a distressful feeling for some; fear indicated your faith was not strong enough.

**Prayer.** Several individuals spoke of attending church earlier in their lives yet

only a few went currently. Most did not attend church often. Many spoke of missing the social aspects of church, others received calls from church members or clergy. A few individuals mentioned others praying for them. On the other hand, almost all participants participated in private religiosity. Prayer served as an active exchange. People used prayer to receive support and symptom relief. Individuals described how they prayed. Ms. Nelson spoke of talking to her God when she was lonely and no one else was around.

Many described how their prayers were answered. Mr. Thomas had recently completed radiation for his leiomyosarcoma which decreased his pain considerably. Additional treatment plans included chemotherapy and possible amputation of his leg due to the large tumor on his thigh. He spoke of miracles in his life but not specifically in regard to his cancer.

*I had so many prayers, not that I thought came through or hope they came through but actually came through. It sound like a mystery. It sounds strange. It sound like, oh God, you got to be kidding me, but I'm just gonna say this and I be done with that. A lot of people do say a lot of things, but one thing I know and this is and God my witness, I've seen so many miracles that I pray for come to, come to pass.*

In addition, Ms. Robinson who had two craniotomies for brain metastases in the past 18 months explained how her prayers were answered. *“If I feel like I can't make it or do something, I will pray to Jesus. It happens. Right after I say my prayers, it happens. Whatever I pray for happens, no matter what it is.”*

Most individuals spoke of prayer being a private experience. A few mentioned that others prayed for them or sometimes prayed with them. Mr. Scott, just released from

prison apparently because of his advanced lung cancer, discussed how tired the cancer and its treatment made him. He also spoke about his decreased spiritual energy which he explained affected his ability to pray and also seemed to affect his physical strength. He called on a friend to help increase his spiritual energy and ultimately make him feel better.

*Friend of mine she'll call me. She high in spiritual energy and strength. She's a minister of the word, right. When I talk to her, she lifts my spiritual energy and she lifts my strength. When I talk to her, we can sit down and talk for an hour on the phone, hour and a half, two hours. When I get through talking to her I feel better, I go, I can go read a little bit and then study.*

Some participants prayed for symptom relief and others prayed to distract themselves from the symptoms. Both methods decreased the symptom's distress. Prayer resulted in decreased pain, fear, worry, depressed mood, tiredness, anorexia, improved sleep, and improved overall well-being. Participants often referred to prayer like a medication or a fuel. It seemed they needed to fill up their tank with prayer. Prayer blocked out pain. Prayer gave relief from pain in the middle of night when sleeping proved difficult. Ms. Cochran said *"these pains is still here, but I can block em out by talking with God."* Mr. Harris notes *"That's the time to talk, when you hurting. Maybe that is the reason it goes away."* Besides pain, participants spoke about their faith and other symptoms. Some seemed to use prayer as a distraction, something to get their mind off of their pain. Mr. Thomas said *"when you pray, it takes your mind. The pain might be hurting so bad you can't stand it, but got prayer, you mind don't meditate on the pain so you don't even feel it."*



***Faith, prayer and the medical community.*** Participants discussed the intersection of spirituality and the medical community and provided some important information about trust and communication. Ms. Washington said that the doctors did not understand her faith. She spoke about listening to what the doctor said needed to be done to treat her advanced cancer. She acknowledged that they did their job when she said, "they tell me what they are suppose to." First she recapped a discussion with her doctor about her prognosis.

*Prayer works, sure do. I pray all the time, I pray and I talk to the Lord all the time. You know, it just like I was telling Ms. (doctor name), she said (participant name) ah, you know the situation you're in. You know what the result is. You know what's going to happen. We need you to do this, we need you to do that.*

She responded to the doctor and described her faith and reminded the doctor that she had outlived the doctor's prediction already.

*So, I tell her, I say, ok I understand Ms. (doctor name). I know you do your job, but my God tell me I'm going to be ok. Tells me everything is going to be alright. So that's how I make it. It's really do, how I really make it. I talk to him every day, all day. And I know he's, I know he's been with me cause if it wasn't for him, the statement that they told me at the emergency room, I was, that particular day, they didn't expect me to live a year with, and just like I told them, I proved them wrong, I did. And they tell me what they're supposed to do, they do their job. They just look at me, they pat me on the shoulder and say, I'm glad you have good faith but they don't understand. Faith will take you a long*

*way, if you have the true faith. It will. And that's what I have, that's how I make it, each and every day. Sure do.*

Often the participants heard what the doctors told them but their faith often contradicted what the doctor said. When Ms. Moore heard from her doctors that her cancer had metastasized, she turned to her faith, *"I rejected all the results they give me and I started my prayer. Prayed and talked to my God, that's He's my doctor. He's the one that will heal me. He's the one that will cure me."* Some spoke about how their faith and their personal God worked through doctors.

Ms. Hill's (the bilateral amputee) story of cancer was different than most others. She had no pain or problems with eating. She spoke a bit about being tired and occasionally feeling depressed. She spoke at length about the power of her faith to heal and the role of her doctors. She first mentioned that in the end, she went to her God to be healed, but that right now her faith brought the doctors into her life. She trusted her faith and now she needed to follow the doctor's plans.

*If the Lord send me to a doctor, then it's the doctor's job to tell me what to do, now it's man's time. So he sent me to a doctor. If I wasn't gonna do what this doctor said, I wouldn't even come see this man. I be like man, what you talking about. But this is where he sent me. You know, the Lord don't send where you don't need to be. This is where I need to be. And that's why I do everything they tell me.*

Trust in her faith transferred to the doctor and back and forth. Ms. Hill continued:

*If you have faith that in God, like you do your doctor, you have peace of mind when everything else is going on around you. This we have, we come to the*

*doctor and we have, we trust him to do the right thing. So we need to trust God to do the right thing and if we can do that, let them both work together. Then we'll have a peace of mind. But if we take one and not the other, that's where the conflict come in. If we feel that we can, we don't need God because we have the doctor or if we feel we don't need the doctor, cause we have God, we messing up. We got to let them work together for good.....but you have to put it together and the only way that comes about is trusting in the Lord and trusting in your doctor. See, it's two trusts you have to have.*

Similar to this woman's views, Mr. Thomas, who faced the possibility of having his leg amputated, described his relationship with his doctor and his nurse very positively. He credited this good relationship to “*staying prayed up*” and doing the right thing.

Ms. Nelson, described a different relationship between her faith and her doctors. As mentioned previously, this 30 year old was proud of how she managed her cancer and multiple symptoms by advocating for herself. Her faith gave her courage to speak up for herself.

*I had to guide myself back to my father up above. Once I got a close relationship with God, that got me stronger, and to speak up for myself and my health....Just trust in him and believe. He will lead you in the right path. Do not be afraid. And that's what, you know, it took me a while to get there, and now that I reached that point, I can speak up for myself, because I, at first I, I was not that type, to speak up for myself. I was quiet and God said to speak up for yourself. It's ok to speak up. You tell these doctors how you feel. This is your body.*

Spirituality was a powerful coping strategy for most but not all of the study participants. Four men never spoke of faith, religion or prayer. They all experienced symptoms of various intensities and used the other strategies described. Besides gender, no one characteristic was common for all four men. They had different cancers, different social support, and different treatments. The interviewers did not ask any of the participants directly about the use of spirituality as a coping mechanism so it is unclear how they would have responded. All the other individuals brought up the strategy without being asked which spoke to the importance of the strategy in their life. No one said they felt betrayed by God or angry at God.

### **Barriers and facilitators.**

Barriers and facilitators of symptom management were woven throughout the interviews. For purposes of this study, facilitators of symptom self- management were defined as anything that makes it easier or removes difficulty for the individual to manage symptoms. Barriers were defined as anything that restrains or obstructs the ability of an individual to manage symptoms. When specifically asked what makes it hard to deal with or manage symptoms, participants could rarely identify barriers but in discussions of their lives and how they coped, difficulties became apparent. Some participants mentioned family members being unsupportive, either through absence or through unhelpful actions. Ms. Cooke said her family did not come around much anymore and she had to rely on her roommate for assistance. Ms. Smith lost her job after her cancer diagnosis and had to move in with her mother. She was frustrated when her mother, who was a retired nurse, and her daughter, who was studying to be a nurse, would not help her change the dressing on her surgical incision. Some participants

worried about how family members were handling their cancer diagnoses which distracted them from caring for themselves. Ms. Green spoke of her mother's reaction when she found out about her cancer.

*I thought she was going to have a heart attack when I told her I had cancer. I try not to tell her too much. Her whole chest blowed up, she held on to the table, I thought she was dead then.*

Other participants spoke of family members who were reliable caregivers but were also too protective, or treated participants differently after their diagnosis. Some participants' desire for independence clashed with the approaches, roles and actions of family members who treated them as if they were now incapable of managing their own lives. Mr. Harris lived with his mother and two sisters and felt his family needed to back off a bit. He said "*well they love me to death, and say to me to always take it easy, don't do this and don't do that. And I tell them go sit down, I got it under control.*" Some participants lived with family members out of necessity, but longed to move into a place of their own although the circumstances surrounding their illness, mainly financial, made it difficult to support independent living. Only one participant mentioned health care providers who were at times unsupportive and did not provide the information they requested.

Financial concerns and a lack of health insurance were barriers for some. Some spoke of losing jobs after they were diagnosed with cancer. Some reported stress caused by living with other family members. A specific barrier to symptom self-management identified by various participants was the cost of co-pays at the clinic as well as the costs of healthy foods and over-the-counter medications.

People in their lives who were identified as barriers were often also identified as facilitators when they had a positive effect on the participants' efforts to manage their symptoms. Some identified family members who frequently checked on them and provided emotional and financial support. Participants were frequently welcomed and encouraged to move into their siblings' or mother's home. Children and grandchildren often provided the participants with happiness and feelings of love. Some participants received help with transportation from family members; other turned to family members to help explain and gather information about their cancer and its treatment. Ms. Hall lived with her grandson who did all the household chores. She spoke of many family members who were close by who checked on her frequently and provided transportation. *"They all around, the family. You know, I think that helps because they right there for me whenever I need them."* A few of the participants who lived with non-family members spoke of deep appreciation for roommates who helped care for them. One woman spoke appreciatively of a group of friends from church who had provided her with support over the years as well as through her time with cancer.

Health care providers and clinic staff who educated the participants and made sure they understood the treatment plans were also identified by the sample as supportive and caring. Participants felt that someone was looking out for them and noted the team approach where doctors communicated across disciplines to provide quality care. Health care providers were described as providing education and making sure participants understood their treatment plans. Some participants said they benefited from interaction with other cancer patients they met in the clinic, either in the waiting room or in a support

group that met weekly in the radiation oncology department. The exchange of cancer stories provided support but did not include specific help in symptoms management.

### **Summary**

The purpose of this study was to explore the symptom experience and symptom self-management practices of low-income African American adults with advanced cancer. Participants described multiple symptoms that became part of their cancer experience. The majority had pain and often required complicated medications, diet changes, and rest. Symptoms affecting eating changed the type of food they ate, the way they ate it, as well as the social interactions surrounding eating. Because of symptoms, especially fatigue, participants often balanced rest and activity and shifted their schedules so they could complete important tasks. Cognitive changes slowed communication, causing frustration for many. These individuals responded to the symptoms by trying different activities and finding strategies to decrease their distress. Living at home, sometimes alone, meant that decisions on what to do to find relief was up to the individual. Family and supportive healthcare providers helped the individuals but ultimately they were in charge of deciding what medicine to take, what to eat, and when to rest. Financial issues sometimes made it harder to manage symptoms related to co-pays and healthy but expensive foods. Overall participants used spirituality to cope with their symptom distress. Because of their faith, they felt that God was in control of the big picture and many used prayer to ask for symptoms relief or just to communicate to gain focus and strength.

## **Chapter Five: Discussion**

### **Introduction**

This descriptive, qualitative study was designed to explore the symptom experience and symptom self-management practices of low-income African American adults with advanced cancer. The goal of care for individuals with advanced cancer is to help them achieve the best possible quality of life. To attain this, effective symptom management is essential.

The individuals in this study experienced multiple symptoms resulting from the cancer itself, cancer treatments, and co-morbid conditions. In-depth interviews provided an understanding of both the experience of symptoms and the impact of symptoms on day-to-day functioning. Additionally, this study described how these individuals controlled and managed their symptoms on daily basis.

The challenges of symptom self-management require monitoring of one's symptoms and daily decision-making regarding medications, diet, rest, and activity. Engaging individuals in interviews allowed them to share the perspectives of their experiences within the context of everyday living in a way that surveys and other quantitative approaches could not. The findings presented here describe how symptoms and the work of managing symptoms dominate the daily existence of individuals living with advanced cancer.

### **The Symptom Experience**

Since the focus of the current study was to describe the symptom experience, participants were eligible only if they reported at least two symptoms with, at least, moderate severity. This allowed exploration individuals' managing multiple symptoms



simultaneously. The sample of individuals was intentionally diverse to capture more information in this descriptive study; multiple cancer types and treatment combinations were represented in the sample. In this study, participants described symptoms that controlled their lives. Their stories told how they worked to discover ways to find comfort, eat, move, and communicate.

Recent studies on symptom experiences in advanced cancer have used quantitative methods. Reporting on 22 studies in their systematic review of quantitative studies in this area, Gilbertson-White and colleagues (2011) found that 50% of the studies evaluated 14 symptoms including pain, dyspnea, nausea, depression, constipation, anorexia, sleep disturbance, anxiety, vomiting, fatigue, weight loss, cough, dysphasia, and drowsiness. Seven studies examined relationships between symptoms and potential predictors (i.e., demographics, cancer type, and healthcare delivery environment). Fourteen studies examined relationships among symptoms and outcomes (i.e., functional status, psychological status, quality-of-life, survival time). Unfortunately, the review found significant methodological variation among these studies, making it difficult to draw conclusions about the relationships among symptoms and associated characteristics.

Another approach to studying co-existing symptoms is through the examination of symptom clusters (Barsevick, 2007). Studies that identify symptom clusters in advanced cancer often use different methodological approaches and describe different varieties of clusters (i.e., number of symptoms in the clusters, composition of the clusters), which makes the findings from different studies difficult to compare (Nguyen, et al., 2011; Tsai, Wu, Chiu, & Chen, 2010; Walsh & Rybicki, 2006; Wang, Tsai, Chen, Lin, & Lin, 2008; Zimmerman, et al., 2008).

The findings presented here included information on the experience of co-existing symptoms. Symptoms often overlapped and had a significant impact on each other. For instance, sleep, pain, and cough co-occurred and exacerbated each other in a subset of participants with lung disease or metastatic cancer.

In the findings presented here, the symptoms were described by their impact on the participant's functional status. Symptoms changed the "normal" day to a day that required adjustments in schedules, rest times, diet, and medications. Participants changed their normal activities (i.e., employment and entertainment) and replaced them with daily naps and watching television. Symptoms also interfered with the ability to complete basic personal and social functions like eating and communicating. The level of impairment—what the patient could eat, how far or how easily he or she could walk or speak, etc.—became an index for gauging the severity of symptoms.

In prior research with individuals diagnosed with 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 1,000 individuals with advanced cancer, participants with a poor performance function (measured by ECOG 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 the symptom experience was significantly associated with the ability to participate in activities of daily living (ADL). 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 due to symptoms.

