A Cross-Cultural Examination of the Needs and Behaviors of Female Caregivers of Cancer Patients at the End of Life: A Theoretical Elaboration

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Dedication

This work is dedicated to my grandmothers, Eulene Johnson, Mable Lynch, to Rebecca Davis and others who cared tirelessly for loved ones as well as to those women who graciously shared their narratives and challenges in giving much more than they knew they had in the name of love, service, and ministry.

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Abstract of Dissertation

A Cross-Cultural Examination of the Needs and Behaviors of Female Caregivers of Cancer Patients at the End of Life: A Theoretical Elaboration

Purpose: Efficiencies in cancer care provide for the shortening of acute care inpatient stay and subsequent earlier discharges for continued care in the home. As such, family members and friends are needing to adopt the caregiver role – voluntarily or involuntarily – without training and often without professional support (Laizner, Shegda Yost, Barg, & McCorkle, 1993). Cancer creates extraordinary demands upon the family caregiver as they navigate treatment systems and struggle to manage treatment associated symptoms. The construct that is used to capture the strain on caregivers is burden. Caregiver burden is defined by Givens and colleagues (Given, Given, & Kozachik, 2001) as "the distress that caregivers feel as a result of providing care." The Caregiving Health Effects Study (Schulz & Beach, 1999) revealed that this distress has can exacerbate and become detrimental to health status.

This study focused on understanding distinctions between White and Black female caregivers as such relates to the burden of caregiving and the influence of culture in their justification of the role and the influences of such on the perception of burden. In addition, a better understanding of caregiver needs within the context of African American carers was sought in order to suggest viable constructs for use in intervention development.

Design and Methods: Using a cross-sectional survey, Phase I assembled and interviewed a sample of 254 female caregivers (133 Caucasian and 121 African American) from which, actual caregiver burden, perceived caregiver burden, and the cultural justifications for caregiving were assessed. In addition, twenty-two African American women from this sample were drawn for the qualitative component of the study (Phase II) that served to confirm or elicit theoretical constructs relating to the caregiving experience. Data were collected for Phase I using a study instrument containing the scales and other study associated items. The instrument took 15 minutes to administer. Phase II data were collective in narrative format using a structured interview guide. All interviews were conducted by telephone in conversations that ranged from 60-90 minutes. They were recorded and transcribed verbatim.

Results: Analyses for the first phase of the study indicated that for this population of women caring for loved ones with advanced stage cancers, the differences with respect to the actual burden were not significant. White women, however, perceived that their burden was significantly greater than that of African American women, even when controlling for multiple factors such as race, age, education, relationship to patient and cultural justification. Nonetheless, perception of burden did not correlate with actual burden. In addition, when cultural background provided meaning to their role as an informal caregiver, their perceptions of burden were lower. Finally, overall women who were caring for spouses were able to justify their roles more than those caring for other types of family members or close friends.

Findings from Phase II of this study lend an understanding to some of the differences that were found in Phase I findings. As mentioned, African American women perceived their caregiver burden to be lower than did White women. In addition, White women were more likely to be caring for a spouse than were African American caregivers in this study. While several concepts emerged from the data that can be used to suggest constructs, two strong concepts arising from the Phase II analysis of the narratives of Black women were "family matters" and "relationship to patient". The more closely related the caregiver was to the patient the more positive the role was perceived. In addition, there were family related issues that either supported or affirmed the caregiver's role identity or the degree to which they felt the role was either put upon them (no one would but me) or chosen (no one could but me). It could be that White women caring for long term spouses, who do not differ with regard to cultural justification of the role of caregiving, experience similar family related issues or similar feelings and attitudes identified in the construct of "relationship to patient". In addition, the caring role in the lives of African American women yield them rather familiar with the role and perhaps less burdened by it. Many of the participants expressed having cared for and lost a loved one prior to the episode of record. In fact, some participants, interviewed in Phase II, were actually caring from more than one person at the time of the interview. Such familiarity and internalization of the role perhaps contributes to a lower perception of burden as well. Finally, participants in Phase II often credited religion as the source of strength and the reason for their acceptance of the role and its associated challenges. If one deems a role as a spiritual "calling", they may be reluctant to label it a burden.

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CHAPTER ONE

Statement of the Problem

Survival rates for cancer continue to improve. In fact, for cancers diagnosed between 1983 and 1985, the American Cancer Society states a 53% five-year survival rate. For those diagnosed between 1992 and 1998, this rate improves to 62% (American Cancer Society, 2003). Today, with continued advances in cancer innovations and therapeutics, more and more will survive and thus the impetus behind the National Cancer Institute Challenge Goal to reduce suffering and death due to cancer by the year 2015 (von Eschenbach, 2004).

These innovations in cancer care have enabled providers to now manage cancers formerly believed untreatable (McCorkle, 1988). In addition, efficiencies in care provide for the shortening of acute care inpatient stay and subsequent earlier discharges resulting in continued care in the home. As such, family members and friends are needing to adopt the caregiver role – voluntarily or involuntarily – without training and often without professional support (Laizner et al., 1993). Cancer creates extraordinary demands upon the family caregiver as they navigate treatment systems and struggle to manage treatment-associated symptoms.

Many complex cancer treatment chemotherapeutic and radiology regimens, once only delivered on an inpatient basis with stay requirements are now rendered routinely in physicians' offices and outpatient clinics (Mor, Allen, Siegel, & Houts, 1992). Now, family members serving as caregivers are representing the medical team in the home. They provide medical services, monitor symptoms, make complex decisions about when

to call the physician or bring the patient in for emergency care. They are expected to do this with little preparation, training or compensation (US General Accounting Office, 1994).

In addition to the physical consequences of surgery, chemotherapy, radiation and other treatment protocols, caregivers must sustain the psychological and emotional struggles of the patient – not to mention their own. In fact, many caregivers (providing home care for people at end of life) are likely to experience significant emotional distress if they are not able to participate in their usual activities and interests (Cameron, Franche, Cheung, & Stewart, 2002).

There is no question that as technology advances for cancer treatment the caregiving burden will reap the benefits through more facile approaches to care. Raveis (Raveis, 2003) captures these advances as:

- Improvements in the precision of cancer screening tools enable cancers to be detected earlier at more curable stages
- Refinements in imaging technology that provide for much cleaner and more precise images of organs and tissues
- Less mutilating surgical procedures which diminish post operative complications
- Progresses in the management of symptoms that result from cancer and its treatments
- Treatments like biological therapies that enable the body's immune system to fight cancer and repair treatment-related side effects

Such advances may serve to improve outcomes and reduce treatment related symptoms and side effects. They may not impact the more psychosocial effects of caregiving. Such will need to be more targeted interventions.

Nature and History of the Problem

In the optimal situation, caregiving burden would be minimal, support substantial, the capacity (physical and emotional) of the caregiver would be sufficient for the roles, and ample information and direction would be provided by professionals and delivered clearly enough to render the caregiver comfortable with the many complex decisions that come with caring for a loved-one. Unfortunately, such is far from the current state of caregiving.

Notwithstanding progress, the needs of family caregivers of cancer patients (and other chronic diseases) is great (Given et al., 2004; Turner, Wallace, Anderson, & Bird, 2004). Very few educational and informational resources are available to families impacted by cancer and rarely is the family unit viewed as the object for intervention. Rather, the family is often expected to become an extension of the care provider without the preparation to do so – a daunting task. Within the growing spectrum of families providing care for cancer patients, the subject of end-of-life care has become a catalyst for conversations among some public health experts (Rao et al., 2005; Rao, Anderson, & Smith, 2002). Stover states "end of life care has often been overlooked in public health and in traditional medical models as we struggle with health education and prevention and treatment of disease (Stover, 2002; Stover, 2002). Our focus on populations at the

earlier and middle stages of life results in a tendency to overlook the understanding of what is needed for and during the end of life."

The aforementioned interest in the subject of end-of-life care over the past five years was one of the primary factors in the creation of a concept mapping process used by the Association of State and Territorial Chronic Disease Directors (ASTCDD). From October, 2002 through September 2003, ASTCDD used concept mapping to identify specific actions that state or local health departments could take to enable others "to enhance the lives of seriously ill, injured, or dying people." They derived nine categories of actions one of which, "Patient, Family, and Caregiver Education", has relevance to public health's role in the protection of caregivers (Rao et al., 2005). The actions identified as appropriate for public health practitioners specific to caregivers at the end-of-life include:

- Encourage people to talk about end-of-life issues with their family and providers
- Make informational resources on end-of-life available in all physicians' offices, clinics, and home care agencies
- Provide educational training across chronic disease programs for family members and persons dealing with end-of-life
- Support the use of living wills, healthcare agents, family consent procedures, and organ donation.

Description of Extent of the Problem

Rao and colleagues (Rao et al., 2002) also recognize the need to examine end-of-life more closely in the context of a public health issue. They cite characteristics of

public health, borrowed from others making the case for diabetes (Glasgow, Wagner, Vinicor, Smith, & Norman, 1999; Vinicor, 1994), which include; large burden, major impact (health consequences and cost), and potential for prevention. Finlay has argued, and others have agreed, that "just as perinatal mortality is a marker of nutrition and public health as well as of perinatal services, the care of our dying is an indicator that reflects the overall quality of our care and compassion" (Finlay, 2003; D'Onofrio & Ryndes, 2003).

Likewise, government agencies have recognized the need to address the health and support needs of family caregivers. The National Cancer Institute, in collaboration with the Veterans Health Administration, recognizes the need to advance the science of informal caregiving. In preparation for the Interagency Workshop on the Science and Practice of Informal Caregiving, held on January 2, 2006, over 2 dozen research recommendations were generated among the Federal agencies that are investing in caregiving research (Unpublished planning document, contact: lindaehealth@nih.gov).

As the National Cancer Institute and other agencies prepared to build a research agenda for cancer caregiving, a set of research recommendations were drafted. Close to 30 recommendations were proposed. This study has the opportunity to contribute to 6 of the recommendations. These six recommendations purport that research on cancer caregivers is needed:

- "To target caregivers from minority, as well as economically distressed groups – to focus on variations or adaptations needed to minimize caregiver distress related to ethnic, racial, cultural, or socioeconomic diversity,

- To design and test interventions to assist cancer patients and their families to increase their preparedness to deal with the overall care process, including care acquisition, symptom control as well as indirect care,
- To develop interventions that assist the caregiver to engage in activities that promote their own health and resilience should be carried out to identify strategies of health promotion,
- To identify dimensions of the caregiver-patient relationship, characteristics of both members of the dyad and variables that affect their relationship,
- To focus research on potential positive (as opposed to negative) responses to providing care and how such positive responses may buffer the caregiver's negative reaction, and
- To broaden the scope to investigate the impact of providing care on the entire family, particularly on the secondary level caregivers.

The critical need to address the needs of family caregivers (particularly in the area of cancer end-of-life caregiving) has been described above and will be elaborated upon in the review of relevant literature section. The clarion call evidenced in this body of research gave rise to questions about the status of training and support for African American (many of whom have high mortality rates resulting from chronic diseases in general and cancer specifically, and who have been traditionally underserved or never served by education and prophylactic strategies) family caregivers of cancer patients.

Cancer is among the most psychologically distressing illnesses for the hundreds of thousands of patients who have been diagnosed with cancer and for their families (Meyerowitz, Richardson, Hudson, & Leedham, 1998). For specific subpopulations, like

African Americans and Hispanics, the combined effects of bearing a disproportionate burden of cancer, greater susceptibility to unfavorable outcomes, greater limitations on treatment and decisions that result in a prolonging of life support even at the very last moments of life, present a population for whom death from cancer is no stranger. The caregivers providing support to them at this critical phase of life are certainly to be likewise disproportionately burdened and vulnerable to the physical, mental, and psychosocial consequences of caregiving. Interventions for specific subgroups of caregivers who are caring for patients at the end of life should be viewed as a responsibility – and perhaps a priority - for public health education and health promotion practitioners in that they might serve to improve the quality to life for terminal cancer patients at the end of life, reduce the morbidity that accompanies caregiving at the end of life, and potentially reduce the costs to the health care system expended in providing aggressive life-sustaining protocols during the last days of life.

Proposed Research

The intent of this study was to examine a specific segment of the caregiving community at a specific point in the caregiving continuum - African American caregivers caring for loved ones at the end of life. In a climate where health disparities and the urgency accompanying attention to reduction of cancer disparities, very little attention is focused on the fact that cancer still claims lives and its effects remain disparate for African Americans. Given cancer's unequal burden on African Americans and the impact of caregiving on family members caring for patients, this study operated under the presupposition that lessening the burden of caregiving on African American carers of

cancer patients at the end of life could serve to reduce the increased morbidity that cancer deaths leave behind in those who cared for their loved ones at the end-of-life. Specifically, this study focused on understanding distinctions between White and Black female caregivers as such relates to the burden of caregiving and the influence of culture in their perceptions of burden. In addition, a better understanding of caregiver needs within the context of African American carers was sought.

While the construct of burden has been greatly assessed in studies of caregivers, the first phase of this study will assess burden as well as cultural reasons for serving as a caregiver to loved ones. Given the dearth of research in the specific area of African American caregivers of cancer patients, the researcher proposed, in the second phase, to conduct a qualitative inquiry consisting of in-depth interviews. In-depth interviews with African American caregivers who have assisted family members at the end-of-life were conducted in order to elicit a more thorough understanding of the constructs and behavioral contexts associated with care for members of this population.

The purpose of Phase II of the study was to gain an understanding of the issues confronting African American females caring for loved ones at the end-of-life and to place these issues in a theoretical framework. More specifically, this understanding inquiry aimed toward a theoretical elaboration that could be used to guide the development of approaches that might be useful in intervening in manner that influence attitudes, enhances self-efficacy for caregiving, and supports the adoption of behaviors that might ameliorate the deleterious effects of caregiving.

Using a mixture of quantitative and qualitative research methodologies, the study attempts to 1) examine burden (perceived and actual) and cultural justifications for

caregiving across two subpopulations of caregivers, 2) provide a theoretical elaboration of common constructs that will meet the needs of African American caregivers, and 3) map these constructs to a model developed by Pinquart and Sorensen (Pinquart & Sorensen, 2005) in order to explore specific domains including; use of resources, cultural norms, positive appraisals, and burden. This model, which is elaborated upon in the next section, evolved from a meta-analysis examining studies focusing on the influence of race, ethnicity, and culture in the caregiving experience. Theoretical elaboration is a process for refining a theory, model or concept in order to carefully specify circumstances in which it does or does not offer potential for explanation for a situation or phenomenon. This study provided an opportunity to examine a particular type of caregiver – cancer caregivers – during a particularly intense circumstance – end of life. As such, the research questions under study were:

Research Question 1:

> Does the burden of caregiving present itself consistently across racial and ethnic subgroups of females caring for loved ones dying of cancer?