Interestingly, research involving symptoms and functional status often use single item instruments like the Karnofsky Performance Score (KPS) or the Eastern Cooperative Oncology Group (ECOG) score. The Karnofsky score runs from 100 to 0, where 100 denotes "perfect" health and 0 denotes death with increments of 10 in between (Mor, Laliberte, Morris, & Wiemann, 1984). For example a KPS score of 70 describes a person who can care for him/her self but is not capable of normal activity or work. The ECOG score runs from 0 to 5, with 0 denoting perfect health and 5, death; thus, a score of 2 describes someone ambulatory and capable of undertaking all of the actions of self-care but unable to carry out any work activities (Oken, et al., 1982). The Doorenbos study used an index of ADL, which asks nine questions about dressing, eating, walking, and transportation. A summary score was then used with higher scores indicating greater dependence performing ADLs. While an index of ADL provides more detailed information than the ECOG score or the Karnofsky score, qualitative work, provides a more detailed description of functional status and its relationship to symptomatology in individuals with advanced cancer.

### **Being in pain.**

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. "Being 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 significant distress from pain that was caused by treatments. Participants described multiple types of pain occurring over time and sometimes concurrently.

Few qualitative studies have explored the African American cancer pain experience. Im and colleagues' (2008) described the meaning of cancer pain in African Americans using an online forum; however, their sample of 11 included only two who were taking any pain medications. Descriptions of their pain or its intensity were not provided. Participants in this study said they were reluctant to express pain or seek help because they were raised "to be strong". Similarly, Meghani and Houldin (2007) studied the meanings of and attitudes about cancer pain among African Americans; stoicism emerged as the main theme among the participants in that work. In contrast, the participants in the current study gave rich descriptions of their pain and the daily distress it caused. Participants acknowledged the force of cancer pain and the fact that it gave them no choice but to rest and to take medication for relief. They did not "just" endure the pain but acted on it, often with self initiated actions or by calling on their faith. Although some expected to experience some pain related to their cancer, no mention of ignoring or minimizing the experience was mentioned. Living with pain was a hardship that was part of their lives, yet the participants exhibited courage and determination to be active and productive.

#### **Symptoms associated with functioning in everyday life.**

This study provided detailed information on how symptoms of advanced cancer were associated with functioning in everyday life. Three areas were described: eating, moving/doing and communicating. Though symptoms significantly 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.

*Eating.* Many individuals experienced a high level and frequency of distress from symptoms that affected both their capacity to eat and their digestion. Anorexia was a daily struggle for several participants. In a recent review of evidence-based approaches to symptoms, Dy and Apostol (2010) found that anorexia may not significantly affect the quality of life, although the individuals in this sample disagreed. Lacking the desire to eat changed the way these individuals received nutrition, and it often produced a daily struggle. Many in the sample spoke about changes in their ability to taste and smell, often, but not always, due to chemotherapy and described the impact on their desire to cook and to eat certain foods.

Few previous studies have described how individuals with cancer experience anorexia and taste/smell 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 due to their anorexia. In another study of individuals receiving chemotherapy, nearly one-third of the sample of 518 participants who experienced taste/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 while others

learned to accept a new normal. This "new normal" included food that was tasteless or liquid food from a can instead of solid food that could be chewed and savored.

*Moving/doing.* The major symptoms mentioned related to the functional activities of moving and doing were tiredness and weakness, fatigue. Fatigue, a word used by only one study participant, is well studied in the cancer population. Fatigue was the most common symptom in individuals with advanced cancer and was experienced by almost the entire present 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 that they did before cancer. Again, their normal day had been transformed into a day ruled by symptoms.

Fatigue and functional impairment have been studied across cancer types, most frequently in studies of individuals with lung cancer (Hung, et al., 2011). In a study that compared the impact of dyspnea, pain, and fatigue on daily life activities in ambulatory participants with advanced lung cancer, participants were asked about symptom severity and whether symptoms interfered with daily life activities (normal work, walking, sleep, mood, relations with other people, enjoyment of life, and general activities) (Tanaka, Akechi, Okuyama, Nishiwaki, & Uchitomi, 2002). Dyspnea and fatigue were found to interfere with at least one daily life activity in more than half the individuals. Pain interfered with at least one daily life activity in 40% of the individuals. Similar to the current findings, dyspnea and fatigue interfered predominantly with physical activities, such as walking and work, whereas pain interfered with all activities throughout the day.

Participants in a qualitative study of lung cancer patients consistently reported the frustration caused by fatigue as it interfered with their independence (John, 2010). As in findings presented here, they tried to balance periods of activity and rest as they battled relentless fatigue.

*Communicating.* The major symptoms affecting communication were cognitive changes. Recently, there has been an increasing focus on the cognitive changes that can result from cancer and its treatments. Pain medications, different types of antineoplastic agents, and other drugs may contribute directly to cognitive dysfunction or may indirectly make individuals vulnerable to opioid effects, slowing mental processing or reducing alertness (Kurita, Lundorff, Pimenta, & Sjogren, 2009). Memory impairment and difficulty concentrating were recently explored in a descriptive phenomenological study (Mitchell & Turton, 2011). Study participants here found the experience to be emotionally disturbing, particularly, as it worsened over the course of receiving chemotherapeutic regimens. Individuals discussed the experience and distress from cognitive changes without being prompted.

One participant with vocal cord cancer in the current study described his inability to communicate. This was similar to findings from a qualitative study of 10 individuals with head and neck cancer, (Semple, Dunwoody, George Kernohan, McCaughan, & Sullivan, 2008). Problems with speech caused distress and anxiety, and the negative impact on their lifestyle resulted in feelings of hopelessness and helplessness, although others in the same study indicated that over time these cancer-related speech impairments and disrupted communication did not necessarily translate into major limitations on their

lifestyles. In the current study, the participant with vocal cord cancer had yet not begun treatment but was already considering taking classes in sign language.

### **Strategies**

Study participants dealt with stressful symptoms through a range of coping strategies, mainly behavioral and spiritual. Behavioral strategies were lifestyle changes that they incorporated into their daily activities. Spiritual strategies included the use of faith and prayer and had a deeply significant impact on all dimensions of the patients' lives.

#### **Behavioral coping.**

To cope with their distress, study participants told us about what they did on a day-to-day basis to relieve and deal with symptoms. A recent systematic review exploring self-care at the end of life found that, to date, no published research had used a patient-centered approach to explore the elements constituting self-care strategies (Johnston, McGill, Milligan, McElroy, Foster & Kearney, 2009). Although this review found evidence on how people managed their end-of-life care, specific behaviors were offered to the individuals on a list from which to choose. None of the studies specifically asked individuals how they managed illness themselves. The current study viewed the individuals living with advanced cancer as the experts and asked them not what they were told to do, but what they did. The focus of the qualitative inquiry was not the treatment plans that clinicians had instructed patients to follow but, rather, the interventions initiated by the patients themselves to manage their symptoms of advanced cancer. Additionally, the present study narrated the experience of low-income African



Americans, an underserved community with a high disease burden, whose perspectives are rarely included in research.

**Medication.** The study under discussion found that patients dealing with symptoms regularly used medication adjustments as a major behavioral coping strategy. Many of the participants reported a reluctance to take pain medication, similar to findings from the study by Meghani and Keane (2007). In this 2007 study, African Americans, diagnosed with solid tumors, with self-reported cancer pain of at least one month provided information about taking pain medication. Although similar in terms of racial background, the participants differed from the current sample in that they were predominantly educated, middle class, and insured individuals. Nonetheless, over 25% were concerned about taking too much pain medication, and over one-third reported side effects that they attributed to taking analgesics. Very similar to the sample in the current study, most participants in Meghani and Keane's study were troubled about using pain medication with 69% reporting an internal conflict between 'wanting to' versus 'having to' take the pain medications. These individuals acknowledged the many limitations of pain medications and wished they could do without them yet ultimately resorted to taking them to reduce the pain. Unlike the sample in the current study, some of the participants were reluctant to take the medication because they believed that pain medication masked the underlying disease and its progression, while some expressed feelings of guilt or shame about using pain medication. The current sample gave general reasons for not wanting to take pain medications such as a dislike of medications, fear of addiction, or exhaustion with the demands of medication schedules, but they did not share the feelings of guilt or shame expressed by participants in the Meghani and Keane study.

Anderson and colleagues (2002) identified various barriers to cancer pain management for socioeconomically disadvantaged minority individuals with cancer including communication barriers, reluctance to report pain, stoicism, concerns about possible addiction, and tolerance to opioid medications. Participants in the current study were also concerned about addiction yet were not reluctant to report pain. Most participants in the current study had moderate to severe pain and often had lived with it for an extended period of time. Perhaps their view of the pain differed from that of the other study populations because of the long-term daily experience of pain experienced by many participants in the current sample.

Schumacher and colleagues (2002) reported on a study that described the difficulties with pain management from the perspective of an individual with metastatic cancer. Data were obtained from audiotaped and transcribed interactions among intervention nurses, individuals, and family caregivers who were participating in a randomized clinical trial of a nursing intervention called the PRO-SELF Pain Control Program. Findings showed that individuals had difficulty in many areas when they attempted to take a regimen of pain medication. These areas included obtaining the medications, obtaining and processing information, adjusting prescribed regimens to meet individual needs, managing side effects, managing new or unusual pain, and managing multiple symptoms simultaneously. In the current study, many individuals discussed the challenges of titrating their pain medication appropriately and managing side effects. In both studies, participants discussed making decisions about which drug to take, how much to take, and the timing of the drug administration. These studies offer important descriptions of an element frequently missing from the palliative care

literature: the complexity of pain medication regimens that patients with advanced cancer must manage at home.

*Lifestyle modifications.* Participants in the current study frequently made changes to diet and activity to relieve symptoms. They also discussed complementary and alternative medicine (CAM) modalities, mainly in the area of diet modifications. In a study of African American men with prostate cancer, many were skeptical of CAM modalities (Jones, et al., 2007). In the findings presented here, limited use of CAM was reported. Herbal teas, aromatherapy, massage, and breathing exercises were used by a few participants to treat symptoms. In a study of individuals with cancer receiving palliative care, cost was identified as a barrier to the use of CAM (Elliott, Kealey, & Olver, 2008); the current study found that financial difficulty kept participants from buying healthy food.

Participants in a study by Bernhardson, Tishelman and Rutqvist (2009) described various approaches to the problem of illness-related taste/smell changes. One strategy was to alter food choices; other strategies included freshening the mouth (through oral hygiene practices, chewing gum, sucking on candy) and avoiding odors. The current study reported similar findings related to food choices, and also collected information similar to data in qualitative and quantitative work by Hopkinson and colleagues (Hopkinson, 2007; Hopkinson, Wright, McDonald, & Corner, 2006). Their work focused on the challenges of eating and showed that changing eating habits was part of life for patients with advanced cancer. Participants utilized various strategies including adjustments in diet; this was a similar strategy used by participants in the current study. Participants in Hopkinson's studies discussed the effect of eating changes on personal

relationships. The resulting tension among family members was not discussed in the current study. As reported by both Hopkinson and here, people experiencing eating difficulties struggle to find solutions to this daily problem. Most individuals who experienced taste changes were diligent in trying new foods and food preparation. In this area and others, individuals expressed a longing for their life before cancer, where the pleasure of eating and the social aspect of meals was a normal part of their day.

Activity modifications included resting, slowing down, and changing activities. Research in the area of psychosocial interventions for reducing fatigue specifically during cancer treatment in adults sheds some light on this area. A systematic review on psychosocial interventions for reducing fatigue during cancer treatment showed that there is limited evidence that such interventions are successful (Goedendorp, Gielissen, Verhagen, & Bleijenberg, 2009). The most promising interventions included patient education, education on self-care, coping techniques and learned activity management. In the current study, participants primarily followed the dictates of their bodies while accomplishing the tasks of their daily schedules. In a study of the daily activities of patients with metastatic breast cancer, the women remained very active, yet they also reported a high frequency of taking naps and resting (DeSanto-Madeya, Gross and Bauer-Wu, 2007), similar to findings in the current study where the need to rest influenced the amount of daily work the participant was able to complete. Both studies reported that symptoms such as pain, sleep disturbances and nausea significantly hindered the carrying out of daily activities.

Overall, the individuals in the current study, attempting to control symptoms through medications and changes in diet and activity, were determined and focused in

their efforts to do whatever they thought would provide relief. They mostly took care of themselves independently, with occasional help from healthcare providers and family. Most study participants also turned to their spirituality for emotional relief and reassurance, and as a way to balance the ongoing distress of symptoms and the unrelenting work of symptom management.

### **Spiritual Coping.**

The use of religion and spirituality by African Americans as a primary coping mechanism in the context of serious health problems, such as depression, cancer, heart disease and mental illness, has been well documented (Koenig, 2001; Dessio et al, 2004). In a study of the role of ethnicity and spiritual coping in cases of advanced cancer, African Americans were more likely to report using spirituality as a coping mechanism as compared to their White counterparts (True, et al., 2005). As mentioned earlier, a qualitative descriptive study (Meghani and Houldin, 2007) that explored the meaning of cancer pain for African Americans found that faith and belief in God were at the core of the participants' experience; they frequently prayed, meditated, read the Bible and talked to God. A study of spirituality in low-income men with metastatic prostate cancer (Zavala, Maliski, Kwan, Fink, & Litwin, 2009) found that the highest levels of spirituality were seen in less-educated men of color, specifically African Americans. In another study of low income African American men treated for prostate cancer, faith empowered the men to become active participants in their care (Maliski, Connor, Williams, & Litwin, 2010). The current study of African Americans with advanced cancer corroborates the earlier literature on the subject, with spirituality identified as a major coping strategy and equally important to patients from different educational

backgrounds. Without being prompted during the interview, participants in the study under discussion described how they prayed and communicated with God, and how they derived comfort, courage and hope through their faith.

Whereas most participants of the current study used prayer as a strategy to solve personal problems and minimize symptoms, they attended church services and interacted with church members only minimally, most likely due to their symptom burden. Balboni and colleagues (2007) found that illness-related physical limitations caused their sample of 230 individuals (19% African American) with advanced cancer to be less engaged with religious communities. Another study of individuals (15% non-White) with advanced cancer found that participants were still quite deeply and regularly engaged with their religious communities. They spoke often of the use of prayer, through which they asked for strength to manage symptoms and negotiate their cancer experience, similar to the participants in the current study (Alcorn, et al., 2010). Participants in a study of rural dwelling African Americans living at home with life limited illness described their experience and how they managed their lives. A personal relationship with God was a major theme and praying was used to manage pain, dyspnea, and insomnia. They felt that God communicated with them through answered prayers (Campbell & Ash, 2007). An extensive literature review of the influence of spiritual beliefs and practices on the treatment preferences of African Americans found similar findings to this study. Themes in the review mirror themes in the current study including the use of prayer to cope with illness, the belief in God's power to decide life and death, the belief that doctors are God's instrument to promote healing, and the belief in miracles or divine interventions (Johnson, Elbert-Avila, & Tulskey, 2005). As described in Chapter

Four, participants often expressed the belief that it was up to God to not only answer prayers but to direct the doctors and ultimately to decide how their lives would play out.