Supporting Hypothesis 1:

> There is no difference in caregiver burden amongst females caring for loved ones dying of cancer with respect to race and ethnicity.

Research Question 2:

> Can cultural influences and values be used to describe any differences in racial and ethnic subgroups of caregivers?

Supporting Hypothesis 2:

There is no difference in the cultural justifications of caregiving with respect to race and ethnicity.

Research Question 3a:

Are there constructs specific to African American women caring for loved ones with terminal cancer that might support interventions aimed at changing specific caregiving related behaviors?

Research Question 3b:

If so, do these constructs align with other constructs commonly used in health behavior change?

Research Question 3c:

If not, do these constructs serve to support an explanatory model for specific caregiving behaviors?

Significance of the Proposed Research

Doswell (2002) states, "we must develop methodological and theoretical approaches that both explain ethnic and racial differences, and take into account the uniqueness of African Americans and other minority cultures." A review of research findings on end-of-life decision making among racially or ethnically diverse groups (Kwak & Haley, 2005) concluded that of 33 empirical studies in this area, one of the common methodological limitations of these studies was their lack of guidance by use of theoretical frameworks. It is hoped that through this work, we might begin to add to the body of knowledge and to better understand African American caregivers and consider theoretical constructs that can be used to develop interventions to ensure that caring for

one dying of cancer will not result in contributing to the morbidity for a population already disproportionately burdened with co-morbidities.

"Effective interventions are most likely to be those that are grounded in health education and health promotion theory. The use of theory needs to extend beyond the 'theory of the problem' and also draw on the 'theory of the intervention,' which can be used to better specify the determinants of intervention effectiveness and sustainability….the use of theory-based interventions, evaluated through appropriate designs, contributes to understanding why interventions do or do not work under particular conditions." This study proposes to act upon this challenge which is presented to the field (Rimer, Glanz, & Rasband, 2001).

The review of literature that follows will provide the evidence that supports the study rational provided in this introductory chapter. Specifically, Chapter 2 will examine the population of caregivers, the state of research in this area, constructs for caregiving already well defined, the engagement of family members as extensions of the health care provider(s), the caregiving induced morbidity, and frameworks relevant to and guiding the study.

CHAPTER TWO

Literature Review

This chapter provides the scientific and research background which supports the premise of this study. Described herein is descriptive data on end-of-life caregivers in general and information (albeit minimal because of the paucity of data) on the African American family caregiver in similar circumstances. Additionally, this chapter discusses the key elements regarding caregivers needs, attitudes about death and dying, the health related consequences of caregiving (physical and psychosocial), challenges in communicating, and the role that culture and spirituality has in caregiving. While the chapter concludes with specific information pertinent to African American caregivers each section interjects context with regard to African Americans where appropriate recognizing that the research related to this population is extremely limited.

A seminal document on end-of-life is a 1997 report by the Institute of Medicine (IOM) Committee on Care at the End of Life (Committee on Care at the End of Life, 1997). In its suggestion of areas for future study, this report recommended further exploration of different forms of social support and relationships between caregivers' experiences and social and demographic characteristics. Most relevant to this study, the Committee states that,

> *"The increasing racial and ethnic diversity in the United States has led those committed to improved end-of-life care to try to learn more about how perceptions, preferences, and behaviors vary and how communication and care strategies can respect differences in the context*

of organizational systems designed to provide reliable, excellent, and efficient care……..in addition to a strong basic science and clinical knowledge base – better support for patients and families will depend on a better understanding of the cultural, emotional, affective, and nonrational aspects of perceptions of symptoms, attitudes, behaviors and decision making."

The Population of Caregivers

In 1993, Laizner conducted a review of selected articles in an attempt to gain insight into caregiver needs when family members are the caregivers (Laizner et al., 1993). At this time they defined caregiver as an individual responsible for the majority of caregiving tasks, including emotional support and supervision of the family member with cancer. For the most part, the studies reviewed (14) revealed that the primary caregiver across the studies were mostly women caring for either a husband or a parent. Also, the average age across studies was 61 and the respondents were predominantly white. Since then, there have been a few attempts to understand the magnitude of family caregiving in the United States and to try to gain demographics of this population. In 1997, the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) released findings of a national survey (n=1509), *Family Caregiving in the US: Findings from a National Survey* (National Alliance for Caregiving & American Association of Retired Persons, 1997). In September, 2001, the National Family Caregiver Association released the results of a *Survey of Self-Identified Family Caregivers* (n=236, smaller than some of the studies examined by Laizner). The NAC

and AARP conducted another national survey in April, 2004 to attempt to discern the number of people within the US serving as caregivers and specifics about them (National Alliance for Caregiving & American Association of Retired Persons, 2004). This appears to be one of the most comprehensive reporting of the demographics of caregiving in the US. For this survey, demographic and household data were collected from a randomly selected respondent in each household contacted using a random digit dial technique. These respondents were asked if anyone in the household was a caregiver and if so that this individual assisted another with at least one activity of daily living (ADL) or instrumental activities of daily living (IADL). The survey results were weighted by demographic data (based upon gender, age, race, and household type) and the same weight was used to estimate caregiving households in the US. Using this sampling and weighting strategy, the survey found that there are 44.4 million American caregivers which equates to 21% of the adult population (over 18 years) who provide unpaid care to an adult. Using varied existing national data sets, Arno and colleagues derived a prevalence estimate a bit lower at 25.8 million – the midrange estimate for a range between 24.0 million and 27.6 million. While this is substantially lower, it represents a prevalence estimate for 1997 and while the trend for treating patients at home by informal caregivers is increasing its unlikely that the prevalence would increase from 27.6 to 44.4 in less than a decade. It is unclear, however, how the household estimate of 22.9 households presented by NAC/AAPR (National Alliance for Caregiving & American Association of Retired Persons, 2004) survey differs from Arno's estimate of 27.6 million caregivers – given the variation in data sets. Notwithstanding the uncertainty in prevalence, the *Caregiving in the US* survey findings (National Alliance for Caregiving

& American Association of Retired Persons, 2004) elucidates the following additional information on caregivers (n=1247):

- the majority of caregivers are helping relatives (83%)
- the typical caregiver is a 46 year old woman who has some college experience and is providing more than 20 hours of care each week to her mother
- nearly 4 in 10 caregivers are men
- female caregivers are providing more hours of care and they are providing a higher level of care than male caregivers
- more than a third (37%) indicate that no one else is providing unpaid assistance for the person for whom they care
- the older a caregiver is, the more likely the caregiver is to say that caregiving has made their health worse.

State of Caregiving Research

When one examines the literature on caregiving, you find that much of the research (and literature) in caregiving, end-of-life and the convergent of both topics has been done outside the US in Europe where palliative care services, in general, are more integrated into care. In fact, in the UK, two-thirds of cancer patients who die receive care from structured and formal palliative care services (Addington-Hall, 2002).

Needs of Family Caregivers

Research conducted by Given (Given et al., 2004) provides information on the needs of family caregivers at the end of life. Informal caregivers hold a number of roles

depending on the needs of the patient or loved one. People with terminal illness may eventually come to rely on others for assistance with daily activities. In a study of terminally ill patients, researchers assessed the needs and frequency of informal caregiver assistance (Emmanuel et al., 1999). Interviews were conducted with 988 terminally ill patients with cancer, heart disease, or chronic obstructive pulmonary disease to learn about the amount and type of assistance they received from their informal caregivers. Eighty-six percent of patients needed some sort of assistance. Patients needed assistance most frequently with transportation (62 percent) and homemaking tasks (55.2 percent). Almost three-quarters (72 percent) of the informal caregivers were women. Family members and friends provided most of the care for the patients in need.

Potential Health Risks of Caregivers

There is also sufficient evidence addressing impact related to the potential health risks that accompany the responsibility of caregiving. A seminal study in the examination of caregiving as a risk factor for mortality was the Caregiver Health Effects Study (CHES), a prospective population-based cohort study that tracked caregivers from 1993 through 1998 with an average of 4.5 years of follow-up (Schulz & Beach, 1999). The study aimed at examining relationships between caregiving demands among spousal caregiver between 66 and 96 years of age (mean = 79.6) and 4-year all-cause mortality. A total of 392 caregivers and 427 noncaregivers (controls) living with and caring for their spouses were studied. The 819 participants enrolled in the study were matched for age and gender. At the end of 4 years, the study found mortality risks for participants who were providing care and experiencing caregiver strain were 63% higher than those whose

spouse was not disabled (RR, 1.63; 95% CI, 1.00-2.65). Similarly, older participants, males, African Americans and those with at least 1 prevalent disease at baseline had higher 4-year mortality rates (Schulz & Beach, 1999). Thirty three percent (33%) of the study's sample who were strained caregivers with prevalent disease died within the 4-year follow-up period. Additional health related indicators and outcomes from the cohort had been previously studied (Schulz et al., 1977). Findings revealed that strained caregivers compared with noncaregiving controls had significantly higher levels of depressive symptoms, higher levels of anxiety, and lower levels of perceived health. They also reported less time for exercise, adequate rest or self-care when sick. This CHES documents a need to evaluate older married couples as one unit and assess how the demands of caregiving may impact the mortality given the vulnerabilities that exist (Schulz et al., 1977).

Wallsten had similar findings in a similarly designed longitudinal study of 234 older couples (118 spousal caregivers and 116 comparison couples). She concluded that spousal older caregivers are in poorer physical health than noncaregivers but have no greater numbers of social supports to assist in the caregiving role. African Americans were in poorer physical health than Whites and still possessed no greater numbers of social support than White caregivers (Wallsten, 2000).

Public Health Implications

The information above is believe sufficient enough to render caregiving as meeting the public health criteria for large burden and impact (as such relates to health consequences). To further substantiate the burden and the impact, several have attempted

to examine the cost associated with caregiving. In addition to understanding the national prevalence of informal caregiving, Arno also set out to determine the economic value of informal caregiving using several existing national data sets (Arno, Levine, & Memmott, 1999). This was done by determining the reasonable market wage that would have to be paid to replace informal caregiving and the average number of caregiving hours. There were several inconsistent estimates of hours in published studies but the estimate from the above mentioned NAC/AARP survey was utilized (17.9 hours per week) because it was the most conservative estimate. Using this average weekly figure along with the number of estimated caregivers, approximately 24 billion hours of caregiving is performed each year nationwide. Using these figures, Arno estimates the economic value of informal caregiving in 1997 was $197 billion. This amount is not included in calculations of national health care spending another $200 billion would need to be added to that figure of a trillion dollars (Arno et al., 1999).

What's most important in examining the economics of caregiving is that the provision of informal caregiving significantly reduces (although not well accounted for) the cost of providing care at the end-of-life. The Medicare Payment Advisory Commission (MedPAC) reports that a quarter of the total Medicare budget is spent on services for beneficiaries in their last year of life (Hogan et al., 2000). Moreover, of that spent in the last year of life, 40% of it goes toward the last month of life (Lubitz & Riley, 1993). When deaths occur in hospitals, the cost for Medicare beneficiaries were twice (in 1993 – expect much higher now given costs of advanced life-prolonging protocols) those for beneficiaries who died outside of the hospital setting (Saphir, 1999). There have been some increases in use of hospice by Medicare beneficiaries and the primary diagnosis of

63% of hospice users is cancer. It's also estimated that 45% of all cancer patients use hospice (Hogan et al., 2000). For all cancer, however, African Americans are least likely to receive hospice care (virnig, McBean, & Dholakia, 2002). When examining hospice use, Virnig expected to see higher rates of hospice use and longer stay among those whose earlier treatments of cancer may not have been successful (virnig, McBean, & Dholakia, 2002). However, hospice use and length of stay were relatively consistent across cancers, which is purportedly due to the clinical uncertainty for end-stage cancer patients. While on the surface it may seem that increasing cancer patients' use of hospice and the duration of hospice stay could save in health care costs, such may not be as expected. In an examination of studies examining use of hospice and advance directives, Emanuel concludes that "existing data suggests that hospice and advance directives can save between 25% and 40% of health care costs during the last month of life, with savings decreasing to 10% to 17% over the last 6 months of life and decreasing further to 0% to 10% over the last year of life (Emanuel, 1996)." While not what is touted by advocates for increasing hospice use, use of hospice and advance directives should still be encouraged because it addresses improved quality of life at end of life and is more likely to assure that patients are able to exercise autonomy over end-of-life decisions.

This factor of quality of life and health promotion at the end-of-life is consistent with the aims of public health practice. D'Onofrio and Ryndes (D'Onofrio & Ryndes, 2003) make a case for improving access to end-of-life care (hospice) as the practice of responsible public health practice. In its protection of those most at risk of injury, disease and negative health consequences, and the attention given to women and children during the vulnerabilities of pregnancy, birth, and the beginning stages of life, public health has

"largely ignored the heightened needs, dependency, and increased vulnerability of people at the other end of life." More specifically, they describe public health's role at the end of life is to support the values of hospice by promoting the health of people at the end of life which is realized in the "relief of pain and suffering, maintenance of an individual's functional abilities and social relationships to the extent possible, reflections on the meaning of life, peaceful life closure, and support for grieving family members."

As for whether the large burden caused by caregiving and the major impact it yields has a potential for prevention, the evidence is evolving. Intervention development has not reached levels commensurate with the need. The need, however, can better be met with greater understanding of the problem and of constructs that lead to theory-building that can be applied to intervention development.

Caregivers' Health and Well Being

For most, there seem to be strong preferences for dying at home. In a small qualitative prospective exploratory study of end-of-life caregivers, Wennman-Larsen and Tishelman (Wennman-Larsen & Tishelman, 2002) found that some of the caregivers in their study did not "experience a real choice" in taking on their role in caregiver. Others stated that they accepted the role in order to comply with the desires of their loved ones to die at home. Still others stated that the existing in-hospital alternatives to dying at home were simply not acceptable. All in all, they were all in agreement that there were more benefits for their relatives to be able to die at home. Most blacks, however, either have passed through a hospital just before death or die in a hospital. As such, "going to

the hospital" has come to signify dying for many middle and lower-income blacks (Perry, 1993).

The health and well-being of the caregiver is critical for patients being cared for at home (Ramirez, Addington-Hall, & Richards, 1998). Unlike other types of caregivers, the role of family caregivers at the end of life and the demands it brings are also accompanied by the distress of a negative end with the sick loved one's death or deterioration. Informal caregivers, particularly those whose loved ones are terminal, are not likely to express their own needs and it is unlikely that health care professionals will perceive them as clients or potential recipients of care services (Northouse & Peters-Golden, 1993; Northouse, Mood, Templin, Mellon, & George, 2000). Caregivers of patients at the end of life experience high levels of psychological distress (Higginson, Wade, & McCarthy, 1990), overwhelming anxiety (Higginson, Hodgson, McDonnell, & Butters, 1997), and low marital satisfaction (Toseland, Blanchard, & McCallion, 1995).

In a qualitative study of 18 caregivers (thirteen white European, four Asian, and one Black) in London, Harding and Higginson (Harding & Higginson, 2001) found ambivalence to be a theme that mediated caregivers actions toward accessing support. This ambivalence translated to forsaking self identify in order to assume the duty and role of caretaker, willingly undertaking the role of caregiving with full awareness that such will either postpone or eliminate other life opportunities, and failing to view oneself as a service recipient. In defining ambivalence, Harding and Higginson (Harding & Higginson, 2001) used definitions from Braverman (Braverman, 1987)and (Billig et al., 1988) which are "simultaneous attraction to and repulsion from an action, inhibiting individuals who experience it from making decisions and taking action (Braverman,

1987)," and dilemmas in everyday life that cause individuals to have to carefully consider and balance the gains and losses between options (Billig et al., 1988).

For women of color, the role of caretaker affects their health in a host of ways including increasing physical and mental stress (Stover, 2002). Self-care or thoughts toward self-care are difficult for a caregiver (Rainer & McMurry, 2002; Harding & Higginson, 2001). Schultz, Newsome, Mittelmark, Burton, Hirsch and Jackson (Schulz, Newson, & Jackson, 1997) conducted a case control study of 400 caregivers and 400 controls matched for age and gender. They found that caregivers reported lower levels of perceived health and more depressive and anxiety symptoms. In addition, they were more likely to get insufficient amounts of rest (9.29; 4.96, 17.40), no time to exercise (5.02; 2.98, 8.45), and no time to rest when they were not feeling well (10.09; 4.16, 24.49).

As part of the Caregiver Health Effect Study (CHES), Schulz and colleagues (Schulz et al., 2001) showed that following the death of a spouse, caregivers' health status actually improved significantly. Measures were taken pre-bereavement and post bereavement (symptoms of depression, change in antidepressant medication use, health risk behaviors, or weight). What is surprising is that spouses who did not serve as caregivers (measured by spouse's having a need for assistance in at least 1 activity of daily living) fare significantly worse in the measured outcomes that either caregivers or strained caregivers. This finding suggests that there might be some protective factors associated with serving as a caregiver in some capacity. They also suggest that "the most vulnerable caregivers may not have been represented in the bereaved samples of CHES because they did not outlive their spouses."

Educational efforts should focus on increasing the caregiver's awareness of personal limitations and the procurement of additional support. Specifically, caregivers should be advised to eat well, exercise regularly, obtain adequate sleep, and be attentive to their fluctuating emotional states (Rainer & McMurry, 2002).

Perceptions Surrounding End-of-Life

The research on attitudes relating to death, dying and end-of –life is mounting. More and more studies are exploring the idea of the "good death" and how to enhance quality of life in its final days. In fact, the aim of palliative care is to provide symptom management and control and ultimately yield the most favorable environment preceding death. Vig and colleagues (Vig, Davenport, & Pearlman, 2002) studied older adults with medical illnesses to gain information about their attitudes toward end of life. This small qualitative study (N=16) generated themes around good deaths and bad deaths. "Good" deaths were quick, like heart attacks while death from cancer was deemed a "bad" death.

A 1999 cross sectional, stratified random national survey was conducted to determine factors considered important at the end of life (Steinhauser et al., 2002). The study involved a 26 item questionnaire of 340 seriously ill patients, 332 recently bereaved family members, 361 physicians and 429 other care providers including social workers, nurses, chaplains, and hospice volunteers. Participants rated the importance of each of 44 attributes on a 5 point scale from strongly disagree to strongly agree. The analysis reported seven attributes that were consistently rated important among patients (>70%) but were significantly less important to physicians (P<.001). These seven attributes included; 1) being mentally aware, 2) having funeral arrangements planned, 3) feeling

that one's life was complete, 4) not being a burden to family or society, 5) being able to help others, 6) coming to peace with God, and 7) praying. These attributes remained consistent after Steinhauser and colleagues (Steinhauser et al., 2002) conducted multivariate analyses which controlled for gender, race/ethnicity, socioeconomic status, household composition, religion and religiosity. Of further interest in this study, among patients and family members, women were significantly more likely to agree with talking about the meaning of death (OR, 2.0; 95% CI, 1.3-2.5). Also of note, dying at home was seen as the least important attribute of all groups except other care providers, who rated it second to last in importance. Importance, however, does not mean that the topic is openly discussed. Addressing these factors of importance begins with effective communications. Unfortunately, communications surrounding issues of death, dying and end-of-life are not without challenges.

Communication at End of Life

Communication between patients, families, and health professionals becomes particularly important during the death and dying process, but such discussions are perhaps best begun early in a person's treatment. Interviews with 43 primary care physicians and 47 ambulatory care outpatients showed that patients preferred to have discussions with their doctors about their end-of-life care early in the course of their disease, when they felt more competent to make decisions and indicate their preferences (Pfeifer et al., 1994). They generally felt that these discussions should remain strictly part of the doctor-patient relationship, without input from the family. The physicians were more concerned that having these discussions early could damage their patients'

hope for a positive treatment outcome. The physicians also identified their roles at the end of life as lifesaver, neutral scientist, guide, counselor, and intimate confidant. Family caregivers of cancer patients frequently do not have access to information and support on end-of-life issues. Awareness of the fact that their family member is dying is a gradual process for them (Yates & Stetz, 1999). While one could not argue that favorable communications relating to any health matter is important, at the end-of-life, such is paramount.

One area that has been widely studied with regard to communications at the end of life is the practice of preparing advanced directives. The conundrum is that while most people endorse living wills, few actually complete them. Fagerlin and colleagues (Fagerlin, Ditto, Hawkins, Schneider, & Smucker, 2002) rationalize this phenomenon by considering the act of completing a living will as a preventive health behavior. From this perspective, they suggest that the health belief model (Rosenstock, 1974) and more specifically the construct of perceived susceptibility within this model as a contributing factor to the failure to complete living wills. The fear of serious illness or lingering death prevents people from accepting susceptibility for such and from considering the need for a living will. In addition, research seems to indicate that disease severity does not impact "readiness" of patients or family members to discuss or consider end-of-life related matters (Pfeifer, Mitchell, & Chamberlain, 2003). Living wills and the communication associated with creating and conveying them could improve end-of-life decision making. Most people, however, do not complete them. In order for [older] adults to obtain optimal quality of life at the end of life, it is recommended that those caring for them should be aware of and understand their values and wishes and be able to assure that care is

reflective of such (Vig et al., 2002). Living wills and advanced directives provide caregivers with the greatest insight into the dying person's end-of-life wishes (Rainer & McMurry, 2002). African Americans, like most others, are supportive of advanced directives. Yet, African Americans are least likely to have advanced directives (Caralis et al., 1999; Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991).

As the end of life approaches, communications between family members becomes particularly difficult. In an early study, Krant and Johnson (Krant & Johnston, 1977) reported that 92% of family members considered the possibility of the patient's dying, but most (78%) had never discussed this possibility with the patient. In a cross sectional cohort study with a sample of 193 persons over the age of 60 and seriously ill with cancer and other chronic diseases like congestive heart failure and COPD and their caregivers, Fried, Bailey and Towle (Fried, Bradley, & Towle, 2003) found that there was significant disagreement between patients and their caregivers with respect to degree of physical or cognitive impairment (k=1.10 – 0.25) and severe pain of other symptoms (k=0.20 – 0.28). They conclude that the decisions made by surrogates (caregivers) may not be effectively representing the preferences of the patient (Fried et al., 2003). Current evidence points to an agreement that patient-caregiver communications are fraught with discord. It's been said that, "it is [still] not clear why or how cancer erodes patient-caregiver congruence. Psychological processes that are associated with family communication under cancer strain remain largely unexplained…..it is imperative to investigate the preconceptions and thought processes that are harbored by cancer patients and family members internally (Zhang & Siminoff, 2003)." Phase II of the study will attempt to do so.

In a study cancer patients with late stage lung cancer that was conducted over a 12-month period during 2000, Zhang and Siminoff (Zhang & Siminoff, 2003) identified three psychological processes that contributed the "phenomenon of silence"; psychological distress, mutual protection, and positive thinking. Psychological distress relates to the tremendous amount of cancer-related fear and anguish and the degree of affect and difficulty associated with talking about cancer. Mutual protection is defined by the desire of both patients and family members to protect each other from being exposed to a harmful situation. Positive thinking equates to beliefs that positive thinking and optimism are helpful and perhaps curative. Participants believed that positive thinking not only provided strength to cope with hardship but also caused tumors to shrink and kill cancer cells.

In a study of more than 1300 cancer patients treated by palliative care teams based in facilities in the United Kingdom, Ireland and Italy, Higginson and Costantini (Higginson & Costantini, 2002) found that even with palliative care team input, one or two of every ten patients still experienced problematic communication. They considered communication across three specific domains affecting quality of life for cancer patients and families. These domains included; communication between patient and family, communication between professionals, and communication between patient and family and health professionals. The single factor that was associated with all three domains was problems related to spiritual issues which they defined as a reflection of a crisis in belief. "Hope and spiritual peace cannot be imparted from one person to another, but springs from within an individual. For hope to flourish, honesty must be present in an environment that can hold any possibility. Such an honest environment is fostered

through basic principles of communication (Rainer & McMurry, 2002)." African Americans and members of other medically underserved minority groups may view palliative care as "giving up hope" (Payne, 2000).

"Culture influences everything and everyone in the end-of-life scenario – the decisions considered and the care offered and received by the dying person and her or his loved ones as well as the health and mental health care provider (Hallenbeck, Goldstein, & Mebane, 1996; Werth, Blevins, Toussaint, & Durham, 2002)." The decision making practices used today in end-of-life discussions are based upon the Western concepts that privilege the individual, individual choice (Koenig, 1997), and self-determination rather than to emphasize the collective decision making often common in non-Western cultures (Blackhall, Murphy, Frank, Michel, & Azen.S., 1995; Hallenbeck et al., 1996).

Constructs Related to Caregiving

The Burden and Stressors of Caregiving

Caregiver burden is defined by Givens and colleagues (Given et al., 2001) as "the distress that caregivers feel as a result of providing care." This distress has the potential to exacerbate and become detrimental to health status. An IOM Committee on Care at the End of Life (Committee on Care at the End of Life, 1997) argued that caring for dying patients can be personally rewarding and intellectually challenging. Often patients at the end of life reach a point where they are no longer able to take an active role in decision making about their care (Pantilat, 2002) thus leaving difficult, stress-inducing treatment decisions to those closest to them. In facing the death of a loved one, families

cope with grief, sadness, anxiety, guilt, anger, and other psychological issues (Pantilat, 2002).

Caregiving burden may change over time, resulting in physical and emotional exhaustion for caregivers. One study measured the success of a Family Caregiver Cancer Education Program intended to provide education and support for informal caregivers of homebound cancer patients (Pasacreta, Barg, Nuamah, & McCorkle, 2000). In the study, 187 cancer caregivers participated in three 2-hour group sessions. Participants completed surveys before and 4 months after the intervention. The researchers found that perceptions of burden did not change as a result of the psychoeducation program, even when the intensity of caregiving tasks increased. More men withdrew from the program than women. The study found a positive relationship between the numbers of hours spent caring for the loved one, and the amount of stress experienced by the caregiver. Furthermore, prolonged caregiving was found to diminish the physical and emotional health of the caregivers.

In the National Alliance for Caregiving survey previously discussed, respondents were asked, "what the main problem or illness your [care recipient] has/had?" 8% responded with cancer. When assessing level of care on a 5 point scale, a Level of Burden Index was used. This index is derived from the ADSs, IADLs, and the amount of time devoted to caregiving. This measure along with having a choice to take on caregiving responsibilities and caregiver's reported health status has the largest influence on whether emotional stress, physical strain and financial hardship on the caregiver. Levels of Burden within this sample were; 33% at level 1, 17% at level 2, 15% at level 3, 21% at level 4, and 10% at level 5. Level 4 and level 5 caregivers were more likely to

say they were caring for someone who has cancer. Thirty-five percent of level 5 caregivers reported fair or poor health. The survey further recognized that African Americans caregivers are more likely to experience financial hardship as a result of being a caregiver (22% compared to 10% for whites, 14% for Hispanics, and 11% for Asians), more likely to have children under 18 years of age living in their household (53% compared to 35% for whites, 39% for Hispanics, and 34% for Asians), more likely to be single, never married (32% compared to 14% for whites and 23% for Hispanics), and more likely to work while serving as a caregiver (68% compared to 56% for whites). The majority of caregivers claim to cope with caregiving by praying. However, African Americans are most likely (84%) to use prayer as a coping strategy (79% Hispanic, 71% whites, and 50% Asian). (National Alliance for Caregiving & American Association of Retired Persons, 1997).

The psychosocial status of informal caregivers may change while caring for their loved ones. In a study of 161 cancer patients and their caregivers during the 6 months following surgery, the caregiver's psychological status was measured immediately following release of the patient from the hospital, at 3 months, and at 6 months post surgery (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999). Over a 4-week period shortly following release, the caregivers in the intervention group received a nursing intervention, which included 3 home visits, and 6 telephone calls from nursing staff. Caregiver psychosocial status was assessed using 6 outcome variables: esteem, lack of family support, effect on schedule, effect on finances, effect on physical health, and depression. No differences were found in the psychosocial status of the intervention caregivers as compared to the control-group caregivers. Caregivers in the intervention

group with physical problems of their own experienced results opposite to that of the control group caregivers. Some important factors to consider in providing patient care in the home include the psychosocial and physical condition of the caregiver.