### **Barriers and Facilitators**

In general, the participants in this study identified ways that family and healthcare providers both helped and hindered their ability to care for themselves. Certainly financial challenges were present but, surprisingly, many did not address this as significant since most participants had lived without resources for all of their lives. Although not directly discussed in the interviews, the context of the participant's life contributed to the difficulty or ease with which he or she could manage his or her illness. The sample included individuals with advanced disease, distressful symptoms, few financial resources, and multiple co-morbidities. Only one-ninth of the sample was married and one-third lived alone. Almost half did not have a high school education. The family structure of the households was often multi-generational, with two of the elderly women participants living with grandchildren and another living with and caring for a disabled son. Half of the group reported a history of hypertension. Participants did not include these challenges in their stories of caring for their symptoms, yet the backdrop of a fragile environment must be considered.

Although many challenges were apparent in the participants' lives, the individuals generally maintained positive, optimistic attitudes that were often directly related to their spirituality. They did not consider themselves as dying but, rather, as living. Their belief that the course of their lives was in the hands of God freed them to concentrate on their immediate needs and sustain their efforts to manage their daily demanding daily regimens of self-care.

Most of the sample felt supported by the palliative or oncology services they were receiving. Whether treated in the palliative care clinic or an oncology clinic, they described a nurturing relationship with the staff and medical team. All of the participants were receiving health care at a safety net hospital, the Grady Health Care System. This health care system, part of the community since 1892, had served them and their families for generations. The exceptions within this study, two foreign born participants and relatively new Grady patients, credited Grady with essentially saving their lives. One of these participants mentioned that if he won the lottery, his winnings would be donated to Grady.

While the context of these participants' lives reflected the impact of health disparities in the U.S., none spoke of being discriminated against and only one complained of unsatisfactory care, although issues of discrimination were not the focus of specific interview questions. Participants did not discuss factors that contributed to their financial insecurity or their place in society. They did not discuss the challenges of the vulnerable institution that provided their health care. Certainly the residents of Atlanta are aware of the fragile state of this safety net hospital, which has recently struggled against the threat of financial collapse. Grady has recently experienced multiple rounds of forced layoffs, increases in fees and the elimination of services (M. Williams, 2011). As reported by the local newspaper, it was projected that Grady Hospital provided more than \$300 million in uncompensated care in 2009, caring for the uninsured in the greater Atlanta area. Grady was the safety net these individuals turned to for support in dealing with the challenges of advanced cancer. Unlike participants in an earlier qualitative study of poor urban patients with advanced cancer, who felt unwelcome in the healthcare systems where they were



being treated (Hughes et al., 2007), participants in the current study felt connected to and cared for by this long-established, fragile hallmark of the Atlanta community.

### **Limitations**

The findings of this qualitative study must be considered in light of several methodologic limitations. The sample was a small, purposive sample, and the data included the perceptions of low-income individuals within one hospital system in one city in the Southeast. Their experiences may not reflect those of men and women with advanced cancer in other clinical and geographic settings. The single interview design did not provide information on how individuals' symptoms and strategies of symptom management changed over time. Also, selection bias cannot be ruled out. The initial contact with potential participants was through a health care provider who made the decision whether to consider the individual for the study. When recruiting sick vulnerable individuals, health care providers can serve as gate keepers, protecting their more sick and vulnerable clients from any extra activities. Also individuals who agreed to participate may have been different than those who did not. For example, the individuals who completed the interview may have been feeling better or had more positive attitudes than those who were not interested in participating or were lost to follow up.

Nonetheless, the approach used in this study facilitated the collection of rich, detailed information on the individual's symptom experience. The group was diverse with regard to their cancer type, age, education level, social situation and symptom profile.

## **Implications for Research**

The findings of this study point to many fertile areas for additional research. Certainly research with individuals with cancer must include adequate representation of low income African Americans and other minorities. For too long, researchers have recruited predominantly White, middle to upper class, well educated individuals to participate in research. Researchers must reach out to the African American community to build trust and develop meaningful community engaged research. In addition, studies rarely include participants' income status as a variable, leaving the reader to assume that it is of little importance. Overall, low-income study participants from any community need greater attention from researchers and better representation in research, especially in the areas of cancer support and end-of-life care.

Descriptions of symptom clusters in the cancer literature are plentiful but results and analytical methods vary. The value of qualitative inquiry should be considered as the research community works to determine the importance and clinical implications of symptom clusters in patients with cancer. Also, research in advanced cancer should consider the most useful way to measure functional ability. The ability to carry out daily activities is fundamental to the well-being of individuals. This study and others with similar focus demonstrate the need for further exploration into the relationship between the symptom experience and everyday daily functioning.

Further work describing how individuals make decisions concerning self-care would provide the platform on which to build meaningful interventions to support individuals living with symptoms of cancer and its treatment. Strategies and treatments for symptoms must include the individual's perspective to provide practical and effective

relief. Interventions to relieve distress from taste/smell changes, cognitive changes, and neuropathic pain require additional research. Also, to assist individuals with the process of managing pain and the complexity of medication administration, greater understanding of these complicated tasks is needed.

Finally, this study reinforces earlier work that emphasizes the importance of spirituality in the lives of African Americans with advanced cancer. The research community is obliged to use these findings to determine how spirituality can be incorporated in the assessment and care of African Americans and more forward with intervention research. A community based participatory research approach where members of the religious community can be paired with researchers to develop and test interventions is appropriate for this area of research. In addition, exploration of the relationship of trust, spirituality, and communication with health care providers would benefit clinical care of African Americans as well as the larger cancer community.

### **Implications for Clinical Practice**

The findings of this study direct providers to assess how individuals manage their symptoms and find ways to support those efforts. Specifically, the complexity of medication regimens should be evaluated. Providers must fully consider what taking a medication involves, and how the processes involved in its administration may have a serious impact on the individual's daily life. In addition, the use of CAM and over the counter medications should be routinely assessed. In the assessment of symptoms, clinicians should assess the multiple symptoms discussed in these findings and specifically determine how functional ability is impacted.

Participating in qualitative research produces renewed appreciation of the act of listening. Hearing a person talk about his/her illness as well as the impact on everyday activities gives direction to health care providers. The routine assessments of patients can be a unique opportunity to build personal trust if the provider actively listens to the patient's story and respects the patient's circumstances and cultural background. To support symptom self-management, providers first need to recognize the expertise of the person living with cancer with regard to his or her own care, and incorporate this into the treatment regimen. Providers can then support patients' efforts by helping them evaluate different strategies and encouraging innovative efforts to diminish distress and impact on daily life.

Finally, health care providers and health care systems must acknowledge the role of spirituality in coping with cancer and other serious, life-limiting illnesses. Health care providers and spiritual care providers must open a dialogue to determine the importance of spirituality for individuals with advanced cancer. Current training for healthcare workers is lacking in both the language and the tools to comfortably and competently assess spirituality in the clinical setting.

### **Implications for Health Policy**

Policy implications related to this study are numerous. Since the focus of this study was on low income African Americans with cancer, issues of access to health care must be addressed. In 2009, one in four African Americans lived below the poverty line and one in five African Americans were uninsured (American Cancer Society, 2011b). Since individuals with no health insurance are more likely to be diagnosed with advanced cancer and less likely to receive standard treatment and survive their disease (Ward, et

al., 2004), improved access to health care is an important first step in improving the lives of low income African Americans. Also, as we wait to see how current health care reform efforts evolve, our country's safety net hospitals need support to enable them to provide care for our neediest citizens. Health care reform efforts must include mechanisms to provide palliative care access to all. Palliative care and hospice services improve patient-centered outcomes such as symptom distress and patient and family satisfaction. With the support of palliative care and hospice, patients may receive the care they need instead of emergency room care and hospitalizations. This can reduce health care spending for America's sickest and most costly patient populations (Meier, 2011). Funding for palliative care research must be a policy priority to develop new interventions that improve the symptom experience and expand the findings presented here. Policies focused on increasing health care access, palliative care services, and research in palliative care are needed to ensure equitable access to optimal care for all individuals with cancer, regardless of socioeconomic status. Finally, policy requiring the collection of information on SES is extremely important to identify and monitor disparities and evaluate the effectiveness of interventions. Unfortunately SES is not routinely collected on medical records in the US. Collection of individual indicators of SES such as income and education, should be required in research and on medical records to better understand the role of SES (American Cancer Society, 2011b) in health care.

## **Conclusion**

People with advanced cancer have to negotiate a high frequency of multiple distressful symptoms with severe to moderate severity requiring multiple medications and

management strategies. This study describes the day-to-day experience of African American individuals with few financial resources living with and managing the symptoms of advanced cancer. Pain, both physical and emotional, was described by most. Other symptoms affected eating, moving, and communicating and were described in the context of those activities. Additionally this study described what individuals do to care for themselves, not what they are told to do. Overall, study participants made adjustments in medications and lifestyle. They relied on spirituality to cope with the experience of cancer and to provide symptom relief. Information gained from this study can help guide research in symptom self-management and provide direction for clinicians working with this minority group. Hopefully, the findings from this study, will be used to help individuals with advanced cancer live out their days as fully, productively, and comfortably as possible.

## References

- Adler, P. A., & Adler, P. (1998). Observational Techniques. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and Interpreting Qualitative Materials*: Thousand Oaks: Sage.
- Alcorn, S. R., Balboni, M. J., Prigerson, H. G., Reynolds, A., Phelps, A. C., Wright, A. A., et al. (2010). "If God wanted me yesterday, I wouldn't be here today": religious and spiritual themes in patients' experiences of advanced cancer. *Journal of Palliative Medicine*, *13*(5), 581-588. doi: 10.1089/jpm.2009.0343
- Allen, R. S., Allen, J. Y., Hilgeman, M. M., & DeCoster, J. (2008). End-of-life decision-making, decisional conflict, and enhanced information: race effects. *Journal of the American Geriatrics Society*, *56*(10), 1904-1909. doi: 10.1111/j.1532-5415.2008.01929.x
- American Cancer Society. (2008). *Cancer Facts and Figures 2008*. Atlanta: American Cancer Society.
- American Cancer Society. (2011a). *Cancer Facts & Figures 2011*. Atlanta: American Cancer Society.
- American Cancer Society. (2011b). *Cancer Facts and Figures for African Americans 2011-2012 American Cancer Society*. Atlanta.
- Anderson, K. O., Green, C. R., & Payne, R. (2009). Racial and ethnic disparities in pain: causes and consequences of unequal care. *Journal of Pain*, *10*(12), 1187-1204. doi: 10.1016/j.jpain.2009.10.002
- Anderson, K. O., Mendoza, T. R., Valero, V., Richman, S. P., Russell, C., Hurley, J., et al. (2000). Minority cancer patients and their providers: pain management

attitudes and practice. *Cancer*, 88(8), 1929-1938. doi: 10.1002/(SICI)1097-0142(20000415)88:8<1929::AID-CNCR23>3.0.CO;2-2

Anderson, K. O., Richman, S. P., Hurley, J., Palos, G., Valero, V., Mendoza, T. R., et al. (2002). Cancer pain management among underserved minority outpatients: perceived needs and barriers to optimal control. *Cancer*, 94(8), 2295-2304. doi: 10.1002/cncr.10414

Aranda, S., Schofield, P., Weih, L., Yates, P., Milne, D., Faulkner, R., et al. (2005). Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *Eur J Cancer Care (Engl)*, 14(3), 211-222.

Arozullah, A. M., Calhoun, E. A., Wolf, M., Finley, D. K., Fitzner, K. A., Heckinger, E. A., et al. (2004). The financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol*, 2(3), 271-278.

Ashing-Giwa, K., Ganz, P. A., & Petersen, L. (1999). Quality of life of African-American and white long term breast carcinoma survivors. *Cancer*, 85(2), 418-426.

Baker, S. M., Brawley, O. W., & Marks, L. S. (2005). Effects of untreated syphilis in the negro male, 1932 to 1972: a closure comes to the Tuskegee study, 2004. *Urology*, 65(6), 1259-1262. doi: 10.1016/j.urology.2004.10.023

Balboni, T. A., Paulk, M. E., Balboni, M. J., Phelps, A. C., Loggers, E. T., Wright, A. A., et al. (2010). Provision of Spiritual Care to Patients With Advanced Cancer: Associations With Medical Care and Quality of Life Near Death. *Journal of Clinical Oncology*, 28(3), 445-452. doi: 10.1200/jco.2009.24.8005



- Balboni, T. A., Vanderwerker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S., Peteet, J. R., et al. (2007). Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations With End-of-Life Treatment Preferences and Quality of Life. *Journal of Clinical Oncology*, *25*(5), 555-560. doi: 10.1200/jco.2006.07.9046
- Barnes, E. A., & Bruera, E. (2002). Fatigue in patients with advanced cancer: a review. *International Journal of Gynecological Cancer*, *12*(5), 424-428. doi: 10.1046/j.1525-1438.2002.t01-1-01147.x
- Barsevick, A. M. (2007). The elusive concept of the symptom cluster. *Oncology Nursing Forum*, *34*(5), 971-980. doi: 10.1188/07.ONF.971-980
- Benkert, R., Hollie, B., Nordstrom, C. K., Wickson, B., & Bins-Emerick, L. (2009). Trust, mistrust, racial identity and patient satisfaction in urban African American primary care patients of nurse practitioners. *Journal of Nursing Scholarship*, *41*(2), 211-219. doi: 10.1111/j.1547-5069.2009.01273.x
- Benkert, R., Peters, R., Tate, N., & Dinardo, E. (2008). Trust of nurse practitioners and physicians among African Americans with hypertension. *Journal of the American Academy of Nurse Practitioners*, *20*(5), 273-280. doi: 10.1111/j.1745-7599.2008.00317.x
- Bernard, H. R., & Ryan, G. W. (2010). *Analyzing Qualitative Data*. Los Angeles: Sage.
- Bernhardson, B. M., Tishelman, C., & Rutqvist, L. E. (2008). Taste and Smell Changes in Patients Receiving Cancer Chemotherapy: Distress, Impact on Daily Life, and Self-care Strategies. *Cancer Nursing*. doi: 0.1097/01.NCC.0000338489.40509.c1

- Bernhardson, B. M., Tishelman, C., & Rutqvist, L. E. (2009). Olfactory changes among patients receiving chemotherapy. *European Journal of Oncology Nursing, 13*(1), 9-15. doi: 10.1016/j.ejon.2008.10.002
- Blacksher, E. (2002). On being poor and feeling poor: low socioeconomic status and the moral self. *Theoretical Medicine and Bioethics, 23*(6), 455-470.
- Blacksher, E., & Christopher, M. (2002). On the road to reform: advocacy and activism in end-of-life care. *Journal of Palliative Medicine, 5*(1), 13-22. doi: 10.1089/10966210252784971
- Blaes, A. H., Kreitzer, M. J., Torkelson, C., & Haddad, T. (2011). Nonpharmacologic complementary therapies in symptom management for breast cancer survivors. *Seminars in Oncology, 38*(3), 394-402. doi: S0093-7754(11)00079-0
- Bonham, V. L. (2001). Race, ethnicity, and pain treatment: striving to understand the causes and solutions to the disparities in pain treatment. *Journal of Law, Medicine and Ethics, 29*(1), 52-68.
- Borthwick, D., Knowles, G., McNamara, S., Dea, R. O., & Stroner, P. (2003). Assessing fatigue and self-care strategies in patients receiving radiotherapy for non-small cell lung cancer. *European Journal of Oncology Nursing, 7*(4), 231-241. doi: S1462388903000462
- Brant, J. M., Beck, S., & Miaskowski, C. (2010). Building dynamic models and theories to advance the science of symptom management research. *Journal of Advanced Nursing, 66*(1), 228-240.
- Braun, U. K., Beyth, R. J., Ford, M. E., & McCullough, L. B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life

- decision making. *Journal of General Internal Medicine*, 23(3), 267-274. doi: 10.1007/s11606-007-0487-7
- Brawley, O. W., & Berger, M. Z. (2008). Cancer and disparities in health: perspectives on health statistics and research questions. *Cancer*, 113(7 Suppl), 1744-1754. doi: 10.1002/cncr.23800
- Bruera, E., Kuehn, N., Miller, M. J., Selmsler, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7(2), 6-9.
- Burgess, D. J., Fu, S. S., & van Ryn, M. (2004). Why Do Providers Contribute to Disparities and What Can Be Done About It?. *JGIM: Journal of General Internal Medicine*, 19(11), 1154-1159. doi: 10.1111/j.1525-1497.2004.30227.x
- Burgess, D. J., van Ryn, M., Crowley-Matoka, M., & Malat, J. (2006). Understanding the Provider Contribution to Race/Ethnicity Disparities in Pain Treatment: Insights from Dual Process Models of Stereotyping. [Article]. *Pain Medicine*, 7(2), 119-134. doi: 10.1111/j.1526-4637.2006.00105.x
- Byers, T. E., Wolf, H. J., Bauer, K. R., Bolick-Aldrich, S., Chen, V. W., Finch, J. L., et al. (2008). The impact of socioeconomic status on survival after cancer in the United States : findings from the National Program of Cancer Registries Patterns of Care Study. *Cancer*, 113(3), 582-591. doi: 10.1002/cncr.23567
- Campbell, C. L., & Ash, C. R. (2007). Keeping faith. *Journal of Hospice & Palliative Nursing*, 9(1), 31-41.

- Campbell, C. L., Williams, I. C., & Orr, T. (2010). Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing, 12*(4), 214-224. doi: 10.1097/NJH.0b013e3181de1174
- Campbell, L. C., Keefe, F. J., McKee, D. C., Edwards, C. L., Herman, S. H., Johnson, L. E., et al. (2004). Prostate cancer in African Americans: relationship of patient and partner self-efficacy to quality of life. *Journal of Pain & Symptom Management, 28*(5), 433-444. doi: 10.1016/j.jpainsymman.2004.02.020
- Chang, V. T., Hwang, S. S., & Feuerman, M. (2000). Validation of the Edmonton Symptom Assessment Scale. *Cancer, 88*(9), 2164-2171. doi: 10.1002/(SICI)1097-0142(20000501)88:9<2164::AID-CNCR24>3.0.CO;2-5
- Chang, V. T., & Ingham, J. (2003). Symptom Control. *Cancer Investigation, 21*(4), 564. doi: 10.1081/cnv-120022376
- Chou, F. Y. (2004). Testing a predictive model of the use of HIV/AIDS symptom self-care strategies. *Aids Patient Care and STDS, 18*(2), 109-117. doi: 10.1089/108729104322802533
- Chou, F. Y., Dodd, M., Abrams, D., & Padilla, G. (2007). Symptoms, self-care, and quality of life of Chinese American patients with cancer. *Oncology Nursing Forum, 34*(6), 1162-1167.
- Cleeland, C. S., Ferreira, K. A., Kimura, M., Teixeira, M. J., Mendoza, T. R., da Nobrega, J. C., et al. (2007). Multiple symptoms and their impact as patient-reported outcomes. . *Journal of National Cancer Institute Monographs, 35*(37), 16-21. doi: 10.1093/jncimonographs/lgm005

- Clegg, L. X., Reichman, M. E., Miller, B. A., Hankey, B. F., Singh, G. K., Lin, Y. D., et al. (2008). Impact of socioeconomic status on cancer incidence and stage at diagnosis: selected findings from the surveillance, epidemiology, and end results: National Longitudinal Mortality Study. *Cancer Causes Control*. doi: 10.1007/s10552-008-9256-0
- Corbie-Smith, G., Moody-Ayers, S., & Thrasher, A. D. (2004). Closing the circle between minority inclusion in research and health disparities. *Archives of Internal Medicine*, *164*(13), 1362-1364. doi: 10.1001/archinte.164.13.1362
- Corbie-Smith, G., Thomas, S. B., & St George, D. M. (2002). Distrust, race, and research. *Archives of Internal Medicine*, *162*(21), 2458-2463. doi: 10.1001/archinte.162.21.2458
- Corbie-Smith, G., Thomas, S. B., Williams, M. V., & Moody-Ayers, S. (1999). Attitudes and beliefs of African Americans toward participation in medical research. *Journal of General Internal Medicine*, *14*(9), 537-546. doi: 10.1007/s11966-000-0048-8
- Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, *9*(3), 335-354. doi: 10.1177/1077800403251757
- Corbin, J., & Strauss, A. (1990). Grounded theory research - procedures, canons, and evaluative criteria. *Zeitschrift Fur Soziologie*, *19*(6), 418-427.
- Cozzarelli, C., Wilkinson, A. V., & Tagler, M. J. (2001). Attitudes toward the poor and attributions for poverty. *Journal of Social Issues*, *57*(2), 207-227.
- Craddock, R. B., Adams, P. F., Usui, W. M., & Mitchell, L. (1999). An intervention to increase use and effectiveness of self-care measures for breast cancer chemotherapy patients. *Cancer Nursing*, *22*(4), 312-319.

- Creswell, J. W. (2007). *Qualitative Inquiry and Research Design* (Second ed.). Thousand Oaks: Sage.
- Darby, K., Davis, C., Likes, W., & Bell, J. (2009). Exploring the financial impact of breast cancer for African American medically underserved women: a qualitative study. *Journal of Health Care for the Poor and Underserved, 20*(3), 721-728. doi: 10.1353/hpu.0.0176
- Delgado-Guay, M., Parsons, H. A., Li, Z., Palmer, J. L., & Bruera, E. (2009). Symptom distress in advanced cancer patients with anxiety and depression in the palliative care setting. *Support Care Cancer, 17*(5), 573-579. doi: 10.1007/s00520-008-0529-7
- DeSanto-Madeya, S., Bauer-Wu, S., & Gross, A. (2007). Activities of Daily Living in Women With Advanced Breast Cancer. [Article]. *Oncology Nursing Forum, 34*(4), 841-846. doi: 10.1188/07.onf.841-846
- Dessio, W., Wade, C., Chao, M., Kronenberg, F., Cushman, L. E., & Kalmuss, D. (2004). Religion, spirituality, and healthcare choices of African-American women: results of a national survey. *Ethnicity and Disease, 14*(2), 189-197.
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*(5), 668-676.
- Dodd, M. J., & Miaskowski, C. (2000). The PRO-SELF program: A self-care intervention program for patients receiving cancer treatment. *Seminars in Oncology Nursing, 16*(4), 300-308. doi: DOI: 10.1053/sonu.2000.16586

- Doorenbos, A. Z., Given, C. W., Given, B., & Verbitsky, N. (2006). Symptom Experience in the Last Year of Life Among Individuals with Cancer. *Journal of Pain and Symptom Management, 32*(5), 403-412. doi: 10.1016/j.jpainsymman.2006.05.023
- Douglas, M. K., Pierce, J. U., Rosenkoetter, M., Callister, L. C., Hattar-Pollara, M., Lauderdale, J., et al. (2009). Standards of practice for culturally competent nursing care: a request for comments. *Journal of Transcultural Nursing, 20*(3), 257-269.
- Dy, S. M., & Apostol, C. C. (2010). Evidence-based approaches to other symptoms in advanced cancer. *Cancer J, 16*(5), 507-513. doi: 10.1097/PPO.0b013e3181f45877
- Elliott, J. A., Kealey, C. P., & Olver, I. N. (2008). (Using) complementary and alternative medicine: the perceptions of palliative patients with cancer. *Journal of Palliative Medicine, 11*(1), 58-67. doi: 10.1089/jpm.2007.0102
- Ell, K., Xie, B., Wells, A., Nedjat-Haiem, F., Lee, P. J., & Vourlekis, B. (2008). Economic stress among low-income women with cancer: effects on quality of life. *Cancer, 112*(3), 616-625. doi: 10.1002/cncr.23203
- Emanuel, E. J., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement. *Archives of Internal Medicine, 164*, 1999-2004.
- Eversley, R., Estrin, D., Dibble, S., Wardlaw, L., Pedrosa, M., & Favila-Penney, W. (2005). Post-Treatment Symptoms Among Ethnic Minority Breast Cancer Survivors. [Article]. *Oncology Nursing Forum, 32*(2), 250-256. doi: 10.1188/05.onf.250-256

- Ezenwa, M. O., Ameringer, S., Ward, S. E., & Serlin, R. C. (2006). Racial and ethnic disparities in pain management in the United States. *Journal of Nursing Scholarship, 38*(3), 225-233.
- Fan, G., Hadi, S., & Chow, E. (2007). Symptom clusters in patients with advanced-stage cancer referred for palliative radiation therapy in an outpatient setting. *Support Cancer Therapy, 4*(3), 157-162. doi: 10.3816/SCT.2007.n.010
- Fatone, A. M., Moadel, A. B., Foley, F. W., Fleming, M., & Jandorf, L. (2007). Urban voices: the quality-of-life experience among women of color with breast cancer. *Palliative & Support Care, 5*(2), 115-125.
- Ferreira, K. A., Kimura, M., Teixeira, M. J., Mendoza, T. R., da Nobrega, J. C., Graziani, S. R., et al. (2008). Impact of cancer-related symptom synergisms on health-related quality of life and performance status. *Journal of Pain & Symptom Management, 35*(6), 604-616. doi: 10.1016/j.jpainsymman.2007.07.010
- Fillingim, R. B., King, C. D., Ribeiro-Dasilva, M. C., Rahim-Williams, B., & Riley Iii, J. L. (2009). Sex, Gender, and Pain: A Review of Recent Clinical and Experimental Findings. *The Journal of Pain, 10*(5), 447-485. doi: 10.1016/j.jpain.2008.12.001
- Fiscella, K., & Shin, P. (2005). The inverse care law: implications for healthcare of vulnerable populations. *Journal of Ambulatory Care Management, 28*(4), 304-312. doi: 00004479-200510000-00005
- Fiscella, K., & Williams, D. R. (2004). Health disparities based on socioeconomic inequities: Implications for urban health care. *Academic Medicine, 79*(12), 1139-1147.



- Francoeur, R. B. (2005). Cumulative financial stress and strain in palliative radiation outpatients: The role of age and disability. *Acta Oncologica*, *44*(4), 369-381. doi: N1602072350113N3 10.1080/02841860510029761
- Freeman, H. P. (2004). Poverty, culture, and social injustice: determinants of cancer disparities. *CA: A Cancer Journal for Clinicians*, *54*(2), 72-77.
- Gessert, C. E., Curry, N. M., & Robinson, A. (2001). Ethnicity and end-of-life care: the use of feeding tubes. *Ethnicity & Disease*, *11*(1), 97-106.
- Giardino, E. R., & Wolf, Z. R. (1993). Symptoms: evidence and experience. *Holistic Nursing Practice*, *7*(2), 1-12.
- Giger, J. N., Davidhizar, R. E., & Fordham, P. (2006). Multi-cultural and multi-ethnic considerations and advanced directives: developing cultural competency. *Journal of Cultural Diversity*, *13*(1), 3-9.
- Gilbertson-White, S., Aouizerat, B. E., Jahan, T., & Miaskowski, C. (2011). A review of the literature on multiple symptoms, their predictors, and associated outcomes in patients with advanced cancer. *Palliative & Supportive Care*, *9*(1), 81-102. doi: 10.1017/s147895151000057x
- Given, B., Given, C. W., Sikorskii, A., Jeon, S., McCorkle, R., Champion, V., et al. (2008). Establishing mild, moderate, and severe scores for cancer-related symptoms: how consistent and clinically meaningful are interference-based severity cut-points? *Journal of Pain & Symptom Management*, *35*(2), 126-135. doi: 10.1016/j.jpainsymman.2007.03.012
- Goedendorp, M. M., Gielissen, M. F., Verhagen, C. A., & Bleijenberg, G. (2009). Psychosocial interventions for reducing fatigue during cancer treatment in adults.

*Cochrane Database Syst Rev*(1), CD006953. doi:

10.1002/14651858.CD006953.pub2

Green, J., & Thorogood, N. (2004). *Analysing Qualitative Data. Qualitative Methods for Health Research*. London: Sage Publications.

Greenlee, H., Kwan, M., Ergas, I., Sherman, K., Krathwohl, S., Bonnell, C., et al. (2009).

Complementary and alternative therapy use before and after breast cancer diagnosis: the Pathways Study. *Breast Cancer Research and Treatment*, 117(3), 653-665. doi: 10.1007/s10549-009-0315-3

Gross, A., Liu, Q., & Bauer-Wu, S. (2007). Prevalence and Predictors of Complementary Therapy Use in Advanced-Stage Breast Cancer Patients. *Journal of Clinical Oncology*, 3(6), 292-295

Gysels, M., Shipman, C., & Higginson, I. J. (2008). "I will do it if it will help others:" motivations among patients taking part in qualitative studies in palliative care.

*Journal of Pain & Symptom Management*, 35(4), 347-355. doi:

10.1016/j.jpainsymman.2007.05.012

Hamilton, J. B., Powe, B. D., Pollard, A. B., 3rd, Lee, K. J., & Felton, A. M. (2007).

Spirituality among African American cancer survivors: having a personal relationship with God. *Cancer Nursing*, 30(4), 309-316. doi:

10.1097/01.NCC.0000281730.17985.f5

Hawkins, C. (2000). Anorexia and anxiety in advanced malignancy: the relative problem.