Eva Grunfeld and colleagues (Grunfeld et al., 2004) utilized cancer centers in Ontario to conduct a longitudinal study of 89 caregivers of women with advanced breast cancer. Patients identified a principal caregiver and followed them until their death or for 3 years. Assessments of caregiver health status were conducted every three months of the study using validated instruments (SF-36, Kanofsky Performance Status – KFS index) then every two weeks once the patients was deemed terminal. End-of-life decisions are often made by family members or in a family context (Haley et al., 2002). Rainer and McMurry (Rainer & McMurry, 2002) suggest that caregivers bear an overwhelming responsibility for decision making which requires extraordinary measures. The magnitude of this responsibility warrants educating caregivers and providing them with options for selecting respectful, responsive and supportive care for the dying loved ones. When patients fail to provide a living will, verbal instructions, or health care agent through a durable power of attorney, the tasks typically falls upon the person whom the patient has named as their next of kin. It is then that the role of the family member (or next of kin) becomes utmost in importance – even more important than the patient may have realized when initially identifying the individual (Mozdzierz, Greenblatt, Piro, & Thomasma, 2002).

Keefe and colleagues (Keefe et al., 2002) conducted correlational analyses to examine caregivers' ratings of self-efficacy related to caregiver strain, positive mood, and negative mood. They found that there were negative associations between caregiver self-

efficacy in pain management and caregiver strain and caregiver negative mood. In other words, caregivers who scored higher self-efficacy in management of their loved one's pain were much more likely to report lower levels of caregiver strain and negative mood and higher levels of positive mood. Even when controlling for patient physical well-being, partial correlations between caregiver self-efficacy and positive mood continued to be significant ($r=0.31$, $P<0.05$). What is probably most significant in the Keefe study (Keefe et al., 2002) is that most of the caregivers rated themselves in the moderate to low range for patient pain management. These caregivers may be at risk for developing psychosocial distress as patient's pain and patient's decline in functioning due to pain. One conclusion of the study is that interventions targeted at increasing self-efficacy for pain management could be beneficial for caregivers as well as patients and that if high levels of self-efficacy in management could be maintained it is possible that a higher quality of life for patients and even for caregiver could also be maintained.

Given and colleagues (Given et al., 2004)set out to understand how we might be able to predict caregiver burden and depression by measuring levels of depression (using the Center for Epidemiological Studies – Depression Scale, CES-D) and burden (using subscales of the Caregiver Reaction Assessment, CRA). Givens found that as the number of patient symptoms increases so did the measures of depression in the caregiver. The majority of caregivers reported seven or more patient symptoms and scored higher than sixteen (16) on the depression measure which were at risk for clinical depression on the CES-D scale. Burden –assessment of one's schedule and sense of abandonment – similarly increased with patient symptoms, which is logical in that increasing symptoms led to greater impact on schedule. Interestingly, Given and colleagues found that in the

time prior to patient death, spouses were less depressed than adult children or nonspouse caregivers. Likewise, spouses reported virtually no sense of abandonment. The study team do question the generalizability of these results given that the majority of the sample consisted of women (84%) older than 55 (73%) and only 33% of the sample were nonspouses.

Definitions

There are a few terms, which will be utilized throughout the study that warrant defining. These terms have been defined in varying ways in the literature and it is important to establish their operational definition within the parameters of this particular study. Such terms include:

Activities of daily living — activities related to personal care and include bathing or showering, dressing, getting in or out of bed or a chair, using the toilet or eating. (NCHS)

Caregiver (primary) – an individual responsible for the majority of caregiving tasks, including emotional support and supervision of the family member with cancer (Laizner, Shegda Yost, Barg, & McCorkle, 1993)

Caregiver Burden – the distress that caregivers feel as a result of providing care (Given, Given, & Kozachik, 2001).

Cultural Justifications – cultural reasons why families provide care to relatives that may be based upon their cultural influences (Dilworth-Anderson, Goodwin, & Williams, 2004).

Ambivalence - forsaking self identify in order to assume the duty and role of caretaker, willingly undertaking the role of caregiving with full awareness that such will either

postpone or eliminate other life opportunities, and failing to view oneself as a service recipient (Harding & Higginson, 2001).

Instrumental activities of daily living – activities related to independent living and include preparing meals, managing money, shopping for groceries, or personal items, performing light or heavy housekeeping and using a telephone (NCHS).

Importance of Understanding Culture

"Very sick and dying patients in our society are often dependent upon care from people of very different cultural backgrounds, making misunderstanding and conflict common (Hallenbeck, 2002)." While having a loved one to intercede may provide the patient with a voice from a similar cultural disposition, it potentially renders the family caregiver as the vehicle through which misunderstanding and conflict evolves (Ross H., 2001).

"End of life issues are ingrained with cultural identity and affiliation (Ross H., 2001)." Learning what death means for a patient and a family is an essential part of becoming a culturally competent health care worker (Ross H., 2001). By understanding what is and is not acceptable to a family or individual, end of life care can be vastly improved (Ross H., 2001). "Failure to take culture seriously means that we elevate our own values and fail to understand the value systems held by those of different backgrounds" (Kagawa-Singer & Blackhall, 2001). Things that health professionals might consider when dealing with patients and families from ethnically, religiously, or racially diverse backgrounds include (Ross H., 2001):

- Being aware of family dynamics when discussing medical care choices
- Building trust
- Establishing effective communication
- Providing culturally appropriate publications and information

What and how death is conveyed and the locus of decision making at such a time are important issues influenced by a patient's background and experiences (Pantilat, 2002).

The influence of culture in the meaning and experience of death and dying applies to several domains associated with end-of-life care, such as symptom management, advance-care planning, and grief and bereavement counseling (Crawley.L.M., Marshall, Lo, & Koenig, 2002). Several suggest that African Americans along with Latinos and Asians, view death and suffering as natural and integral aspects of life and in so doing may be less inclined to "fight" cancer (Kagawa-Singer, 1987; Mathews, Lannin, & Mitchell, 1994). In qualitative interviews with 26 rural southern African American women with breast cancer, Mathews and colleagues (Mathews et al., 1994) found that fatalistic views and distrust of physicians led to difficulties in adjustment.

Koenig and Gates-Williams (Koenig & Gates-Williams, 1995) suggest a mnemonic for use by professionals in ascertaining levels of cultural influences at the end-of-life. The mnemonic, ABCDE, represents aspects of a physician/caregiver or family member dialogue by evaluating families' attitudes, beliefs, context, decision making, and environment (ABCDE). In fact, they surmise that a provider's reflection on the ways that culture may shape the world of the patient and family also invites a self-reflection about the providers own biases, values, beliefs and practices.

Regardless to patient's age, families in many non-Western cultures generally prefer to receive medical information about patient's status first then determine what should be shared with the patient (Blackhall et al., 1995). This seems in keeping with another non-Western value which is that many value the welfare of the group over that of the individual and as such, decisions are often made by consensus (Kagawa-Singer, 1998). For all cultures, the family has a vital role in decision making as it relates to the care of the patient. However, the unknown as suggested by Kawaga-Singer and Blackhall (Kagawa-Singer & Blackhall, 2001), is whether the family members support the patient in making his or her own decisions or do they express their love by taking upon themselves the burden [and stressors] of decision making.

The role of professionals in providing greater support to families experiencing the death of a loved one to cancer is well documented. This has been discussed in support of familial communications as well as the cultural context of these experiences. At the end-of-life, patients should be assessed within the context of their family or other key social support systems. In addition, it is helpful for practitioners to possess a general knowledge about the theoretical differences toward end-of-life among groups of patients (Koenig & Gates-Williams, 1995). Others suggest that optimal end of life care results when health professionals 1) ensure desired physical comfort and emotional support, 2) share decision making, 3) are respectful of patient interchanges, 4) support family members by providing information and emotional support, and 5) coordinate care across healthcare service domains (Teno et al., 2004).

Spirituality

While not well defined, the relevance of spirituality and issues that are spiritual in nature are well documented in the literature. The weakness of the definition of spirituality undermines its utility as a construct in end-of-life care. As such, Kaut (Kaut, 2002) set out to provide a 'bio-psychosocial framework for assessing spirituality near the end of life. The interesting aspect of his explorations of definitions for spirituality is that most have little or no correlations with one's religion or religiosity. In fact, Kaut (Kaut, 2002) states that "spirituality can be conceptualized as a dimension of personhood defining the essence of humanity." Moreover, with respect to end of life, he avowed that "the dying person's own definition of spirituality may be less philosophically articulated, founded rather on historical tenets, culturally transmitted values, social influences, and personal introspection" and is likely to be expressed "in observable attitudes, beliefs and behaviors." The key in understanding spirituality as a construct for people at the end of life is to be able to recognize individuals' socio-cultural context (Kagawa-Singer & Blackhall, 2001).

A traditional definition of spirituality is "a basic or inherent quality in all humans that involves a belief in something greater than the self and a faith that positively affirms life (Miller, 1995). Spirituality and the cultural value of caring for one's own may be one of the most important reasons for African Americans assuming the role of family caregiver (Nkongho & Archbold, 1995) and reluctantly pursuing support from outside the family. In a relatively small qualitative inquiry (6 focus groups), Shrank and colleagues (Shrank et al., 2005) found that African American groups (2) overwhelmingly preferred having a spiritual leader participate in end-of-life discussions while white groups were

divided on the topic. Furthermore, they found that the importance of spirituality was the most consistent theme in the African American groups.

Recalling the Steinhauser study mentioned previously (Steinhauser et al., 2002), terminal patients highly valued and gave attention to issues of spirituality. In fact, "coming to peace with God," and pain control were nearly identical in importance for patients and bereaved family members.

African American and Hispanic women describe themselves as Christians and embrace Christian notions of spirituality (Musgrave, Allen, & Allen, 2002). Turner (Turner, 1993) describes death for African Americans as a bridge leading to a better place at which one arrives through death. Indeed, funerals are typically referred to as "home-going services" in the African American community. Turner further explains that the family, the community, and the church are all involved in death education. Children are included in almost every aspect of the dying, death and grieving processes. He urges professional practitioners not to assume anything when dealing with families of dying African American patients. Rather, he suggests that they ask the family what it wants and needs then leave them alone (not hovering over them) to decide what is right for them (Turner, 1993).

When confronted with challenges to their health or well-being, religiosity and spirituality are beneficial characteristics for women of color (Musgrave et al., 2002). Picot and colleagues (Picot, Debanne, Mamazi, & Wykle, 1997) found that African American caregivers (many, if not most of whom are female) scored significantly higher on "seeing God as a source of help" on measures of prayer and comfort from religion. Religiosity as a construct is believed to vary when applied by different groups.

Purportedly, the relationship between religiosity and self-mastery differ between Black and Whites. Picot and colleagues (Picot et al., 1997) explain that African Americans are theologically instructed to totally depend upon a Supreme Being – "taking their burdens to the Lord and leaving them there." White theology, in contrast, teaches that in difficult situations one should independently (individually) problem-solve.

Picot and colleagues (Picot et al., 1997) hypothesize that religiosity may be a moderating variable for stress in that when caregiver resources such as religiosity are high, the effects of stress will be lessened and caregivers will claim greater rewards associated with the role of caregiving.

The spiritual context prescribed to by African Americans at end of life may be a most resilient culturally factor. Perry (Perry, 1993) recognizes similarities between African American customs of death to those of West Africa. Funerals in the African American tradition are typically less formal and more emotional than death rituals of whites (Perry, 1993).

Specific Subgroups of Informal Caregivers

Spouses and Family Members As Carers

According to Given, Given and Kozachik (Given et al., 2001), spouses purportedly spend substantially a greater number of hours per week in the caregiving role than an adult child (Montgomery & Kosloski, 1994). This role is not without a toll. Teel and Press (Teel & Press, 1999) found that spouses reported more fatigue, less energy, and greater difficulties sleeping than nonspousal caregivers. Given that the traditional roles in home health care are typically aligned with women, there is some agreement that these

roles are more normatively expected and more encompassing than the traditional gender role of men. As such, women or wives are likely to experience burden equal to that of husbands (Given et al., 2001). High found in 1988 (High, 1988)and Hopp (Hopp, 2000) later confirmed that married patients identified their spouse as the first choice for surrogate decision making regardless of the presence or absence of living children. In this same national study, only when there were no living children were others appointed as surrogates and these others consisted of health professionals or attorneys.

Differences in household structures may also account for difference in types of caregivers for the terminally ill. In a review of family structures and their relationship to informal caregiving, Peek and colleagues (Peek, Coward, & Peek, 2000) document that difference by race in family and household structure may account for higher likelihood of specific family members serving as informal caregivers. When compared to older Whites, older African Americans are more likely to be cared for by adult children abiding in the same household and less likely to have a marital partner (Peek et al., 2000). Other factors contributing to such difference include:

- African Americans having larger numbers of children (Hofferth, 1984)
- Increased presence of extended family members (including adult children) in African American households
- Greater prevalence of multigenerational households (Coward, Lee, Netzer, Cutler, & Danigelis, 1996)

Using logistic regression, Peek and colleagues (2000) were able to build models estimating the effects of race, demographics and household and family structure variables

on the receipt of care from children. In their first model, gender, age, and education were significantly associated with receipt of care from an adult child. In addition, being female and older was associated with increased likelihood of having an adult child in the role of informal caregiver. Conversely, higher educational levels were associated with a decrease in likelihood of receipt of care from a child.

Maintaining a stable family environment presents a challenge when the death of one of the members encroaches. Such an event "gives rise to a loss of rhythm and constancy" of the family system. All too often, families respond to the discord associated with the prevailing death experience with an abnormal response to an abnormal situation -- or with craziness (Rainer & McMurry, 2002).

Cancer, African Americans & Caregiving

While expanding the study of caregivers and developing interventions aimed at relieving caregiver burden, and increasing support of the services provided by informal/family caregivers has great value, there is ample merit in focusing on the specific needs and understanding how to intervene on the needs of African American caregivers providing care for cancer patients at the end of life. African Americans in the US still bear a disproportionate burden of cancer. African Americans have the highest mortality rates for all cancer combined as well as for many of the major cancers (American Cancer Society, 2005). Of the approximately 1.4 million new cases of invasive cancer in 2005, African Americans will account for a disproportionate number of these (Jemel et al., 2005). While progress has been made and decreases in incidence and mortality are seen for some types of cancers, the incidence rates for African

American men have increased by 20% and the mortality rates by 40% for all cancers combined. In 2005, 137,910 new cases of cancer are expected to be diagnosed in African Americans. A higher proportion of these diagnoses will be advanced staged cancers as opposed to those cancers diagnosed in other populations. This figure is also increased from previous years. This, however, reflects a growth in the population and an increase in the aging population (Ghafoor et al., 2002). Improvements have been realized in the five year survival rate among African Americans – from approximately 27% in 1960-1963 to 55% in 1995-2000 (American Cancer Society, 2005). Even still, African Americans are less likely to survive five years after diagnosis than whites for all cancer sites. This is likely due to poverty which limits access to medical care, diagnosis at later stages when the disease has spread (Ghafoor et al., 2002) and disparities in treatment (Shavers & Brown, 2002).