*Journal of Human Nutrition and Dietetics*, 13(2), 113-117. doi: 10.1046/j.1365-

277x.2000.00219.x

- Health Disparities- Closing the Gap. (2008) Retrieved November 20, 2011, from [http://ncmhd.nih.gov/hdFactSheet\\_gap.asp](http://ncmhd.nih.gov/hdFactSheet_gap.asp)
- Henderson, P. D., Gore, S. V., Davis, B. L., & Condon, E. H. (2003). African American women coping with breast cancer: a qualitative analysis. *Oncology Nursing Forum*, 30(4), 641-647.
- Higginbottom, G. M. (2004). Sampling issues in qualitative research. *Nurse Res*, 12(1), 7-19.
- Higginson, I. J., & Costantini, M. (2008). Dying with cancer, living well with advanced cancer. *European Journal of Cancer*, 44(10), 1414-1424. doi: 10.1016/j.ejca.2008.02.024
- Hofman, N. G. (2004). Toward critical research ethics: transforming ethical conduct in qualitative health care research. *Health Care for Women International*, 25(7), 647-662. doi: 10.1080/07399330490458088
- Hopkinson, J. B. (2007). How people with advanced cancer manage changing eating habits. *Journal of Advanced Nursing*, 59(5), 454-462.
- Hopkinson, J. B., Wright, D. N., McDonald, J. W., & Corner, J. L. (2006). The prevalence of concern about weight loss and change in eating habits in people with advanced cancer. *Journal of Pain & Symptom Management*, 32(4), 322-331.
- Hughes, A. (2005). Poverty and palliative care in the US: issues facing the urban poor. *International Journal of Palliative Nursing*, 11(1), 6-13.
- Hughes, A., Gudmundsdottir, M., & Davies, B. (2007). Everyday struggling to survive: experience of the urban poor living with advanced cancer. *Oncology Nursing Forum*, 34(6), 1113-1118. doi: 10.1188/07.ONF.1113-1118

- Hummer, R. A., & Hamilton, E. R. (2010). Race and Ethnicity in Fragile Families. *The Future of Children*, 20(2), 113-131.
- Hung, R., Krebs, P., Coups, E. J., Feinstein, M. B., Park, B. J., Burkhalter, J., et al. (2011). Fatigue and Functional Impairment in Early-Stage Non-Small Cell Lung Cancer Survivors. *Journal of Pain and Symptom Management*, 41(2), 426-435. doi: 10.1016/j.jpainsymman.2010.05.017
- Hwang, S. S., Chang, V. T., Cogswell, J., Alejandro, Y., Osenenko, P., Morales, E., et al. (2004). Study of unmet needs in symptomatic veterans with advanced cancer: incidence, independent predictors and unmet needs outcome model. *Journal of Pain and Symptom Management*, 28(5), 421-432. doi: DOI: 10.1016/j.jpainsymman.2004.02.023
- Hwang, S. S., Chang, V. T., Fairclough, D. L., Cogswell, J., & Kasimis, B. (2003). Longitudinal Quality of Life in Advanced Cancer Patients: Pilot Study Results from a VA Medical Cancer Center. *Journal of Pain and Symptom Management*, 25(3), 225-235. doi: 10.1016/S0885-3924(02)00641-3
- Im, E. O., Chee, W., Guevara, E., Liu, Y., Lim, H. J., Tsai, H. M., et al. (2007). Gender and ethnic differences in cancer pain experience: a multiethnic survey in the United States. *Nursing Research*, 56(5), 296-306. doi: 10.1097/01.NNR.0000289502.45284.b5
- Im, E. O., Lim, H. J., Clark, M., & Chee, W. (2008). African American cancer patients' pain experience. *Cancer Nursing*, 31(1), 38-46. doi: 10.1097/01.NCC.0000305685.59507.9e

- Jimenez, A., Madero, R., Alonso, A., Martinez-Marin, V., Vilches, Y., Martinez, B., et al. (2011). Symptom clusters in advanced cancer. *Journal of Pain & Symptom Management, 42*(1), 24-31. doi: S0885-3924(11)00030-3
- John, L. D. (2010). Self-care strategies used by patients with lung cancer to promote quality of life. *Oncology Nursing Forum, 37*(3), 339-347. doi: A25180544HU35653
- Johnson, K. S., Elbert-Avila, K. I., & Tulsky, J. A. (2005). The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc, 53*(4), 711-719. doi: 10.1111/j.1532-5415.2005.53224.x
- Johnson, K. S., Kuchibhatla, M., & Tulsky, J. A. (2009). Racial Differences in Self-Reported Exposure to Information about Hospice Care. *Journal of Palliative Medicine, 12*(10), 921-927. doi: 10.1089/jpm.2009.0066
- Johnston, B., McGill, M., Milligan, S., McElroy, D., Foster, C., & Kearney, N. (2009). Self care and end of life care in advanced cancer: Literature review. [doi: 10.1016/j.ejon.2009.04.003]. *European Journal of Oncology Nursing, 13*(5), 386-398.
- Jones, J. (1993). *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press.
- Jones, R. A., Taylor, A. G., Bourguignon, C., Steeves, R., Fraser, G., Lippert, M., et al. (2007). Complementary and alternative medicine modality use and beliefs among African American prostate cancer survivors. *Oncology Nursing Forum, 34*(2), 359-364. doi: 10.1188/07.ONF.359-364

- Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. [Article]. *Nursing Standard*, 23(23), 42-46.
- Kato, I., Severson, R. K., & Schwartz, A. G. (2001). Conditional median survival of patients with advanced carcinoma: surveillance, epidemiology, and end results data. *Cancer*, 92(8), 2211-2219. doi: 10.1002/1097-0142(20011015)92:8<2211::AID-CNCR1565>3.0.CO;2-W
- King, P. A. (1992). Twenty years after. The legacy of the Tuskegee Syphilis Study. The dangers of difference. *Hastings Center Report*, 22(6), 35-38.
- Kirkova, J., & Walsh, D. (2007). Cancer symptom clusters--a dynamic construct. *Support Care Cancer*, 15(9), 1011-1013. doi: 10.1007/s00520-007-0259-2
- Koenig, B. A., Back, A. L., & Crawley, L. M. (2003). Qualitative methods in end-of-life research: Recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management*, 25(4), S43-S52. doi: 10.1016/s0885-3924(03)00060-5
- Kumagai, A. K., & Lypton, M. L. (2009). Beyond cultural competence: critical consciousness, social justice, and multicultural education. *Academic Medicine*, 84(6), 782-787. doi: 10.1097/ACM.0b013e3181a42398 [doi]
- Kurita, G. P., Lundorff, L., Pimenta, C. A., & Sjogren, P. (2009). The cognitive effects of opioids in cancer: a systematic review. *Support Care Cancer*, 17(1), 11-21. doi: 10.1007/s00520-008-0497-y
- Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the Craft of Qualitative Research Interviewing* (2nd ed.). Los Angeles: Sage Publications.

- Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist, 45*(5), 634-641. doi: 45/5/634
- Labori, K. J., Hjermstad, M. J., Wester, T., Buanes, T., & Loge, J. H. (2006). Symptom profiles and palliative care in advanced pancreatic cancer: a prospective study. *Support Care Cancer, 14*(11), 1126-1133. doi: 10.1007/s00520-006-0067-0
- Lantz, P. M., House, J. S., Lepkowski, J. M., Williams, D. R., Mero, R. P., & Chen, J. (1998). Socioeconomic factors, health behaviors, and mortality: results from a nationally representative prospective study of US adults. *JAMA, 279*(21), 1703-1708. doi: joc72105
- Lantz, P. M., Lynch, J. W., House, J. S., Lepkowski, J. M., Mero, R. P., Musick, M. A., et al. (2001). Socioeconomic disparities in health change in a longitudinal study of US adults: the role of health-risk behaviors. *Social Science and Medicine, 53*(1), 29-40. doi: S0277953600003191
- Lee, M. M., Chang, J. S., Jacobs, B., & Wrensch, M. R. (2002). Complementary and alternative medicine use among men with prostate cancer in 4 ethnic populations. *American Journal of Public Health, 92*(10), 1606-1609.
- Lengacher, C. A., Bennett, M. P., Kip, K. E., Gonzalez, L., Jacobsen, P., & Cox, C. E. (2006). Relief of symptoms, side effects, and psychological distress through use of complementary and alternative medicine in women with breast cancer. *Oncology Nursing Forum, 33*(1), 97-104.
- Loggers, E. T., Maciejewski, P. K., Paulk, E., DeSanto-Madeya, S., Nilsson, M., Viswanath, K., et al. (2009). Racial Differences in Predictors of Intensive End-of-

Life Care in Patients With Advanced Cancer. *J Clin Oncol*, 27(33), 5559-5564.

doi: 10.1200/jco.2009.22.4733

Lott, B. (2002). Cognitive and behavioral distancing from the poor. *American Psychologist*, 57(2), 100-110.

Lundberg, P. C., & Rattanasuwan, O. (2007). Experiences of fatigue and self-management of Thai Buddhist cancer patients undergoing radiation therapy.

*Cancer Nursing*, 30(2), 146-155. doi: 10.1097/01.NCC.0000265005.02559.43

Mack, J. W., Paulk, M. E., Viswanath, K., & Prigerson, H. G. (2010). Racial disparities in the outcomes of communication on medical care received near death. *Archives of Internal Medicine*, 170(17), 1533-1540. doi: 10.1001/archinternmed.2010.322

Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28(7), 1203-1208. doi: JCO.2009.25.4672 10.1200/JCO.2009.25.4672

Maliski, S. L., Connor, S. E., Williams, L., & Litwin, M. S. (2010). Faith among low-income, African American/black men treated for prostate cancer. *Cancer Nursing*, 33(6), 470-478. doi: 10.1097/NCC.0b013e3181e1f7ff

Maliski, S. L., Kwan, L., Krupski, T. L., Fink, A., & Litwin, M. S. (2004). Low-income prostate cancer patients have poor self-efficacy for communicating with their physicians. *Journal of Urology*, 171(4), 279-279.

Mechanic, D., & Tanner, J. (2007). Vulnerable people, groups, and populations: societal view. *Health Affairs*, 26(5), 1220-1230. doi: 10.1377/hlthaff.26.5.1220



- Meghani, S. H., & Houldin, A. D. (2007). The meanings of and attitudes about cancer pain among African Americans. *Oncology Nursing Forum*, *34*(6), 1179-1186.
- Meghani, S. H., & Keane, A. (2007). Preference for analgesic treatment for cancer pain among African Americans. *Journal of Pain & Symptom Management*, *34*(2), 136-147. doi: 10.1016/j.jpainsymman.2006.10.019
- Meier, D. E. (2011). Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q*, *89*(3), 343-380. doi: 10.1111/j.1468-0009.2011.00632.x
- Miaskowski, C. (2004). Gender Differences in Pain, Fatigue, and Depression in Patients With Cancer. *Journal of the National Cancer Institute Monographs*, *2004*(32), 139-143. doi: 10.1093/jncimonographs/lgh024
- Miaskowski, C., Aouizerat, B. E., Dodd, M., & Cooper, B. (2007). Conceptual issues in symptom clusters research and their implications for quality-of-life assessment in patients with cancer. *Journal of the National Cancer Institute Monographs* (37), 39-46. doi: 10.1093/jncimonographs/lgm003
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis* (Second ed.). Thousand Oaks: Sage.
- Mitchell, T., & Turton, P. (2011). 'Chemobrain': concentration and memory effects in people receiving chemotherapy - a descriptive phenomenological study. *European Journal of Cancer Care*, *20*(4), 539-548. doi: 10.1111/j.1365-354.2011.01244.x
- Mor, V., Laliberte, L., Morris, J. N., & Wiemann, M. (1984). The Karnofsky Performance Status Scale. An examination of its reliability and validity in a research setting. *Cancer*, *53*(9), 2002-2007.

- Morasso, G., Capelli, M., Viterbori, P., Di Leo, S., Alberisio, A., Costantini, M., et al. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain and Symptom Management*, 17(6), 402-409. doi: S0885392499000342
- Morgan, P. D., Gaston-Johansson, F., & Mock, V. (2006). Spiritual well-being, religious coping, and the quality of life of African American breast cancer treatment: a pilot study. *ABNF*, 17(2), 73-77.
- Nail, L. M., Jones, L. S., Greene, D., Schipper, D. L., & Jensen, R. (1991). Use and perceived efficacy of self-care activities in patients receiving chemotherapy. *Oncology Nursing Forum*, 18(5), 883-887.
- Nekolaichuk, C., Watanabe, S., & Beaumont, C. (2008). The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991--2006). *Palliat Med*, 22(2), 111-122. doi: 10.1177/0269216307087659
- Newlin, K., Knafl, K., & Melkus, G. D. (2002). African-American spirituality: a concept analysis. *Advances in nursing science*, 25(2), 57-70.
- Nguyen, J., Cramarossa, G., Bruner, D., Chen, E., Khan, L., Leung, A., et al. (2011). A literature review of symptom clusters in patients with breast cancer. *Expert Review of Pharmacoeconomic & Outcomes Research*, 11(5), 533-539. doi: 10.1586/erp.11.55
- NIHM Multisite HIV STD Prevent Trial Group (2008). The role of Community Advisory Boards (CABs) in Project Eban. *Journal of Acquired Immune Deficiency Syndromes*, 49 Suppl 1, S68-74. doi: 10.1097/QAI.0b013e31818447f5
- NINR (2011). *NINR Strategic Plan*. (11-7783). Bethesda: National Institutes of Health.

- Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T. E., McFadden, E. T., et al. (1982). Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*, 5(6), 649-655.
- Payne, R., Medina, E., & Hampton, J. W. (2003). Quality of life concerns in patients with breast cancer. *Cancer*, 97(S1), 311-317.
- Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E., et al. (2009). Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients With Advanced Cancer. *JAMA*, 301(11), 1140-1147. doi: 10.1001/jama.2009.341
- Phipps, E., True, G., Harris, D., Chong, U., Tester, W., Chavin, S. I., et al. (2003). Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology*, 21(3), 549-554.
- Pisu, M., Azuero, A., McNees, P., Burkhardt, J., Benz, R., & Meneses, K. (2010). The out of pocket cost of breast cancer survivors: a review. *J Cancer Surviv*, 4(3), 202-209. doi: 10.1007/s11764-010-0125-y
- Rhodes, R. L., Teno, J. M., & Welch, L. C. (2006). Access to hospice for African Americans: Are they informed about the option of hospice? [Article]. *Journal of Palliative Medicine*, 9(2), 268-272.
- Richards, L., & Morse, J. M. (2007). *User's Guide to Qualitative Methods* (Second ed.). Thousand Oaks: Sage.

- Richardson, A., & Ream, E. K. (1997). Self-care behaviours initiated by chemotherapy patients in response to fatigue. *International Journal of Nursing Studies*, 34(1), 35-43. doi: S0020748996000314
- Richardson, L. A., & Jones, G. W. (2009). A review of the reliability and validity of the Edmonton Symptom Assessment System. *Current Oncology*, 16(1), 55.
- Riechelmann, R. P., Krzyzanowska, M. K., O'Carroll, A., & Zimmermann, C. (2007). Symptom and medication profiles among cancer patients attending a palliative care clinic. *Supportive Care in Cancer*, 15(12), 1407-1412. doi: 10.1007/s00520-007-0253-8
- Rosenzweig, M. Q., Wiehagen, T., Brufsky, A., & Arnold, R. (2009). Challenges of illness in metastatic breast cancer: a low-income African American perspective. *Palliat Support Care*, 7(2), 143-152. doi: 10.1017/S1478951509000194
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340.
- Schmid, B., Allen, R. S., Haley, P. P., & Decoster, J. (2010). Family matters: dyadic agreement in end-of-life medical decision making. *Gerontologist*, 50(2), 226-237. doi: 10.1093/geront/gnp166
- Schumacher, K. L., Koresawa, S., West, C., Hawkins, C., Johnson, C., Wais, E., et al. (2002). Putting cancer pain management regimens into practice at home. *Journal of Pain & Symptom Management*, 23(5), 369-382.
- Searight, H. R., & Gafford, J. (2005). Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians. *American Family Physician*, 71(3), 515-522.

- Semple, C. J., Dunwoody, L., George Kernohan, W., McCaughan, E., & Sullivan, K. (2008). Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. *Journal of Advanced Nursing*, *63*(1), 85-93. doi: 10.1111/j.1365-2648.2008.04698.x
- Sherwood, P. R., Donovan, H. S., Rosenzweig, M., Hamilton, R., & Bender, C. M. (2008). A house of cards: the impact of treatment costs on women with breast and ovarian cancer. *Cancer Nursing*, *31*(6), 470-477. doi: 10.1097/01.NCC.0000339255.75947.a8
- Simon, C. E., Crowther, M., & Higginson, H. K. (2007). The stage-specific role of spirituality among African American Christian women throughout the breast cancer experience. *Cultural Diversity and Ethnic Minority Psychology*, *13*(1), 26-34.
- Smedley, B. D., Stith, A., Y., & Nelson, A. R. (Eds.). (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington: National Academies Press.
- Smith, A. K., Davis, R. B., & Krakauer, E. L. (2007). Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: impact on advance care planning and treatment preferences. *Journal of General Internal Medicine*, *22*(11), 1579-1582. doi: 10.1007/s11606-007-0370-6
- Smith, A. K., McCarthy, E. P., Paulk, E., Balboni, T. A., Maciejewski, P. K., Block, S. D., et al. (2008). Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *Journal of Clinical Oncology*, *26*(25), 4131-4137. doi:

10.1200/JCO.2007.14.8452 [doi]

- Smith, Y. R., Johnson, A. M., Newman, L. A., Greene, A., Johnson, T. R., & Rogers, J. L. (2007). Perceptions of clinical research participation among African American women. *J Womens Health (Larchmt)*, *16*(3), 423-428.
- Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease. *Journal of Pain and Symptom Management*, *31*(1), 58-69.
- Stone, J. R., & Dula, A. (2009). Race/Ethnicity, Trust, and Health Disparities: Trustworthiness, Ethics, and Action. In S. Kosoko-Lasaki, C. T. Cook & R. L. O'Brien (Eds.), *Cultural Proficiency in Addressing Health Disparities* (pp. 37-56). Sudbury: Jones and Bartlett.
- Tammemagi, C. M., Neslund-Dudas, C., Simoff, M., & Kvale, P. (2004). Lung carcinoma symptoms - An independent predictor of survival and an important mediator of African-American disparity in survival. *Cancer*, *101*(7), 1655-1663.
- Tanaka, K., Akechi, T., Okuyama, T., Nishiwaki, Y., & Uchitomi, Y. (2002). Impact of dyspnea, pain, and fatigue on daily life activities in ambulatory patients with advanced lung cancer. *Journal of Pain & Symptom Management*, *23*(5), 417-423. doi: S0885392402003767
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., et al. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, *291*(1), 88-93. doi: 10.1001/jama.291.1.88

- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48(4), 388-396.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. doi: 10.1093/intqhc/mzm042
- Trice, E. D., & Prigerson, H. G. (2009). Communication in end-stage cancer: review of the literature and future research. *Journal of Health Communication*, 14 Suppl 1, 95-108. doi: 10.1080/10810730902806786
- True, G., Phipps, E. J., Braitman, L. E., Harralson, T., Harris, D., & Tester, W. (2005). Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine*, 30(2), 174-179. doi: 10.1207/s15324796abm3002\_10
- Tsai, J. S., Wu, C. H., Chiu, T. Y., & Chen, C. Y. (2010). Significance of symptom clustering in palliative care of advanced cancer patients. *Journal of Pain & Symptom Management*, 39(4), 655-662. doi: 10.1016/j.jpainsymman.2009.09.005
- Tsai, J. S., Wu, C. H., Chiu, T. Y., Hu, W. Y., & Chen, C. Y. (2006). Symptom patterns of advanced cancer patients in a palliative care unit. *Palliative Medicine*, 20(6), 617-622. doi: 10.1177/0269216306071065
- Vallerand, A. H., Hasenau, S., Templin, T., & Collins-Bohler, D. (2005). Disparities between black and white patients with cancer pain: the effect of perception of control over pain. *Pain Med*, 6(3), 242-250.

- van Ryn, M. (2002). Research on the Provider Contribution to Race/Ethnicity Disparities in Medical Care. *Medical Care*, 40(1), I140-I151.
- van Ryn, M., & Burke, J. (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science and Medicine*, 50(6), 813-828. doi: S027795369900338X
- Volandes, A. E., Paasche-Orlow, M., Gillick, M. R., Cook, E. F., Shaykevich, S., Abbo, E. D., et al. (2008). Health literacy not race predicts end-of-life care preferences. *J Palliative Medicine*, 11(5), 754-762. doi: 10.1089/jpm.2007.0224
- Walsh, D., Donnelly, S., & Rybicki, L. (2000). The symptoms of advanced cancer: relationship to age, gender, and performance status in 1,000 patients. *Supportive Care in Cancer*, 8(3), 175-179.
- Walsh, D., & Rybicki, L. (2006). Symptom clustering in advanced cancer. *Support Care Cancer*, 14(8), 831-836. doi: 10.1007/s00520-005-0899-z
- Ward, E., Jemal, A., Cokkinides, V., Singh, G. K., Cardinez, C., Ghafoor, A., et al. (2004). Cancer disparities by race/ethnicity and socioeconomic status. *CA Cancer J Clin*, 54(2), 78-93.
- Wang, S. Y., Tsai, C. M., Chen, B. C., Lin, C. H., & Lin, C. C. (2008). Symptom clusters and relationships to symptom interference with daily life in Taiwanese lung cancer patients. *Journal of Pain & Symptom Management*, 35(3), 258-266. doi: 10.1016/j.jpainsymman.2007.03.017
- Wells, M., Sarna, L., Cooley, M. E., Brown, J. K., Chernecky, C., Williams, R. D., et al. (2007). Use of complementary and alternative medicine therapies to control



symptoms in women living with lung cancer. *Cancer Nursing*, 30(1), 45-55; quiz 56-47. doi: 00002820-200701000-00008

Williams, D. R., & Mohammed, S. A. (2009). Discrimination and racial disparities in health: evidence and needed research. *Journal of Behavioral Medicine*, 32(1), 20-47. doi: 10.1007/s10865-008-9185-0

Williams, M. (2011, July 20). New Grady CEO faces financial, political hurdles, *The Atlanta Journal-Constitution*. Retrived from <http://www.ajc.com>

Williams, P. D., Balabagno, A. O., Manahan, L., Piamjariyakul, U., Ranallo, L., Laurente, C. M., et al. (2010). Symptom monitoring and self-care practices among Filipino cancer patients. *Cancer Nursing*, 33(1), 37-46. doi: 10.1097/NCC.0b013e3181b0f2b4

Williams, P. D., Lopez, V., Ying, C. S., Piamjariyakul, U., Wenru, W., Hung, G. T., et al. (2010). Symptom monitoring and self-care practices among oncology adults in China. *Cancer Nursing*, 33(3), 184-193. doi: 10.1097/NCC.0b013e3181c29598

Williams, P. D., Piamjariyakul, U., Ducey, K., Badura, J., Boltz, K. D., Olberding, K., et al. (2006). Cancer treatment, symptom monitoring, and self-care in adults: pilot study. *Cancer Nursing*, 29(5), 347-355.

Yarbro, C. H., Wujcik, D., & Gobel, B. H. (Eds.). (2011). *Cancer Nursing : Principles and Practice* (7th ed.). Sudbury, Mass. : Jones and Bartlett Publishers.

Yoon, J., Malin, J., Tisnado, D., Tao, M., Adams, J., Timmer, M., et al. (2008). Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Research and Treatment*, 108(1), 69.

Zavala, M. W., Maliski, S. L., Kwan, L., Fink, A., & Litwin, M. S. (2009). Spirituality and quality of life in low-income men with metastatic prostate cancer.

*Psychooncology*, 18(7), 753-761. doi: 10.1002/pon.1460

Zimmerman, C., Cheung, W. Y., & Le, L. W. (2008). Symptom Clusters in patients with advanced cancer. *Journal of Clinical Oncology*, 26 (May 20 suppl; abstr 9566).

Figure 1: The Symptom Experience

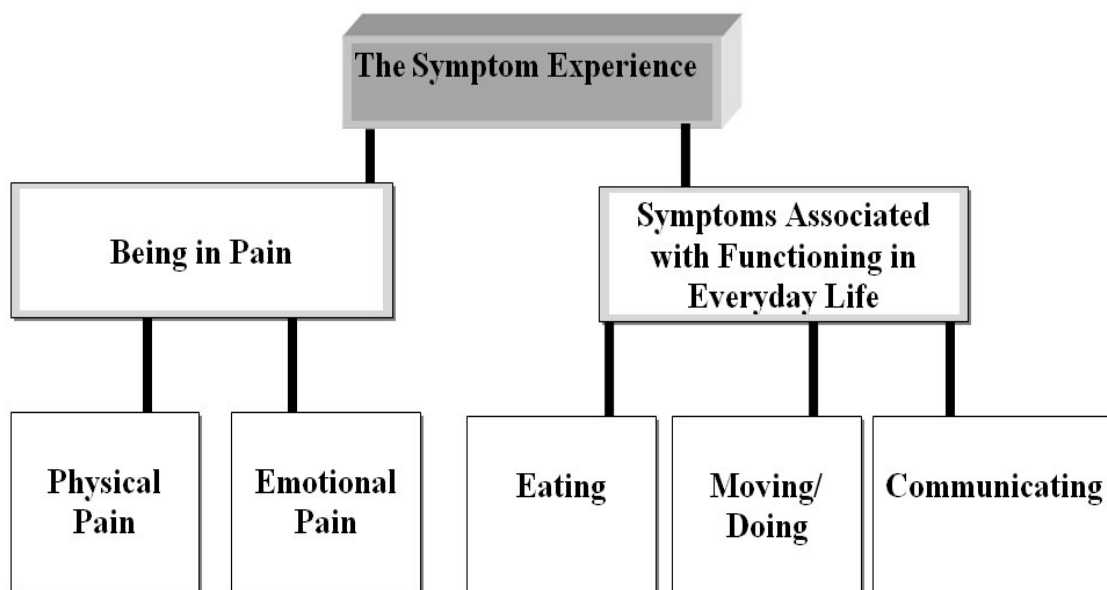
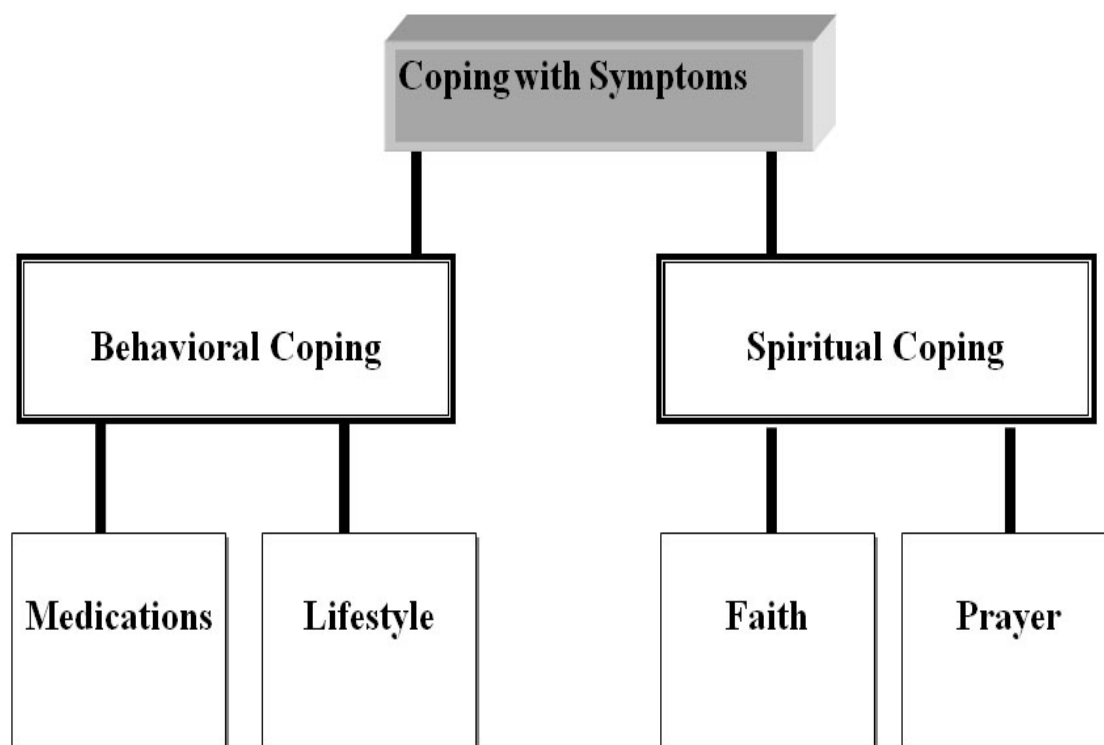


Figure 2: Coping with Symptoms



<b>Table 1: Demographic Characteristics (n=27)</b>			
<b>Variable</b>		<b>n</b>	<b>%</b>
<b>Age: mean (range)</b>	57 (30-79)		
<b>Gender</b>			
Female		18	63
Male		9	37
<b>Marital Status</b>			
Single		14	52
Divorced/separated		7	26
Married		3	11
Widowed		2	7
In a committed relationship		1	4
<b>Residence</b>			
Own home or apartment		15	56
Family home or apartment		10	37
Non family member's home or apartment		2	7
<b>Number in Household</b>			
One		7	26
Two to three		12	44
Four to five		6	22
Six to eight		0	0
Nine to ten		2	7
<b>Born in the US</b>			
Yes		25	92
No		2	8
<b>Present financial status</b>			
I go without		2	7
I have barely enough to get by		14	52
I feel secure most of the time		6	22
I am very comfortable		3	11
No Answer		2	7
<b>Family's financial status when growing up</b>			
We went without		4	15
We barely had enough to get by		4	15
We felt secure most of the time		14	52
We got everything we wanted		4	15
No Answer		1	4
<b>Education</b>			
Less than high school		10	37
High school graduate		10	37
Some college		2	8
College graduate		3	11
Graduate School		2	8

<b>Variable</b>		<b>n</b>	<b>%</b>
<b>Health Insurance Type</b>			
Medicaid		11	41
Medicare and Medicaid		5	19
Medicare		2	7
No insurance		8	30
Other		1	4

<b>Table 2: Clinical Characteristics (n=27)</b>		
<b>Variable</b>	<b>n</b>	<b>%</b>
<b>Cancer Diagnosis</b>		
Breast	9	33
Lung	8	30
Prostate	3	11
Ovarian	3	11
Cervical	1	4
Leiomyosarcoma	1	4
Renal Cell	1	4
Vocal Cord	1	4
<b>Recruitment Source</b>		
Palliative Care Clinic	13	48
Breast Cancer Clinic	5	19
Lung Cancer Clinic	5	19
General Oncology Clinic	2	11
Gynecology Oncology Clinic	1	4
Radiation Oncology Clinic	1	4
<b>Served by palliative care clinic</b>		
Yes	14	52
No	13	48
<b>Co-morbidities per self report</b>		
None	8	30
Hypertension	15	56
Respiratory Disease	5	19
Diabetes	3	11
Cardiac Disease	3	11
Deep Vein Thrombosis	2	7
Lupus	1	4
Stroke	1	4
Arthritis	1	4
Vascular Disease	1	4
Gout	1	4
<b>Location of Interview</b>		
Home	16	59
Hospital	11	41