Research has shown that African-Americans, particularly those in inner cities, have higher death rates due to cancer. A study of cancer patients treated between 1973 and 1992 at Harlem Hospital (n=615) showed a survival rate of 19.7 percent, which was substantially lower than the national average for the same period (Freeman & Alshafie, 2002). Death due to colorectal cancer was particularly high in the sample, despite the fact that the national rate had greatly declined. The authors' explanation for the higher death rate was similar to that given above which was due to the presentation at a late stage as well as the combined effects of poverty, lack of education, and lack of access to health care resources (Freeman & Alshafie, 2002).

A study of the rate of surgical resection for patients with non-small cell lung cancer found that African-Americans are less likely to receive surgical treatment than

Caucasians and are likely to die sooner than Caucasians (Bach, Crainer, Warren, & Begg, 1999). The study also found that the survival rate for those who had the surgery was the same, regardless of race, as it was among those who did not undergo surgery. Bach and colleagues concluded that the lower survival rate among African-Americans with non-small cell lung cancer, compared with Caucasians, is largely explained by the lower rate of surgical treatment (Bach et al., 1999).

In addition to unfavorable outcomes from cancer, research has indicated that many African-Americans want aggressive treatment (Mouton, 1997; McKinley, Garrett, Evans, & Danis, 1996). One study comparing differences between African-American (n=92) and Caucasian (n=114) cancer patients in North Carolina found that the African-American patients wanted more life-sustaining treatments and were less likely to want a living will than the Caucasian patients (McKinley et al., 1996). The researchers concluded that the two ethnic groups simply make different choices about end-of-life care. The prevailing thought, however, as we will see in Chapter 2, is that such differences are due to African Americans' lack of trust in the medical care system.

An important public health matter to consider is the cost effectiveness of providing costly and futile end-of-life treatment for the sole purpose of granting the desires of family caregivers. Survey research to examine the advanced care planning and end-of life decisions of 540 relatives of persons who died reveals significant racial variations (Hopp & Duffy.S.A., 2000). In the study which included 454 whites and 86 blacks, blacks were more likely to make treatment decisions that were based on the desire to provide all possible care in prolonging the life of their loved one (P=.013). Whites, in contrast, were more likely to discuss treatment preferences with patient before death

(P=.034), to complete living wills (P=.001), and to designate a Durable Power of Attorney for HealthCare (P=0.32). Phipps and colleagues (Phipps et al., 2003) had similar findings in a study of 68 patient/caregiver dyads. Most interesting, however, in the Cultural Variations Study (Phipps et al., 2003), Phipps and colleagues found that patients and caregivers often disagreed regarding preferences for or against the three life-sustaining measures used in the study, CPR, tube feeding and mechanical ventilation. Levin and Sprung (Levin & Sprung, 2003) confirmed this in a study of responders, 200 from each of four ethnic groups; European Americans, African Americans, Korean Americans, and Mexican Americans.

As mentioned several times already, women are more likely to be carers than men. Little is known about women of color and their experiences as consumers of health care and as caregivers (Kaplan, 2002). Kaplan, however, states that what is known is that many women of color will die in pain and alone. Werth and colleagues (Werth et al., 2002), along with Murphy and colleagues (Murphy et al., 1996) represent a preponderance of data supporting and describing that African Americans are less likely to withdraw life-sustaining treatments at the end of life and are less likely than whites to have advanced directives. Few studies, however, have examined the reasons for these differences in end of life choices. Those that have, found generalizations surrounding lack of trust which might suggest that ethnic minority groups are inherently mistrustful when presented options for care at the end of life (Crawley.L.M. et al., 2002).

Many others have documented difference between African Americans and Whites with respect to end-of-life care and preferences. African Americans are significantly less likely than whites to possess advanced care directives or do-not-resuscitate orders

(Caralis et al., 1999; Murphy et al., 1996) and more likely to want aggressive medical care at the end of life. McKinley and colleagues found that 37% of African American terminally ill cancer patients wanted cardiopulmonary resuscitation as compared to only 16% of white patients (McKinley et al., 1996). In a survey among elderly from four different ethnic groups conducted by Blackhall and colleagues (Blackhall et al., 1999), results revealed that while African Americans could identify situations in which they favored withholding or withdrawing life support, when responding to an item where asked to place themselves as the hypothetical patient, they were more likely than white respondents to remain on life support. While many relate these differences to mistrust of the medical care system, some take issue with this rationale claiming that framing the issue in this way implies that the main problem with end-of-life care rests with the attitudes of African Americans (Crawley.L.M. et al., 2002). Moreover, in McKinley's study, 96% of the study participants trusted the medical system and less than 20% feared that their medical care was inadequate.

In addition to the explanation of mistrust as a rationale for greater use and desire for life sustaining treatments by African Americans at the end of life, Tschann, Kaufman and Micco (Tschann, Kaufman, & Micco, 2003) found that the presence of family member at death may reduce the use of technology and increase the use of comfort care in the last days of life. In a retrospective cohort analysis of 370 inpatients who died at an urban community hospital during a 1-year period (1997), Tschann and colleagues found that African American patients were least likely of all ethnic groups to have a family members present at death (32% versus 48-51%, $P < .02$). Results from a study of the elderly (65 years of age and older) living in community settings by Garrett and colleagues

(Garrett, Harris, Norburn, Patrick, & Danis, 1993) revealed that blacks were more likely than whites to rank "how long" they lived (25%) as more important than "how well" they lived (6%). This would explain greater propensity for dying in the hospital and aggressive pursuit of life-saving intervention – even to the last moment of life.

In the Picot study, African American caregivers perceived greater rewards as caregivers than did White caregivers (Picot et al., 1997). Moreover, they found that mediation models showed a significant mediating effect of comfort from religion ($t = 5.42$, $p<.0001$) and prayer ($t=2.58$, $p<.005$). They concluded that race had both direct and indirect effects on perceived caregiver rewards with the indirect effect being mediated by comfort from religion and prayer. Of interest is the utility of these perceptions of reward in contributing to messages and interventions aimed at African American caregivers. Perhaps it is easier for families to request advanced technologies than not. Some believe that the lack of assertiveness is at the core of caregivers' problems (Kane, 1984). If such is the case, then asserting life sustaining measures at all costs for whatever reason (mistrust included) might suggest a difference in the tenacity of African American caregivers.

Theory and Theoretical Elaboration

Some qualitative researchers purport that a review of the literature flies in the face of the guiding premise of allowing the data to inform the research in and inductive manner (Miles & Huberman, 1994; Strauss & Corbin, 1994). However, it can be used to inform or structure the inductive process by providing a priori concepts derived from relevant previous research. In qualitative research the review of the literature is

appropriately referred to as a Review of Relevant Discourse and gives the researcher an account of that which exists that provides relevance to the study and the process of inquiry.

In behavioral inquiry, the role of theory is to help interpret problem situations and plan feasible and promising interventions. They explain behavior and suggest ways to achieve behavior change. In a review of the use of theory, researchers found that slightly less than half of all health behavior and health promotion articles explicitly reported use of one or more theories (Glanz, Lewis, & Rimer, 1997). Leaders in the field surmise that "a small but significant proportion of health promotion professionals consistently aim to use theory to untangle and simplify the complexities of human nature (Green, Gold, Tan, & Kreuter, 1994)". The understanding and application of theory is essential to the success of programs aimed at behavior change. To date, few if any theoretical constructs evolved from the search of meaning beyond the majority population. In order to appropriately address health disparities and design interventions to overcome such, there is a dire need for the examination of theory and an evolution of theory outside the Eurocentric views and perspectives.

To date, there are very few interventions aimed at caregivers. Fewer still, apply theoretical approaches or constructs to these interventions. This is mainly due to the lack of theory to guide interventions designed for caregivers. This study will utilize a conceptual framework that includes culture and considers such as contributing to caregiver health status. This framework which is described below will anchor the study to specific dimensions under which constructs might fit. To do this, the study utilizes quantitative methods to assess primary constructs (caregiver burden and cultural

justifications) for caregiving and qualitative methodologies for the purpose of theoretical elaboration.

Theoretical elaboration does not have allegiance to any particular theoretical framework or construct. Rather, it is a methodology from which theory is further described, expanded, and integrated for use in particular situations and circumstances (Vaughan, 1992).

Before going further into the discussion of theory, it is important to define several key terms as they will be used repeatedly throughout the documentation for the study. These terms include theory, constructs, and frameworks or models. First, a *theory* is systematic way of understanding events or situations. A theory is "a set of interrelated *concepts*, definitions, and propositions that present a systematic view of events or situations by specifying relations among variables in order to explain and predict the events or situations (Glanz et al., 1997)." Concepts are the building blocks or elements of theory. They may vary in the extent to which they have meaning outside the context of specific theories. When *concepts* have been developed or adopted for specific use in a particular theory, they are referred to as *constructs*. *Frameworks* are program planning tools that draw upon multiple theories to understand health behavior and assist in developing effective intervention strategies (Glanz et al., 1997). Finally, "models" can be used interchangeably for some theory and some frameworks depending upon their underlying purposes or concepts.

Theory and the use of theory is emphasized in the training of health promotion practitioners. D'Onofrio (D'Onofrio, 1992) suggests, however, that when applying theory to real situations, health educators should be active consumers. As active

consumers, health educators should question and analyze the utility of theory through three steps:

1. dismantling the myth of theory as the almighty standard,
2. acknowledging the limitations of theory in practical settings, and
3. take the initiative to directly identify and discuss issues that arise through applications of theory real world situations (D'Onofrio, 1992).

This study accepts such a challenge. Many interventions fail to achieve desired results with ethnic minority populations partially due to cultural inappropriateness of relevance and partially due to the use of theory or protocols that are not culturally grounded. Given that the traditional theories used for health behavior are derived from Eurocentric frames of reference, studies to explore the application of theories and their constructs to non-European populations are needed. Furthermore, when theories are derived from Eurocentric world views, steps should be taken to assure that they are well-fitted beyond a western paradigm. Airhihenbuwa (1995) suggests that health education efforts pause when attempting to apply traditional health behavior theories to non-Western cultures and consider their appropriateness for group or subgroups of differing worldviews. It has been said that "the inability to 'see' from several angles is perhaps the one common fallacy in provincial scholarship (Asante, 1987)."

Ethnocentrism is described as an assumption that individuals make that their way of believing and behaving is either preferred or correct (Ferguson, 1991). Asante (Asante, 1980) asserts that human beings recognize three basic postures to which the human condition ascribes: feeling, knowing, and acting. Europeans traditionally refer to these stances as affective, cognitive, and conative. Afrology, the Afrocentric study of

African-derived concepts, issues and behaviors (Asante, 1980), recognizes these three stances as interrelated, not as separate domains (Asante, 1987). A key principle in taking an afrocentric approach to inquiry is *nommo*, which is the "generative and productive power of the spoken word (Asante, 1987). The Black culture is characterized by an "oral tradition," where knowledge, attitudes, ideas, and notions are traditionally conveyed orally, not through written word (Hamilton, 1972). As such, inquiry directed toward understanding knowledge, attitudes, ideas and notions toward specific behaviors in African Americans may be well served through a qualitative approach.

Given the importance in the use of theory and the focus of this research, allowing theory to direct the study is optimal. Likewise, aligning the research to theory serves to increase transferability (Miles & Huberman, 1994). Through the chapter several theoretical constructs or concepts linked to the caregiving experience have be cited. For the reasons presented above, using a model within which culture, race and ethnicity are represented is deemed important to the researcher. Although the study of caregiving is an evolving area of scientific inquiry, this work seemingly lacks a uniformity in measurement or situation that could support the building of a clear knowledge base that guides intervention development. Studies vary with respect to the patient diagnoses which are likely to yield vast differences in the caregiving experience. For example, caring for an elderly family member with Alzheimers or dementia is likely to be different than caring for an adult child with cancer. So, what we know about caregiving is limited to the extent that we can compare evidence gained across studies and contexts of caregiving.

Conceptual Framework & Model

To further support the uncertainty that numerous, conflicting studies raise, there are two particular meta-analyses that specifically examine ethnic differences in the caregiving experience. In 2002, Dilworth-Anderson and colleagues (Dilworth-Anderson, Williams, & Gibson, 2002) reviewed 59 articles published between 1980 and 200 that specifically addressed race, ethnicity, and culture. Their findings revealed varied and inconsistent outcomes across racial and ethnic groups. They cite sampling, inconsistent measurement, and nontheoretical approaches for such inconsistencies. Furthermore, they suggest that such inconsistencies limit the understanding of caregiving amongst diverse populations. The authors recommend greater integration of quantitative models of stress processing with qualitative approaches for expounding upon the frameworks, perspectives and constructs that define and give meaning to certain caregiver associated concepts (e.g., burden and coping) from cultural contexts.

More recently, Pinquart and Sorensen (Pinquart & Sorensen, 2005) conducted a meta-analysis of 116 empirical studies on ethnic differences in stressors, resources, and psychological outcomes of family caregivers. They also found interesting differences across studies and also cite sampling and failures to control for confounding factors as contributing factors for limiting understanding. However, what is most compelling in the findings of Pinquart and Sorenson (Pinquart & Sorensen, 2005) is their assertion that despite differences in caregiving characteristics – like minorities experiencing worse physical health but better psychological health than Whites – all caregivers can benefit from greater understandings about specific differences in subgroups of caregivers. They conclude that "given existing health disparities and the increased physical health

problems in response to stress among ethnic minorities, caregiver interventions for this population not only have to focus on psychological well-being and depression as outcomes but also create programs to improve the physical health of caregivers and care receivers." In addition, they believe that "intervention with White caregivers may also benefit from knowledge gained for studies of ethnic minorities…….many interventions with Whites focus on reducing negative effects of caregiving, but do not address increasing positive emotion and incorporating or focusing on aspects of caregiving that increase subjective well-being." A greater understanding of the seemingly positive appraisal that minorities exhibit to cope with the high stress levels associated with caregiving may be found to be useful in interventions for all caregivers.