**Table 3: Demographic and Clinical Characteristics per Individual**

Pseudonym	Age	Cancer Type	Yrs. of Ed.	Marital Status	Lives With	Financial Situation	Co-Morbidities	Cancer Treatment	Attended Palliative Care Clinic
Ms. Smith	55	Ovarian	16	Separated	Mom And Daughter	Barely Enough	Hypertension	Chemotherapy Surgery	Yes
Mr. Taylor	63	Prostate	12	Divorced	Alone	Barely Enough	Hypertension	Chemotherapy	Yes
Ms. Cockran	57	Breast	12	Divorced	Children, Grandchildren, Friend	Barely Enough	Hypertension Asthma	Chemotherapy Radiation Surgery	Yes
Mr. Thomas	53	Leiomyosarcoma	9	Single	Roommates	I Go Without	DVT	Radiation	Yes
Ms. Nelson	29	Breast	12	Committed Relationship	Partner, Children, Other Family members	Very Comfortable	None	Chemotherapy	Yes
Mr. Williams	56	Lung	14	Divorced	Alone	No Answer	None	Chemotherapy Radiation	Yes
Mr. Johnson	62	Prostate	11	Married	Spouse, Mother-In-Law	Barely Enough	Hypertension	Chemotherapy	Yes
Ms. Patrick	45	Renal Cell	12	Separated	Mom And Mom's Boyfriend	Barely Enough	None	Chemotherapy Surgery	Yes
Ms. Lee	58	Cervical	18	Single	Alone	Feel Secure Most of the Time	None	Chemotherapy Radiation	Yes



**Table 3: Demographic and Clinical Characteristics per Individual (continued)**

Pseudonym	Age	Cancer Type	Yrs. of Ed.	Marital Status	Lives With	Financial Situation	Co-Morbidities	Cancer Treatment	Attended Palliative Care Clinic
Ms. Green	56	Lung	8	Single	Spouse, Son, Daughter-In-Law, Grandchildren	Feel Secure Most of the Time	Stroke, Hypertension, Pneumonia	Chemotherapy Radiation	No
Ms. Carter	60	Ovarian	12	Single	Grandson	Barely Enough	Asthma	Chemotherapy	Yes
Mr. Scott	65	Lung	3	Single	Brother, Sister In Law And Niece	Feel Secure Most Of The Time	Bronchitis	Chemotherapy	Yes
Ms. Lewis	48	Ovarian	12	Single	Friend	Very Comfortable	DVT, Hypertension	Chemotherapy Surgery	No
Ms. Washington	42	Breast	11	Single	Children	Barely Enough	Hypertension	Chemotherapy Radiation Surgery	No
Ms. Moore	58	Breast	18	Married	Husband And Children	Barely Enough	None	Chemotherapy Radiation Surgery	No
Ms. Hill	70	Breast	12	Single	Alone	I Go Without	Hypertension, Vascular Disease	Chemotherapy	No
Ms. Clark	52	Breast	14	Single	Daughter	Very Comfortable	Heart Murmur, S/P MI, Arthritis	Chemotherapy Radiation	No
Ms. Miller	51	Breast	5	Single	Alone	Barely Enough	Hypertension, Asthma, Diabetes	Chemotherapy Radiation Surgery	No

**Table 3: Demographic and Clinical Characteristics per Individual (continued)**

Pseudonym	Age	Cancer Type	Yrs. of Ed.	Marital Status	Lives With	Financial Situation	Co-Morbidities	Cancer Treatment	Attended Palliative Care Clinic
Mr. Harris	66	Prostate	9	Single	Mom And Sisters	Barely Enough	Diabetes, Hypertension	Chemotherapy Radiation	No
Mr. Wilson	63	Lung	16	Married	Spouse	Barely Enough	None	Chemotherapy Radiation	No
Ms. Cooke	55	Lung	11	Single	Alone	Feel Secure Most Of The Time	Hypertension, Diabetes, Gout	Chemotherapy Surgery	Yes
Ms. Hall	79	Breast	11	Widowed	Grandson	Barely Enough	Hypertension	Chemotherapy Surgery	Yes
Ms. Evans	65	Breast	10	Divorced	Disabled Adult Son	Barely Enough	Hypertension, COPD, Cardiac Disease, Arthritis	Chemotherapy Surgery	No
Mr. Coleman	59	Vocal Cord	12	Divorced	Stepmother	No Answer	Hypertension Cardiac Disease	Surgery	Yes
Ms. Davis	53	Lung	16	Single	Sisters	Feel Secure Most Of The Time	Hypertension Lupus	Surgery	No
Ms. Robinson	56	Lung	12	Widowed	Daughter And Granddaughters	Feel Secure Most Of The Time	None	Chemotherapy Radiation Surgery	No
Mr. King	56	Lung	12	Single	Alone	Barely Enough	None	Chemotherapy Radiation	No

<b>Pseudonym</b>	<b>Pain</b>	<b>Tired</b>	<b>Nausea</b>	<b>Depressed</b>	<b>Anxious</b>	<b>Drowsy</b>	<b>Appetite</b>	<b>Well Being</b>	<b>Shortness of Breath</b>	<b>Constipation</b>
Ms. Smith	6/4	4/1	3/1	3/0	3/0	2/0	0/9	2/5	0/5	0/0
Mr. Taylor	5/5	6/6	3/2	3/0	3/0	2/3	5/6	3/2	3/1	0/2
Ms. Cockran	7/8	7/8	0/6	0/0	3/0	3/0	10/10	5/9	5/5	10/10
Mr. Thomas	8/8	6/6	0/0	0/0	0/1	3/0	0/1	0/2	3/3	2/3
Ms. Nelson	5/4	5/0	0/0	0/0	0/0	5/0	4/3	3/0	0/0	2/0
Mr. Williams	4/5	0/4	0/0	0/0	0/0	2/0	4/7	2/2	0/6	3/8
Mr. Johnson	10/9	0/9	9/0	10/9	10/0	10/9	9/5	8/9	0/0	0/0
Ms. Patrick	4/1	3/1	9/0	10/4	7/2	1/0	1/1	1/1	0/0	0/0
Ms. Lee	2/0	0/0	0/0	0/0	0/0	0/0	4/5	2/2	0/0	4/2
Ms. Green	8/0	10/0	8/0	8/0	10/0	10/6	0/0	10/0	9/0	0/6
Ms. Carter	10/6	5/4	0/0	2/0	0/0	0/5	0/5	5/2	0/0	3/0
Mr. Scott	3/8	4/6	3/4	0/0	0/0	3/0	4/8	8/2	5/6	0/0
Ms. Lewis	10/8	9/9	0/7	8/8	8/8	6/7	7/10	6/8	8/9	10/10
Ms. Washington	7/7	8/7	10/9	7/5	7/7	9/7	6/5	5/10	9/7	8/5
Ms. Moore	6/5	0/5	0/0	0/0	0/4	0/0	0/1	7/6	0/0	8/8
Ms. Hill	0/0	10/8	0/0	0/0	0/0	10/5	0/0	10/0	0/0	10/0
Ms. Clark	8/7	0/10	0/0	8/5	3/0	0/0	0/0	6/5	0/0	2/0
Ms. Miller	10/0	10/10	10/0	10/0	10/0	0/0	10/10	5/5	0/0	0/ No answer
Mr. Harris	8/7	8/7	0/0	0/0	0/5	0/2	5/5	5/3	0/0	0/0
Mr. Wilson	5/6	5/2	0/0	6/1	0/0	6/1	0/0	6/4	0/0	7/0

<b>Table 4: Symptoms Scores per ESAS at Screening/ Pre-Interview (continued)</b> (0 to 10 scale, 0=absence of symptom or best state, 10=worst symptom or state)										
<b>Pseudonym</b>	<b>Pain</b>	<b>Tired</b>	<b>Nausea</b>	<b>Depressed</b>	<b>Anxious</b>	<b>Drowsy</b>	<b>Appetite</b>	<b>Well Being</b>	<b>Shortness of Breath</b>	<b>Constipation</b>
Ms. Cooke	10/9	8/8	0/0	5/5	5/7	8/3	4/7	7/6	9/0	1/0
Ms. Hall	0/0	7/0	0/0	0/0	1/0	0/0	10/9	0/5	7/8	0/0
Ms. Evans	8/7	8/8	0/0	9/5	0/0	8/7	0/1	6/10	7/6	0/0
Mr. Coleman	7/8	4/10	4/0	4/0	4/0	4/0	2/M	2/5	4/10	4/0
Ms. Davis	7/5	0/4	0/0	0/0	0/0	0/3	10/8	3/5	7/5	0/4
Ms. Robinson	9/9	4/1	0/0	0/0	5/2	0/0	0/1	2/2	0/0	0/0
Mr. King	0/6	8/7	0/0	9/0	0/5	0/0	0/0	0/2	5/0	0/0

**Table Five: Symptoms discussed in the interviews**

Symptom s	Ms. Smith	Mr. Taylor	Ms. Cochran	Mr. Thom as	Ms. Nelson	Mr. William s	Mr. Johnson	Ms. Patrick	Ms. Lee	Ms. Green	Ms. Carter	Mr. Scott	Ms. Lewis	Ms. Washington	Ms. Moore	Ms. Hill	Ms. Clark	Ms. miller	Mr. Harris	Mr. Wilson	Ms. Cooke	Ms. hall	Ms. Evans	Mr. Colem an	Ms. Davie	Ms. Robinson	Mr. King
Anorexia	X		X	X			X	X		X	X	X	X	X	X		X	X	X	X	X	X		X	X		
Anxiety					X			X		X				X	X				X		X						X
Balance Disturbance										X							X	X									
Cognitive Changes		X						X	X			X				X	X	X		X						X	
Constipation	X		X	X	X	X	X		X		X		X	X	X	X											
Cough	X		X									X			X												
Depressed Mood		X	X		X	X	X	X		X	X		X	X			X	X	X	X	X		X				
Diarrhea											X													X			
Dizziness									X		X				X		X	X									
Drowsy					X								X	X		X							X				
Fear		X			X	X		X		X		X			X		X		X		X						
Gas			X						X																		
Hair Loss	X				X	X		X	X			X	X		X					X	X		X			X	
Hoarseness																								X			
LossOf Libido		X						X				X															
Nausea	X			X	X	X	X	X		X	X	X	X	X	X				X		X						

**Table Five: Symptoms discussed in the interviews (continued)**

Symptoms	Ms. Smith	Mr. Taylor	Ms. Cochran	Mr. Thomas	Ms. Nelson	Mr. Williams	Mr. Johnson	Ms. Patrick	Ms. Lee	Ms. Green	Ms. Carter	Mr. Scott	Ms. Lewis	Ms. Washington	Ms. Moore	Ms. Hill	Ms. Clark	Ms. Miller	Mr. Harris	Mr. Wilson	Ms. Cooke	Ms. Hall	Ms. Evans	Mr. Coleman	Ms. Davis	Ms. Robinson	Mr. King	
Pain	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	X
Respiratory Congestion												X			X									X				
Shortness of Breath				X		X				X		X	X	X	X	X			X		X	X	X	X	X		X	
Skin burns/Changes			X						X	X							X	X										
Sleep Difficulties	X		X			X	X				X	X	X	X						X	X		X	X	X	X	X	
Sore Throat/Mouth										X				X							X							
Swallowing Difficulties										X																X		
Swollen Extremities				X				X			X						X	X										
Taste/Smell	X							X				X		X					X	X		X						
Tingling/Burning/ Numbness											X			X			X	X	X				X					
Tiredness	X	X	X	X	X	X		X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Urination Difficulties			X				X				X		X															
Vision Difficulties																											X	
Vomiting					X		X	X		X	X	X			X						X							
Weakness		X	X				X	X				X	X	X			X	X			X	X					X	
Worry		X								X				X					X	X						X	X	

<b>Table 6: Strategies discussed in the interviews</b>				
	<b>Behavior Coping</b>		<b>Spiritual Coping</b>	
	<b>Medications</b>	<b>Lifestyle</b>	<b>Faith</b>	<b>Prayer</b>
<b>Ms. Smith</b>	X	X	X	X
<b>Mr. Taylor</b>	X	X	X	
<b>Ms. Cockran</b>	X	X	X	X
<b>Mr. Thomas</b>	X	X	X	X
<b>Ms. Nelson</b>	X	X	X	X
<b>Mr. Williams</b>	X	X	X	X
<b>Mr. Johnson</b>	X	X		
<b>Ms. Patrick</b>	X	X	X	X
<b>Ms. Lee</b>	X	X		X
<b>Ms. Green</b>	X	X	X	X
<b>Ms. Carter</b>	X	X	X	X
<b>Mr. Scott</b>	X	X	X	X
<b>Ms. Lewis</b>	X	X	X	X
<b>Ms. Washington</b>	X	X	X	X
<b>Ms. Moore</b>	X	X	X	X
<b>Ms. Hill</b>	X	X	X	X

<b>Table 6: Strategies discussed in the interviews (continued)</b>				
	<b>Behavior Coping</b>		<b>Spiritual Coping</b>	
<b>Ms. Clark</b>	X	X	X	X
<b>Ms. Miller</b>	X	X	X	
<b>Mr. Harris</b>	X	X	X	X
<b>Mr. Wilson</b>	X	X		
<b>Ms. Cooke</b>	X	X	X	X
<b>Ms. Hall</b>	X	X	X	X
<b>Ms. Evans</b>	X	X	X	X
<b>Mr. Coleman</b>	X	X		X
<b>Ms. Davis</b>	X	X	X	
<b>Ms. Robinson</b>	X	X	X	X
<b>Mr. King</b>	X	X	X	X



### APPENDIX A: Symptom Study Screening Form

**PATIENT NAME:** \_\_\_\_\_

**DATE FORM COMPLETED:** \_\_\_\_\_ **STUDY STAFF:** \_\_\_\_\_

\*\*\*\*\*

**Information to be collected from Healthcare Provider**

Mental status of patient: \_\_\_\_\_

Physical status of patient: \_\_\_\_\_

+++++

**Information to be collected by review of clinic record.**

Age: \_\_\_\_\_ Race: \_\_\_\_\_

Cancer Diagnosis: \_\_\_\_\_ Stage of Cancer: \_\_\_\_\_

Income level: \_\_\_\_\_

Symptom and Scores greater than 4 (per Edmonton Symptom Assessment Scale):

\*\*\*\*\*

<b>Study Inclusion Criteria</b>	<b>YES</b>	<b>NO</b>
African American or black by self report	___	___
21 years or older	___	___
Primary diagnosis of advanced cancer (metastatic or locally advanced refractory disease or for patients with hematologic malignancies who have not responded to antineoplastic therapy)	___	___
Income level $\leq$ 200% of the federal poverty level by self report	___	___
Mentally competent to give informed consent	___	___
Physically able to tolerate an 1-2 hour interview	___	___
Moderate symptom severity (score of 4 or higher for at least two symptoms)	___	___
<b>Patient eligible for study</b>	___	___
Action Taken:		

\_\_\_\_\_

## Appendix B: Edmonton Symptom Assessment Scale

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
Not Tired	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
Not Nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nauseated
Not Depressed	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
Not Anxious	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Not Drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
Best Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Appetite
Best Feeling of Wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst Possible feeling of Wellbeing
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Constipation	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Constipation

## **Appendix C: Emory University School of School of Nursing and Grady Health Services Consent to be a Research Subject**

**Title:** Symptom and Self Management in Low Income African American Patients with Advanced Cancer: A Qualitative Inquiry

**PRINCIPAL INVESTIGATOR:** Kate Yeager, RN, MS

**SPONSOR:** National Institute of Nursing Research, National Institute of Health

### **INTRODUCTION**

You are being asked to participate in a research study because you have cancer and have symptoms. This form is designed to tell you everything you need to think about before you decide to agree to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.** The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Please carefully read this form or have it read to you

- Please listen to the study staff explain the study to you
- Please ask questions about anything that is not clear
- Feel free to take home an unsigned copy of this form and take your time to think about it and talk it over with family or friends

After talking about the information in this consent form with the study team you should know:

- Why this research study is being done
- What will happen during the research
- Any possible benefits to you. Most research is done to learn things that will help people in the future. No one can guarantee that a study will help you.
- The possible risks to you. Consider these carefully.
- What other medical care you could seek instead of being in this research study
- How problems will be treated during the study and after the study is over.
- Who will have access to your study information

### **PURPOSE**

The purpose of this study is to learn about what it is like to care for yourself when you are experiencing symptoms related to cancer.