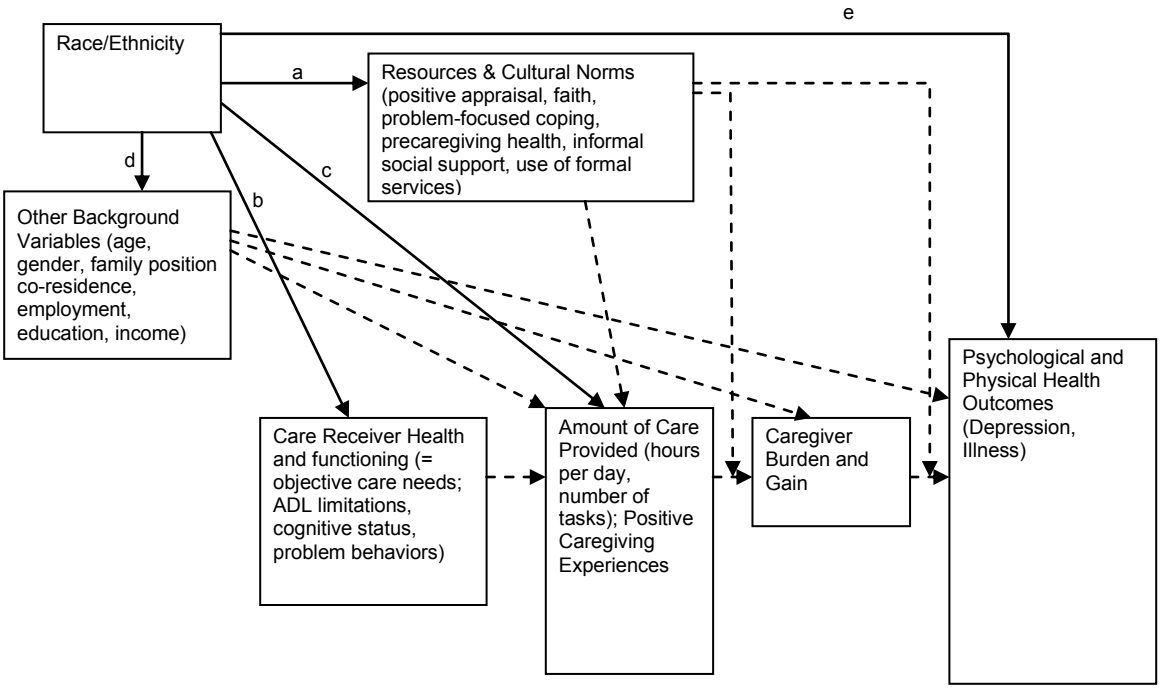
The meta-analysis of Pinquart and Sorensen (Pinquart & Sorensen, 2005) rendered a model depicting the differences in the mean levels of and associations between commonly studied caregiving variables. Figure 1 presents this model which this study will use to support and guide the research questions.

Within the body of literature, Pinquart and Sorensen (Pinquart & Sorensen, 2005) surmise that ethnic differences amongst caregivers present themselves contextually at several levels including; sociocultural (education, employment status), interpersonal (reciprocity and family responsibility), situational (severity of patient's impairment), temporal (timing in the care life cycle like end of life), and personal (coping style and physical health). Despite what they cite as a deficit of theoretical model due to the preponderance of non-theoretical and explorative studies, they present a conceptual model (Figure 1). Proposed in the model is that ethnic differences present themselves in personal resources (pathway a), stressors like care receiver health and functioning

(pathway b), and the amount of care provided (pathway c). In addition, race and ethnicity is linked to differences in caregiver demographics like gender, family position, and income (pathway d) and they further hypothesize, as have others, that there are ethnic differences in caregiver outcomes due to existing differences in baseline physical and mental health (pathway e). As Colenda (Colenda, 2003) might suggest, the need to understand issues associated with end-of-life is best addressed in the community itself. It will be employed as a tool through which the concepts derived from this qualitative inquiry will be organized. As a framework that employs constructs congruent to and in the context of non-western worldview, it is appropriate for use in this study of African American attitudes for caregiving at life's end.

Use of the Pinquart-Sorensen model for the organization of concepts derived from qualitative methodologies provides the opportunity to explore an alternative research pathway.

Figure 1. Pinquart-Sorenson conceptual model for caregiving



Such pathways explore contexts and assets that can be utilized in health promotion programs to protect a specific (vulnerable) group from the health consequences or perhaps lessen the incidence of some unavoidable risk behaviors --- like caregiving (Doswell, 2002).

CHAPTER THREE

Methodology

Introduction

This study examined a particular type of caregiver – cancer caregivers – during a particularly intense circumstance – end of life. As such, the research questions were examined using mixed methodologies. First two research questions were addressed quantitatively using survey methods and the final research question was addressed qualitatively using structured interviews. These methods were referred to as Phase I (survey of a sample of White and African American women) and Phase II (structured interviews with a subset of the sample's African American women). The research questions of this study are as follows:

Research Question 1 (Phase I):

> Does the burden of caregiving present itself consistently across racial and ethnic subgroups of females caring for loved ones dying of cancer?

The null hypothesis associated with research question 1 is:

> There is no difference in caregiver burden amongst females caring for loved ones dying of cancer with respect to race and ethnicity.

Research Question 2 (Phase I):

> Can cultural influences and values be used to describe any differences in racial and ethnic subgroups of caregivers?

The null hypothesis associated with research question 2 is:

There is no difference in the cultural justifications of caregiving with respect to race and ethnicity.

Research Question 3 (Phase II):

a. Are there constructs specific to African American women caring for loved ones with terminal cancer that might support interventions aimed at changing specific caregiving related behaviors?
b. If so, do these constructs align with other constructs commonly used in health behavior change?
c. If not, do these constructs serve to support an explanatory model for specific caregiving behaviors?

Research Design and Approach

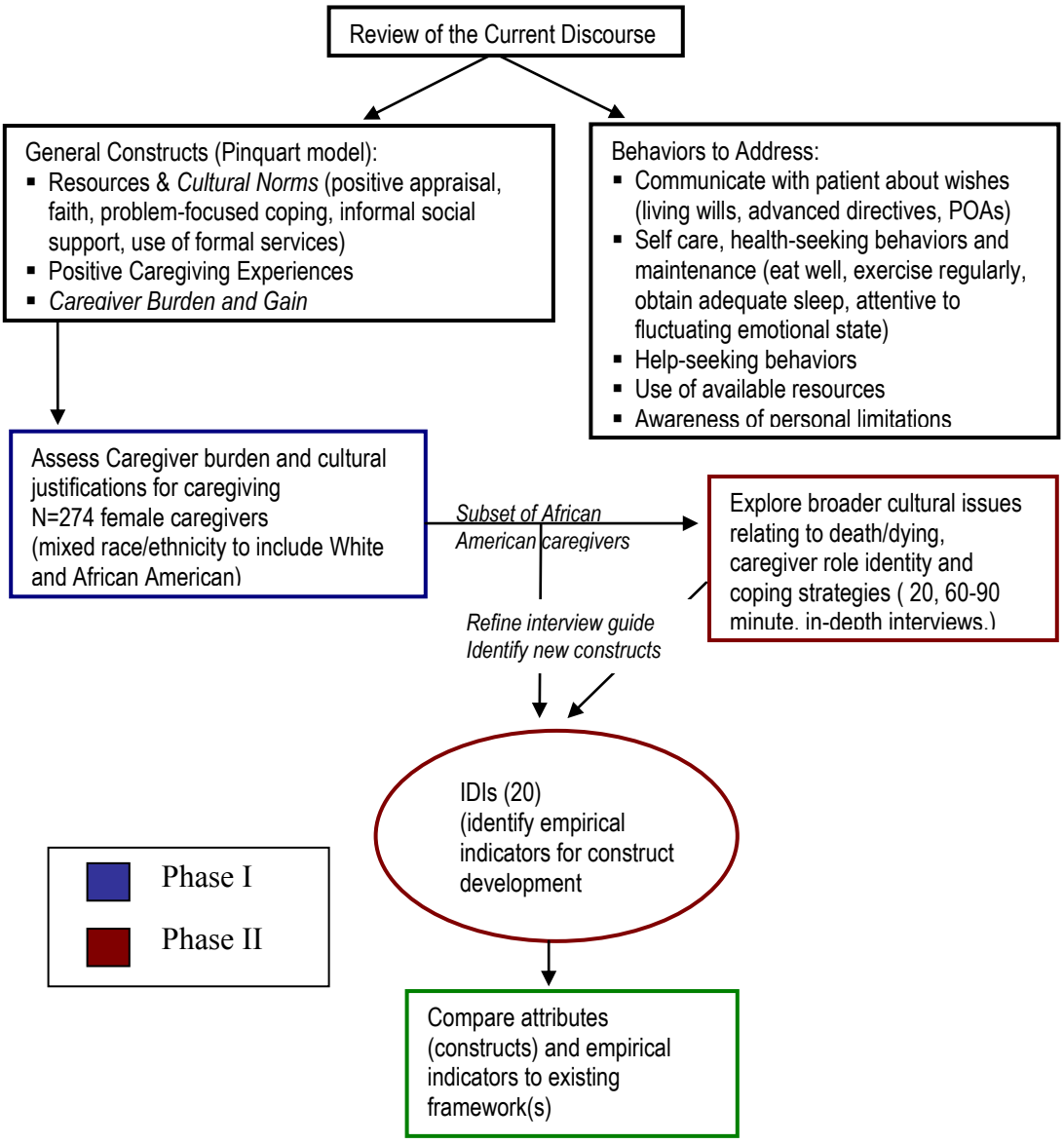
The study was divided into two phases, which are depicted in Figure 2. Using a cross-sectional survey, Phase I assembled and interviewed a sample of 254 female caregivers (133 Caucasian and 121 African American) from which, actual caregiver burden, perceived caregiver burden, and the cultural justifications for caregiving were assessed. In addition, twenty-two African American women from this sample were drawn for the qualitative component of the study (Phase II) that served to confirm or elicit theoretical constructs relating to the caregiving experience. Phase I of the study served to substantiate the caregiving burden within caregivers who were providing care to loved ones whose prognoses for cancer was terminal. This phase of the study was used to address research questions one and two.

Using qualitative research methodologies, Phase II of the study attempted to consider a construct of a theoretical framework for meeting the needs and influencing the behaviors of the African American caregiver. Phase II of the study employed qualitative research methods for theoretical elaboration. Theoretical elaboration is a process for refining a theory, model or concept in order to carefully specify circumstances in which it does or does not offer potential for explanation for a situation or phenomenon (Vaughan, 1992). If existing (grounded) theory seems appropriate to the area of investigation, then these may be elaborated and modified as incoming data are meticulously played against them. A central feature of this approach is often referred to as the constant comparative method (Glaser, 1992; Glaser, 1978). This phase of the study was used to address research question three.

Setting and Sample

Of the caregiver populations, it's purported that cancer caregivers represent less than ten percent of that population (National Alliance for Caregiving & American Association of Retired Persons, 2004). In addition, caregivers in general and particularly those providing care at the end of life have limited availability (Higginson, Wade, & McCarthy, 1990). For this reason, it was expected that recruitment for the study would present a challenge but that challenge was woefully underestimated for the subset of African American women. Given the nature of the study and expected recruitment difficulties –purposeful and theoretical sampling strategies were utilized. Specifically, these strategies included criterion sampling, theoretical sampling, snowball sampling, and convenience sampling.

Figure 2. Study design and strategies



Criterion sampling represents samples where all or most cases meet some criterion, which in this particular study was twofold; the loved one has cancer and is at the end stage. Theoretical sampling attempts to locate examples of the theoretical constructs in order to examine or elaborate upon them. Snowball sampling identifies study participants from people who know other people who fit the study's eligibility criteria. While these nonprobability sampling strategies pose threats and limitations to the

study, particularly in Phase I, they have beneficial tradeoffs, which include saving time and resources when such are of critical concern, which was the case for this study. Despite the compromises they present, these sampling strategies were deemed favorable for the type of research conducted in the study (Lincoln & Guba, 1985; 1998; Creswell, 1998). Eligibility criteria for the study have been derived from prevalence data and the research focus. It included:

- White and African American women (Phase I) caring for loved ones with poor cancer prognoses (advanced, metastatic, terminal – prognosis of less than six months)
- Bereaved caregivers who cared for a loved one who died from cancer within the past 12-18 months (both phases)
- Age 40 and over
- English-speaking
- Primary or secondary caregiver (providing a minimum of 20 hours a week care to a family member)

Exclusionary criteria included:

- Caregivers who might also be health care professionals
- Family caregivers who are distant and therefore provide care to a loved one intermittently

Fink (Fink, 2003) states that there are three situations for use of nonprobability sampling; 1) for surveys of hard-to-identify groups, 2) surveys of specific groups, and 3) surveys in pilot situations. All three situations are applicable to the study. A database conceived and developed by the former Office of Education and Special Initiatives at

NCI was activated for use in this study to support recruitment activities and systematize the screening process. Through this database, study participants for both phases were drawn. The database proved to be relatively effective for recruiting of White caregivers but not so for African American women. This database is described briefly below.

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the Privacy Act enacted by Congress include provisions on the privacy and protection of individually identifiable health information. These regulations have made it increasingly difficult to proactively recruit people to participate in formative research and ask them questions about their health status as it relates to cancer.

The former Office of Education and Special Initiatives (OESI) at the National Cancer Institute routinely conducts a large quantity of formative research to inform the development or test the responses of various audiences to new cancer-related educational resources. These audiences may include cancer patients, their families and informal caregivers, health care professionals, and non-cancer patients in the general public. In order to accommodate this need, a strategy evolved which led to the development of a structure through which those interested in participating could provide information on a strictly voluntary basis.

The information provided by prospective research participants are inputted into a database. The database has major sections for adult patients, family members and informal caregivers, the general public, and health professionals. Common fields for all respondents are contact information; geographic setting (urban, suburban, rural); age; income range; education; ethnicity; languages spoken; and type of research in which they are willing to participate (e.g., in-person, telephone, web). Common fields for patients

include type, stage, and status of cancer; date of diagnosis; if they are under treatment; type of treatment; and care setting. Fields for families/caregivers include relationship to patient, patient's type of cancer, treatment stage, setting for care, and date of death (if deceased). Fields for the general public include risk factors for cancer, diagnostic tests for specific cancers and results. Fields for health care professionals include type of health professional and work setting.

When a specific type of participant is desired, recruitment strategies are put in place to stimulate calls from participants for entry into the database. These strategies often entail flyers that can be distributed to various cancer centers, advocacy groups, or organizations serving the population of need. Interested individuals called a designated toll-free phone number and are screened for eligibility to participate, using screeners based on the audiences and database fields. The screener is modified to accommodate the specific criteria for desired sample of participants. When a study is scheduled, a search of the database is conducted to identify qualified participants, randomly select an appropriate representative sample, and contact them to see if they still are interested in participating. If participant's desire, they may remain in the database after participating in a study. They will then have the potential for being called again after 2 years and invited to participate in another study. This study, however, will require a new set of participants given the temporal criteria associated with caring form a terminal cancer patient – a call goes out similar to that used to populate the database in order to obtain a reasonable size sampling frame from which research participants can be selected.

The privacy policy explains the steps that we take to protect the privacy of people interested in participating in formative research. People who call the toll-free number are

screened solely for the purpose of determining whether they are appropriate participants for formative research on a specific topic. On the screening phone call, participants are read highlights of the database privacy and security policies, and are offered the opportunity to have the full plans mailed to them. They are told that they are free to refuse to answer any questions, that their contact information will be used only to let them know when a study for which they qualify is available and to send them their incentives. They are told that their contact information will not be shared with anyone other than the staff maintaining the database, and they are free to remove their information from the database at any time by calling the toll-free phone number. All potential participants are asked if we have their permission to enter their information into the database. No one will ever see these data except the individuals conducting the studies. All transcripts and study reports prepared for the user are assembled without individual identifiers. This study asked two questions, which required collection of identifying information. These questions addressed participants' willingness to participate in a longer interview (African American women only for Phase II) and the desire to receive study results. As instructed by IRBs, these identifiers were kept in a separate data file from the study data and not linked in any way to a participant's data collected from either of the study phases. No information about the source of the referral to the formative research database or the specific source of treatment received is collected. The screener developed for use in this particular study was submitted for OMB and IRB approvals is represented in the first 8 items of the Phase I instrument provided as Appendix A.

For the most part, the database was used to support recruitment by providing a repository of eligible participants from which the sample can be drawn. In phase I of the study, a sample size of 274 were recruited to yield a level of significance to distinguish variations in caregiver burden and cultural justifications for caregiver in two subgroups of caregivers. Pett and colleagues suggest a sample size of 10 to 15 participants per item of an instrument (Pett, Lackey, & Sullivan, 2003) in which case a sample size of 200 would be acceptable given that there are 22 items between the ZBI (12 items) and the CJCS (10 items). Likewise, according to Lipsey (Lipsey, 1990) provides a power chart for computing α=.05 (two-tailed) or α=.025 (one-tailed). He suggests a rule of thumb that in order to realize a medium effect size (.50) with .80 power a sample size of approximately 65 for each group examined is needed. Given that Phase I of the study will examine burden and cultural justification for White and African American caregivers, a reasonable sample size would include equal or closely balanced numbers of participants in each group.

Regarding Phase II, when discussing the appropriate number of research participants, it is important to note that the intent of interviews is to understand not to infer. As such, and relevant to sampling generalizations are not the aim since the study is not intending to make inferences about the population but to provide greater understanding and insight into the perceptions that particular groups of people have with regard to a particular situation or phenomenon. For this type of inquiry, the recommended number of participants is that which is needed to reach theoretical saturation. Saturation is the point at which "no additional data are being found whereby the researcher can develop properties by category" (Strauss & Corbin, 1994). Saturation

is being viewed as the gold standard by which sample sizes for qualitative inquiry in health services research is determined (Guest, Bunce, & Johnson, 2006). However, for research programs that need to identify sample size in advance of the study, there is no guideline on the appropriate number of participants or estimate of what it might take to reach saturation (Morse, 1994).

There are several recommendations for non-probabilistic sample sizes but none provides a rationale for their recommendation. As such, Guest and colleagues (Guest et al., 2006) set out to systematically document the amount of data saturation and variability over the course of their thematic analysis. Specifically, they were interested in determining how many interviews were needed to get "a reliable sense of thematic exhaustion and variability" within a data set of sixty in-depth interviews with women across two countries in Africa, Ghana and Nigeria. In a rigorous systematic coding and analysis process, they found that after 12 interviews they had created 92% of the codes for all 30 of the transcripts for the interviews conducted in Ghana and 88% of the codes developed across the two countries and for all 60 interviews. Likewise, when examining variability (changes made to the codes) and the frequency of codes, they appeared to stabilize by the twelfth interview. Their conclusion was that "if the goal is to describe a shared perception, belief, or behavior, among a relatively homogeneous group, then a sample of twelve will likely be sufficient, as it was in our study." For this study, however, a sample of 25 to 30 interviews has been recommended by the committee.

It is important to note that the intent of in-depth interviews were to better understand not to infer. As such, and relevant to sampling generalizations are not the aim since the study is not intending to make inferences about the population but to provide

greater understanding and insight into the perceptions that particular groups of people have with regard to a particular situation or phenomenon. The literature suggests that there may be differences in the presentation of caregiver constructs given specific characteristics of the caregiver. As such, theoretical sampling was employed to render variations in the participant pool. Based upon evidence relating to prevalence and use of supportive services, the specific variations in the interviewees included:

- age – women ages 46 to 60, and women 61 to 70 years,
- use of hospice (because in determining how people take an active role in their own self-regulation with regard to cognitive, environmental, social,
- behavioral motives we need to include individual who already demonstrate self-regulation characteristics (hospice users) and those who do not (non seekers of support) (Dzewaltowski, 1994), and
- relationship to the patient (spouse vs. other).

Instrumentation and Materials

While caregiver burden has been extensively studied across disease subpopulations and while numerous instruments that measure burden as well as other dimensions of the caregiving experience exist, for the most part these have been tested across variations of populations of caregivers most commonly being those who care for the elderly, those with dementia or Alzheimer's disease. Very few instruments have been used or tested with this study's population of caregivers of terminally ill cancer patients. For this reason, the study tested specific scales and their fit for this population of caregivers. In addition, phase I assessed cultural justifications that caregivers provide for

their roles using a recently developed scale for such purpose, the Cultural Justification for Caregiving Scale (CJCS). The CJCS is described below. These constructs are represented in a model proposed by Pinquart and Sorensen (Pinquart & Sorensen, 2005) and described in chapter 2 (see Figure 1).

Caregiver Burden. Caregiver burden in this study was measured by the Zarit Burden Interview (ZBI) (Zarit, Orr, & Zarit, 1985). The original ZBI is a 29-item instrument (Zarit, Reever, & Bach-Peterson, 1980). Since its development, however, it has been reduced several times with the most popular version having evolved in 1985 (Zarit et al., 1985). Of the many instruments to assess caregiver burden, this 22-item version of the ZBI has emerged as one of the most popular used (O'Rourke & Tuokko, 2003). This version of the instrument possesses excellent internal consistency with Cronbach alpha scores of .83 (Majerovitz, 1995) and .89 (Zarit, Anthony, & Boutselis, 1987). However, the length of the 22-item version of the ZBI has been seen as a deterrent to its use as a research or clinical assessment tool. For this reason, there have been attempts to shorten the instrument to fewer items (Herbert, Bravo, & Preville, 2001; Whitlatch, Zarit, & von Eye, 1991). Again, these shorter versions reported internal consistencies greater than .80 for shorter versions (12-item) of the instrument. Bedard and colleagues (Bedard et al., 2001) used the findings from previous attempts to produce a 12-item short version and a 4-item screening instrument of the ZBI. Cronbach alphas for the short version of that ZBI were reported to be .88. Reliability was tested with caregivers of patients with Alzheimer's disease, memory or behavior problems. As such, its expected that it is generalizable to most caregivers of older adults with cognitive impairment (Bedard et al., 2001) but not yet tested with this particular population. Its

reliability and use with caregivers of end-stage cancer patients will be explored in this study.

Actual Caregiver Burden. Since the Zarit Burden Index is a measure of self-perception of burden, this measure was compared to one of actual burden of caregiving. To measure actual burden index was extracted from the 2004, *Caregiving in the US* survey conducted by the National Alliance for Caregiving and the American Association of Retired Persons (2004). This survey examined hours of care provided and the type of care; activities of daily living (tasks done directly for the patient like feeding bathing, dressing, etc.) and instrumental activities of daily living (tasks that support the person like grocery shopping, paying bills, arranging services, etc.). These factors were combined in a formula that provided an index of true burden. Tables 1 and 2 below describes the formula used. The appropriate items from the *Caregiving in the US* survey were extracted and inserted into the Phase I survey for this study and the same computation was used in the analysis to arrive at actual burden measures for this sample.

Table 1. Hours and Type of Care Indices

Hours of Care Index (Q27)	Type of Care Index (Q14-Q26)
0-8 hours = 1	1 IADL / 0 ADLs = 1
9-20 hours = 2	2+ IADLs / 0 ADLs = 2
21-40 hours = 3	1 ADL (with or without IADLs) = 3
41+ or "constant care" = 4	2+ ADLs (with or without IADLs) = 4

Table 2. Actual Level of Burden Index

	Combined score
Level 1	2, 3
Level 2	4
Level 3	5
Level 4	6, 7
Level 5	8

Cultural Justifications. The Cultural Justification for Caregiving Scale (CJCS) which was developed by Dilworth-Anderson and colleagues (Dilworth-Anderson et al., 2004) in 2004 was used to assess cultural justifications of caregiving for this study. The 10-item scale measures cultural reasons why families provide care to the elderly. The items within the scale reflect socialization, values, and attitudes of a group. Although the instrument is specifically designed for use with those providing care to elders, it is the only scale that takes cultural distinctions into account and therefore was adapted by simply striking the descriptive "elderly dependent" which appears before "family member" from the items and used to assess the dimensions of the Pinquart model described in Chapter 2. CJCS assesses caregivers' cultural reasons and expectations in providing care. Items are rated on a Likert scale from 1 to 4 with 1 being "strongly disagree", 2 being "somewhat disagree", 3 being somewhat agree, and 4 "strongly agree." Summed items may range from 10 to 40 with higher scores indicating stronger cultural reasons for giving care. The reliability of the CJCS determined by Cronbach's alpha levels for primary, secondary, and tertiary caregivers are reported to be .84, .87, and .94 respectively (personal communication and correspondence, June, 2006).

The Phase I study instrument, which can be found in Appendix A, contains two scales (total 22 items) that was used to collect data from the sample population about

their cultural justifications for serving as caregivers and their burden experience resulting from this role. This instrument was piloted tested with three White and 2 African American women and showed that it could be implemented in 8 to 12 minutes. IRB also requested a shifting of the items to position those rendering data related to the eligibility up front. Shortly after data collection began, the instrument was split into two with identical items; one worded for active caregivers and another for bereaved to ease facilitation of the interview.

For Phase II of the study, an interview guide (see Appendix B) was used to conduct in-depth interviews with the women recruited. Interviews ranged from 60 to 90 minutes in duration. The structured interview guide was also pilot tested with 5 African American women (2 of whom also tested the Phase I instrument) who had cared for and lost loved ones with cancer within the past 18 months. Based upon the pilot interviews and the input received through IRB reviews, the interview guide was modified several times to yield the final version used for the study.

Recruitment and Data Collection Procedure

Several organizations within the local area provided optimal access to the types of study participants eligible for this study. Given their propensity for identifying appropriate study participants, partnerships were fostered to support recruitment. Some of these partners were in the local area and others were spread across the country. For phase I of the study, the assessments were taken by telephone when prospective participants called into the database. For phase II, recruitment support organizations included:

- Veterans Administration – Caregiver Research Support Team

- Comprehensive Cancer Center Palliative Care Centers
- Hospice Organizations (National Capital Hospice and Montgomery County Hospice)
- Community Cancer Centers

Flyers were provided to these organizations (Appendix C). In addition to these organizations, local outreach efforts included:

- Letters to pastors and pastoral counselors
- Letters and phone calls to social workers in major cancer treatment centers
- Letters and phone calls to colleagues within cancer treatment sites

In addition, listservs and online networks provided reach to potential participants. These networks included in the recruitment grid in Appendix D. The initial IRB approved recruitment flyers were widely distributed then modified and resubmitted to IRB for approval to be more attractive to African American participants. All flyers had the same 1-800 number which when searched on Google renders 423 page links (as of May 16, 2008) of independent postings. These postings ranged from newsletters, e-bulletin boards, organizational websites, and more. Along with the above recruitment strategies, the study investigator conducted numerous visits to what are referred to as "mega-churches" of African American denominations in the DC metropolitan area, African American women's book clubs and meetings of the most popular sororities for African American women (Delta Sigma Theta, Alpha Kappa Alpha, National Council of Negro Women, and Black Women's Professional Associations).

Providing incentives to research participants do more than stimulate participation, they are respectful of the research participants' role in and contributions to the study

(Singer, Hoewyk, & Maher, 2000; Church, 1993). While there is no consensus on the appropriate amounts of remuneration one is expected to take into account the demands that participation has on participants and remunerate accordingly and properly (Krueger & Casey, 2000). Incentives were provided to study participants in amounts commensurate with the level of commitment requested (screener/assessment, focus groups, interviews, etc.).

Data collections methods varied by phase of study. Data collection for Phase I began by receipt of calls from prospective participants into the formative research database through the promoted 1-800 number. Upon receipt of the call, all eligibility data were gathered to assess eligibility prior to gathering additional data. Once eligible, the balance of the data corresponding to the items of the instrument was collected. The average duration of Phase I data collection per participant was 13 minutes.

Data collection for phase II of the study was done using in-depth interviews with 22 participants selected from the same sample assembled in Phase I. The interviews served to elicit a broader understanding of the relevant issues of the experience of African American female caregivers from a cultural lens. These issues included but were not limited to perceptions of death, family members' roles in the care of dying loved ones, cultural norms, coping strategies and self-concepts as caregivers. These data were carefully analyzed to explore specific behaviors that might serve to compromise health status or reduce the propensity to seek support in their role(s) as caregiver. Most relative, cultural influences and constructs associated with these behaviors were more intensely explored.