### **PROCEDURES**

If you decide to take part in this study, you will be asked to meet with two interviewers and talk about your symptoms, what you do to manage your symptoms and what helps you or gets in the way of taking care of your symptoms. The interview will take about 60

to 90 minutes. The interview will be recorded. You will also be asked questions about yourself and your cancer. You can choose the location of the interview. The interview can take place in a private room in the hospital or at your home or another private place. We will try and complete the interview in one session but if you are not feeling well or get tired we can schedule a second session within the same week. At the end of the interview, we will ask you if it is all right to call you on the phone if we have any additional questions. You can decide if that is OK or not. About 30 people who receive care at Grady Hospital in Atlanta, Georgia will take part in this study.

#### **RISKS AND DISCOMFORTS**

There is a slight chance you will become more anxious as a result of talking about your symptoms and how you manage them. These feelings, if they occur, usually last just a few minutes. The study staff will make sure you are feeling okay. If not, the session may be stopped and your doctor and nurse will be notified.

#### **BENEFITS**

You may not experience any benefit from taking part in this study. The study results may be used to help other people in the future.

#### **COMPENSATION/COSTS**

You will be given a \$20 grocery gift card for completing the interview. Your parking or public transportation costs will be paid. There are no extra costs to you for participating in this research study.

If you get ill or injured from being in this study, Emory and Grady would give/arrange for you to have urgent health care. Here we explain who would pay for this health care:

Would Emory or Grady Pay? Emory and Grady have not set aside any funds to pay for urgent health care. Also, Emory and Grady have not set aside any funds to pay you if you become ill or injured from being in this study. The only exception to this policy is if it is proven that the negligence of an Emory or Grady employee directly caused your injury or illness. “Negligence” means the failure to follow a standard duty of care.

#### **OTHER OPTIONS**

The option is not to take part in this study. If you decide not to take part in this research study, you would continue to receive your usual medical and nursing care.

#### **CONFIDENTIALITY**

The tapes from the interviews will be typed up and turned into paper documents. Your name and any other identifying information will not be included in the paper documents. The tapes will be destroyed once the paper documents are checked for accuracy. Certain offices and people other than the researchers may look at your medical charts and study records. Government agencies, Emory and Grady employees overseeing proper study conduct may look at your study records. Study sponsors may

also look at your study records. These offices include the Emory Institutional Review Board, the Emory Office of Research Compliance, and the Grady Research Oversight Committee. Emory and Grady will keep any research records we produce private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

#### **WITHDRAWAL FROM THE STUDY**

Taking part in this study is your choice. You can stop at any time. Tell the study staff if you are thinking about stopping or decide to stop. Leaving the study will not affect your medical care. You will still get your regular medical care from your hospital and doctor. The study investigator may stop you for being in the study at any time if they decide it is in your best interest, or if you do not follow study instructions.

#### **Questions**

Contact Kate Yeager at **404-822-0920**:

- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury, or
- if you have questions, concerns or complaints about the research

If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact Dr. Curtis Lewis, Senior Vice President for Grady Health System Medical Affairs at (404) 616-4261 or the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or [irb@emory.edu](mailto:irb@emory.edu).

#### **Consent**

We will give you a copy of this consent form to keep. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you.

Nothing in this form can make you give up any legal rights. By signing this form you will not give up any legal rights. You are free to take home an unsigned copy of this form and talk it over with family or friends.

Please sign below if you agree to participate in this study.

\_\_\_\_\_  
Name of Subject

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Person Conducting Informed Consent Discussion

\_\_\_\_\_  
Date

**Appendix D: Emory University School of Nursing Research Subject HIPAA Authorization to Use or Disclose Health Information that Identifies You for a Research Study**

**Title:** Symptom and Self Management in Low Income African American Patients with Advanced Cancer: A Qualitative Inquiry

**PRINCIPAL INVESTIGATOR:** Kate Yeager, RN, MS

**SPONSOR:** National Institute of Nursing Research, National Institute of Health

Study Number: \_\_\_\_\_

Subject Name: \_\_\_\_\_

The privacy of your health information is important to us. We call your health information that identifies you, your “protected health information” or “PHI.” To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA). We refer to all of these laws in this form as the Privacy Rules. This form explains how we will use your PHI for this study.

Please read this form carefully and if you agree with it, sign it at the end.

**Research Study:** You are being asked to volunteer for a research study because you are experiencing symptoms related to cancer. We want to learn more about living with symptoms, what you do to manage your symptoms and what helps you or gets in the way of taking care of your symptoms. If you participate in the study you will be interviewed for about 60 to 90 minutes and the interview will be recorded.

**PHI That Will Be Used/Disclosed:** Parts of your medical record concerning your cancer and its treatment and the information shared during of the interview.

**Purposes for Which Your PHI Will Be Used:** If you sign this form, you give us your permission to use your PHI for the conduct and oversight of this research study.

**People That Will Use or Disclose Your PHI and Purpose of Use/Disclosure:** Different people and groups will use and disclose your PHI. They will do this only in connection with the research study. The following persons or groups may use and/or disclose your PHI:

The Principal Investigator and the research staff.

The Principal Investigator may use other people and groups to help conduct the study. These people and groups will use your PHI to do this work.

The following groups may also use and disclose your PHI. They will do this to make sure the research is done correctly and safely. The groups are:

- the Emory University Institutional Review Board
- the Grady Research Oversight Committee.
- the Emory University Office of Research Compliance
- research monitors and reviewers
- data and safety monitoring boards
- any government agencies who regulate the research including the Office of Human Subjects Research Protections
- public health agencies
- National Institute of Nursing Research, National Institute of Health

We will use or disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or elder abuse. We also will comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

**Revoking Your Authorization:** You do not have to sign this form. Even if you do, at any time later on you may revoke (take back) your permission. If you want to do this, you must write to:

Kate Yeager, RN, MS  
 Nell Hodgson Woodruff School of Nursing  
 Emory University  
 1520 Clifton Road, NE  
 Atlanta, Georgia 30322-4207

After that point, the researchers would not collect any more of your PHI. But they may use or pass along the information you already gave them so they can follow the law, protect your safety, or make sure the research was done properly. If you have any questions about this, please ask.

**Other Items You Should Know:**

If we disclose information to people who do not have to follow the Privacy Rules, your information will no longer be protected by the Privacy Rules. People who do not have to follow the Privacy Rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them. Let us know if you have questions about this.

You do not have to sign this form. If you do not sign, you may not participate in the research study.

During the study you will generally not have access to records related to the research study. This is to preserve the integrity of the research. You may have access to these records when the study is complete.

If identifiers are removed from your PHI, then the remaining information will not be subject to the Privacy Rules. It may be used or disclosed with other people or organizations, and/or for other purposes.

**Expiration Date:** Your permission to use and disclose your PHI will expire. The expiration will be at the end of the research study and any required record-keeping period.

: If you have any questions regarding the study, you may call Kate Yeager, RN, MS at 404-822-0920. If you have any questions about the study, or your rights as a study subject, you may contact the Emory University Institutional Review Board at 404-712-0720 or 1-877-503-9797, by email at [irb@emory.edu](mailto:irb@emory.edu) or Dr. Curtis Lewis, Senior Vice President for Grady Health System Medical Affairs at (404) 616-4261.

A copy of this form will be given to you.

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Signature of Study Subject

Date \_\_\_\_\_ ---Time \_\_\_\_\_

---

Printed Name of Study Subject

---

Signature of Person Obtaining Authorization

---

Date

---

Time



### Appendix E: Symptom Study Demographic Sheet

Study ID: \_\_\_\_\_

Date: \_\_\_\_\_

1. How old are you? \_\_\_\_\_
2. What is your gender? \_\_\_\_\_
3. Hispanic? \_\_\_ Yes \_\_\_ No
4. Were you born in the United States?  
 \_\_\_ Yes  
 \_\_\_ No
5. How would you describe yourself  
 \_\_\_ Black  
 \_\_\_ African American  
 \_\_\_ Caribbean descent  
 \_\_\_ Haitian descent  
 \_\_\_ Other: Please describe: \_\_\_\_\_
6. What is the last grade you completed in school?  
 \_\_\_ None- I have not had any formal schooling  
 \_\_\_ Elementary School  
 \_\_\_ Middle School or Junior High  
 \_\_\_ High School or GED  
 \_\_\_ Technical School  
 \_\_\_ College  
 \_\_\_ Graduate School
7. Are you currently ....  
 \_\_\_ Married  
 \_\_\_ Separated  
 \_\_\_ Divorced  
 \_\_\_ Widowed  
 \_\_\_ Single-never been married  
 \_\_\_ In a committed relationship  
 \_\_\_ Other: Please describe: \_\_\_\_\_
8. Do you work outside your home?  
 \_\_\_ Yes (How many hours a week do you work? \_\_\_\_\_)  
 \_\_\_ No

9. Where do you live now?

In my own home or apartment

In my family's home or apartment

In someone else's home or apartment (not family)

Other: Please describe: \_\_\_\_\_

10. Does anyone live with you?

Yes

No

11. Who lives with you (check all that apply)

Spouse/partner

My children

Other children

Parents

Other family members

Roommate (non-related, not partner)

Other- Please describe: \_\_\_\_\_

12. How many people live in your household (including you)? \_\_\_\_

13. Which of these statements describes your present financial status?

I go without

I have barely enough to get by

I feel secure most of the time

I am very comfortable

14. When you were growing up, how would you describe your family's financial status

We went without

We barely had enough to get by

We felt secure most of the time

We got everything we wanted

15. How much money do you make each month? This includes any money you receive from wages, salary, your spouse or family, child support, disability, food stamps, TANF, SSI, or anything) \_\_\_\_\_

16. What is your yearly household income?

- 10,000 or less
- between 10,000 and 20, 000
- between 20,000 and 30, 000
- between 30,000 and 40, 000
- between 40,000 and 50, 000
- between 50,000 and 60, 000
- greater than 60,000

17. What type of health insurance do you have?

- private insurance
- Medicare
- Medicaid
- Medicare and Medicaid
- I do not have health insurance
- I am unsure
- other

18. Do you have any other chronic health conditions besides cancer?

- yes
- no

If yes, please describe: \_\_\_\_\_

## Appendix F: Interview Guide

### **Introduction:**

Good morning (afternoon). Thank you for agreeing to participate in this research study about living with symptoms (pain-nausea-tiredness) related to cancer. My name is Kate Yeager and this is Pat Martin. We are both from Emory University. As you know, we are talking to people with cancer to find out how they care for their symptoms. Before we start, there are a few things we would like to go over with you to give you a clearer idea of what we will be doing.

If it is OK with you, once we start the interview I would like to audiotape our conversation as I cannot write fast as we talk. Pat or I may make write down some notes to help us remember specific issues or additional questions. Our conversation is completely confidential. We will not use your name in any of the documents.

This will be our only meeting in person. First, we will first go over some general information and then turn on the tape recorder and begin the interview. The interview will last about an hour. After we are done, you will receive a grocery gift card and reimbursement for your travel to our session today. We have snacks and water available if you would like some. If at any time you become tired or are not feeling well we can stop the interview and rest. At that point we can decide to take a break or finish the interview at another time. Once the interview is complete we will ask your permission to call you in case there are any follow up questions after we review the interview tape.

All the information you give us will be strictly confidential. It will be used for research purposes only. We will not share this information with any of your providers at Grady without your permission.

We are interested in hearing about how you take care of yourself and your symptoms. There is no right or wrong answer to any of our questions. We want to hear what you do to care for yourself not just what people tell you to do or what you think you should do. By sharing your story, you will help us learn more about how people live with symptoms. We will use this information to help others. Your participation in this interview is totally voluntary and you should feel free not to answer any question. You may stop the interview at any time.

Thanks again for meeting with us this morning (afternoon). What questions do you have?

### **Introductory Question:**

Over the past few months, how have things been going for you?  
Tell me about how cancer has affected your life in the last year.

What has it been like living with cancer in the last year (depending on diagnosis date)?

How did you find out you had cancer...tell me your story?

**Symptoms questions (Use as appropriate to dialogue):**

**Use ESAS to begin discussion as needed.**

Tell me about any symptoms you are having right now?

What symptoms have you had in the last week (last month, last year)?

Tell me about what happens when you experience .....(symptom )?

What is it the .....(symptoms) like?

What happens when you have both (symptom A) and (Symptom B) at the same time (or in the same day)?

How do the symptoms affect your day?

Tell me about what a day is like for you when you are having .....(symptom).

**(Don't forget symptoms like depression, anxiety, frustration...)**

**Symptom Management Questions:**

When you have a .....(symptom), what do you do first?

If you think back to when you first started having [symptom], what did you do?

Do your family and friends influence what you do about [symptom]?

How did you happen to try .... (symptom strategy) for your .....(symptom)?

You told me what is like to live with .....(symptom). What do you do to make it better?

Tell me about how you manage these symptoms.

What helps you manage your symptoms?

Describe a time when you were able to make your (Symptom) better?

Tell me about a time when that strategy did not help

What were you thinking about when that happened?

Tell me how you go about \_\_\_\_\_

Who was most helpful to you when you had that symptom?

What did they do?

Tell me about what makes managing your symptoms difficult (hard).

Sometimes it can be really hard to follow all the advice from a doctor or nurse—how does that go for you?

A lot of people tell us about the importance of ..... as they deal with this symptom. Tell

me about how that is for you?

After living with this (symptom), what advice would you give to someone else that just experienced this (symptom)?

Tell me about any people in your life who have helped you deal with your .....(symptom)?

Tell me about any people in your life who have made it harder to deal with your .....(symptom)?

**Closure**

We have talked about a lot of things today. What do you think is the most important “take home” message?

Is there anything you would like to ask me?

**What was it like to tell your story?**

Thank you for visiting with me today.

**Possible Probes:**

Simple nod of the head and a “mm”

Say something more about that?

Give me an example of that.....

Describe another example of that?

Silence-allow pauses in conversation

Tell me about what happened next

**Transitions:**

Let's move on to another question now.