Data Analysis Plan

Analyses for phase I included the following three components. First, descriptive statistics would be presented in order to describe the demographics of the study sample. Bivariate analyses would be conducted to compare racial differences in the major demographic characteristics, including age, education, income and relationship to the patient. Secondly, the psychometric properties of the measures would be examined. The data gathered were done so in the context of two previously validated scales (ZBI and CJCS) and one commonly used index for actual burden. More specifically, exploratory factor analysis, using principal components analysis, was used to investigate the underlying constructs of the Zarit Burden Interview (ZBI) and the Cultural Justifications for Cargiving Scale (CJCS). Internal consistency reliability (Cronbach's α) would be reported for both the ZBI and the CJCS. Thirdly, to address research question one, which is "Does the burden of caregiving present itself consistently across racial and ethnic subgroups of females caring for loved ones dying of cancer?", a multiple (OLS) regression analysis would be conducted, using the score of the ZBI scale as the dependent variable and race, age, education, income, relationship to the patient and CJCS as the independent variables. A significant coefficient on the race dummy variable (at the .05 level) would suggest a racial difference. In addition, an ordered logit regression analysis would be conducted, using the Actual Level of Burden Index as the dependent variable and race, age, education, income, relationship to the patient and CJCS as the independent variables. A significant coefficient on the race dummy variable (at the .05 level) would suggest a racial difference. To address research question two, which is "Can cultural influences and values be used to describe any differences in racial and ethnic subgroups

of caregivers?", a multiple (OLS) regression analysis would be conducted, using the score of the CJCS as the dependent variable and race, age, education, income and relationship to the patient as the independent variables. A significant coefficient on the race dummy variable (at the .05 level) would suggest a racial difference. In addition, an exploratory analysis would be conducted to investigate if cultural influences and values potentially mediate the relationship between race/ethnicity and (both perceived and actual) burden. The exploratory analysis would follow Baron and Kenny's (1986) work. That is, a hypothesized mediating effect would be accepted if a) the independent variable (race/ethnicity) has a significant association with the potential mediator variable (CJCS, in this case), b) the independent variable (race/ethnicity) has a significant association with the outcome variable (perceived as well as actual caregiver burden), and c) the potential mediator variable (CJCS) has a significant association with the outcome variable (perceived as well as actual burden) after controlling for the independent variable (race/ethnicity). If the association between the independent variable and the outcome variable disappears (decreases to zero) when the mediator variable is included, then the mediator variable is considered to have a perfect mediating effect. If the association between the independent variable and the outcome variable decreases a significant amount but not to zero with the inclusion of the mediator variable, then the mediator variable is considered to have a partial mediating effect.

Analysis of qualitative data was conducted for phase II. There are standards for quality against which qualitative research is critiqued. These standards have associations, which are known as reliability and validity but referred respectively to dependability and transferability. Similarly, credibility refers to that which is more commonly referred to

internal validity. Below are listed strategies for overcoming threats to reliability and validity in the context of qualitative research standards. First, in addressing reliability, overcoming threats to reliability (dependability) is a process of meticulous attention to detail with regard to the steps of the study. Such should be done in a manner that others could follow the steps and expect to achieve similar findings.

The most systematic approach to analysis of qualitative data is prescribed in grounded theory methodology (Tesch, 1990; Miles & Huberman, 1994). While this particular study is not grounded theory, its attention to and elaboration of theory lends well to the steps of grounded theory methodology guiding conceptual ordering. Conceptual ordering refers to the organization of data into discrete categories according to their properties and dimensions then elucidating those categories (Strauss & Corbin, 1994). Before describing the specific steps, a few definitions are provided which are aligned with those describing theory in Chapter 2. Definitions supporting the process are provided by Strauss and Corbin (Strauss & Corbin, 1994) include:

- concepts – the building blocks of theory that when developed or adopted for specific use within a theory become constructs.
- phenomena – ideas revealed in the data that represent concepts
- categories – concepts that represent phenomena (also referred to as networks in the analytical system, Atlas *ti*)
- subcategories – concepts that relate to and further clarify categories
- properties – characteristics of a category that define and provide meaning to the category (also referred to as links or associations in the analytical system, Atlas *ti*)

- dimension – a range along which properties of a category might differ or vary
- open coding – an analytical process through which concepts are identified along with the discovery of the associated properties and dimensions
- axial coding – the process of relating categories to subcategories – coding that occurs around the "axis" of a category and links them to levels of dimension and properties
- structure – context or condition in which a category or phenomenon is situated
- process – the sequence of actions, interactions or events that link to specific phenomenon as they evolve
- paradigm – a tool to assist analysts in integrating structure and process
- selective coding – reviewing coding and processing through to integrating or refining (elaborating) a theory

The steps of such an analysis plan include:

1. Using theoretical framework and conceptual models identify a priori major categories and sub-categories
2. Read through each transcript or data set
3. Identify one data set, demark analytical notes in margins
4. After review of several data sets, develop a list of topics – cluster topics
5. Create codes for topics and select matching segments for codes
6. Reduce topical list to categories
7. Finalize and alphabetize codes within each of the categories
8. Assemble data in manner that matches data to each category and compile for preliminary analysis

9. Collect additional data to supplement the analysis or provide further insight into areas where supporting data may have been lacking
10. Recode data if necessary
11. Display information in a spatial format for systematic presentation to reader

To support the implementation of these steps all in-depth interviews will be recorded and transcribed verbatim. Atlas.*ti* is a qualitative software package that will be used to support the analyses performed in Phase II of this study. Atlas.*ti* is partially based upon grounded theory methodology and as such is flexible, adapts to conceptual ordering, and uses and interplay of the researchers thinking to systematically generate theory. This program offers an index system that searches and codes within documents and constructs a database that can be examined hierarchically or within a network to explore connections between concepts. While many qualitative researchers prefer and find manual coding necessary to fully become immersed in the data, Atlas.ti is particularly useful in supporting the researcher in handling large amounts of material (data) and associated theories as was the case for this study.

For the qualitative data collected, confirmation will be done through a process of elaboration, these constructs can be translated into empirical indicators. Specifically, the process is to first, identify the construct of interest, secondly, operationalize that construct given information from the qualitative inquiries; thirdly, examine the literature and what exists related to the constructs and alignment with other similar concepts/constructs; and finally develop the instrument.

Limitations

There are several aspects of the study that preclude broader relevance and serve to either weaken it or narrow its scope. Most prevailing, however, were issues related to recruitment. Advanced illness and terminal prognoses was a significant limiting factor in the study. In addition, there are other limitations, which are as follows:

Threats to Internal Validity

- Sampling or Selection Bias - Studies of small samples are subject to selection bias. Study participants are self-selected and as such may be biased toward caregivers who find it easier to talk about their situations. Likewise, family members are difficult to approach around the time of death and they may change their assessment of the situation after bereavement (Higginson & Costantini, 2002).
- Measurement bias – given the uncertainty of instruments reliability with this particular population of caregivers they may be unable to accurately measure the variables under examination in Phase I (caregiver burden and cultural justification). In addition, participants found if difficult to respond when asked about number of hours they spent providing supportive services to the patient. Many felt they provided "round-the-clock" support.

Threats to External Validity

- The study is limited to caregivers of cancer patients at the end of life because it is assumed that there is homogeneity of the dying process within cancer patients (Osse et al., 2002).

- The study is unable to capture the input of the patient and their perspectives of the caregiver for whom they are likely to have great insight.
- Views of caregivers may be biased because their own concerns and expectations in the role of carer. The actual burden upon them occurs before the patient's death (Addington-Hall & McPherson, US; McPherson & Addington-Hall, 2002).

Overcoming Threats to Validity and Reliability

By following and documenting the data collection process and the analytic steps above, reliability of the study was enhanced. In addition, multiple methods of data collection were employed and data were triangulated which also enhances reliability in the study. Additional steps were taken through the study to minimize the threats to validity. These were to:

- align research to theory or theoretical models,
- pilot test Phase I instrument as well as the Phase II structured interview questions,
- transcribe verbatim the recorded data,
- pay attention to context through which data is derived,
- triangulate multiple data sources and methods,
- obtain participant verification of themes or "member checks" (Lincoln & Guba, 1985), and
- having the researcher as an "insider" with greater commonality in context.

CHAPTER FOUR

Phase I Analysis & Findings

Sample Characteristics

There were a total of 254 female caregivers in Phase I of this study. Table 3 presents the sample characteristics by race. Approximately half (47.6%) of them were African American and 52.4% of them were White. The majority (52.4%) was between 46-60 years of age. The sample was evenly distributed by educational level: over half (51.8%) had not graduated from college, and 48.2% possessed a college degree. The overwhelming majority of African American women (63.3%), however, were not college graduates. About half (51.6%) were "active" caregivers and 48.4% were bereaved caregivers, having lost a loved one within the past 12 months of the survey.

Most of the caregivers (63.3%) had a household income of $80,000 or less per year and less than 40% had household incomes that exceeded that amount. White women were about evenly split with just under half (48.7%) having household incomes above $80K and just over half (51.3%) having income greater. The African American caregivers differed in that almost 80% represent households where the annual income was less than $80K. The sample population of caregivers caring for loved ones with advanced staged cancer indicated that this type of caregiving, while situational did exceed 6 months the majority of the time. Seventy-five percent of the women cared for a loved one for more than seven months. Among the study sample, African American caregivers appeared to be younger, had lower education level, and were most likely to be caring for someone other than a spouse (i.e. parent or close relative).

Table 3. Study Sample Demographics (N=254)

Variable	Total N (%)	White N (%)	Black N (%)	P Value
Age of Caregiver				.02
31-45	68 (26.8%)	29 (21.8%)	39 (32.2%)	
46-60	133 (52.4%)	68 (51.1%)	65 (53.7%)	
61-81	53 (20.9%)	36 (27.1%)	17 (14.0%)	
Education				.00
< college graduate	131 (51.8%)	55 (41.4%)	76 (63.3%)	
≥ college graduate	122 (48.2%)	78 (58.6%)	44 (36.7%)	
Relationship to Patient				.00
Spouse	77 (33.0%)	66 (55.0%)	11 (9.7%)	
Other	156 (67.0%)	54 (45.0%)	102 (90.3%)	
Status of Patient				.00
Living	129 (51.6%)	79 (61.2%)	50 (41.3%)	
Deceased	121 (48.4%)	50 (38.8%)	71 (58.7%)	
Income				.00
≤ $80K/year	136 (63.3%)	55 (48.7%)	81 (79.4%)	
≥ $80K/year	79 (36.7%)	58 (51.3%)	21 (20.6%)	
Duration of Caregiving				.66
≤ 6 months	63 (25.0%)	35 (26.5%)	28 (23.3%)	
≥ 7 months	189 (75.0%)	97 (73.5%)	92 (76.7%)	

Zarit Burden Interview (Perceived Level of Burden)

The Zarit Burden Interview is a 12-item scale that measures the caregiver's perceived burden from the caregiving role. As explained in the Methodology section its validity and reliability has been documented repeatedly across types of caregivers including cancer caregivers. The ZBI scale is represented in the study instrument as items 15 a-l (Appendix F). An exploratory factor analysis was conducted with the current study sample to explore the underlying constructs of Zarit Burden Interview (ZBI). More specifically, principal components extraction with varimax rotation was used to estimate

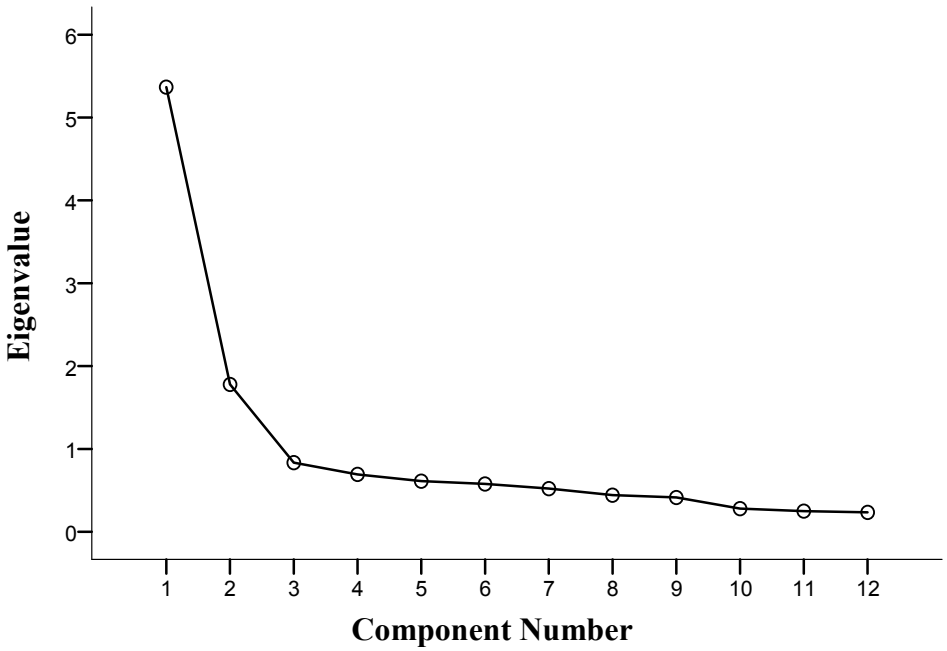
the number of factors for the total sample and by African American and white racial subgroups. Table 4 presents the results for the total sample. As shown in Table 4, eigenvalues for the first two factors were larger than 1. This could be taken as evidence that there were two factors. The scree plot (Figure 3) visually showed that the point of inflexion of the curve was 3, indicating there were two factors. These results were consistent with prior research which has documented two factors on the short-version ZBI (Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001).

Table 4. ZBI Exploratory Factor Analysis Table for Total Sample

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	5.3	44.7	44.7	5.4	44.7	44.7	4.6	38.7	38.7
2	1.8	14.8	59.5	1.8	14.8	59.5	2.5	20.8	59.5
3	.8	7.0	66.5						
4	.7	5.8	72.3						
5	.6	5.1	77.4						
6	.6	4.8	82.2						
7	.5	4.3	86.5						
8	.4	3.7	90.2						
9	.4	3.5	93.6						
10	.3	2.3	96.0						
11	.2	2.1	98.0						
12	.2	2.0	100.0						

Extraction Method: Principal Component Analysis.

Figure 3. ZBI scree plot for total sample



Tables 5 and 6 and Figures 4 and 5 show the results by race. The same pattern for the total sample was observed for each racial subgroup. Tables 7, 8 and 9 are the component matrix for the total sample and by racial subgroup.

Table 5. ZBI Exploratory Factor Analysis Table for African American Respondents

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
	5.5	45.5	45.5	5.5	45.5	45.5	4.5	37.8	37.8
2	1.9	16.2	61.7	1.9	16.2	61.7	2.9	23.8	61.7
3	.8	6.6	68.3						
4	.8	6.3	74.5						
5	.7	5.9	80.4						
6	.5	4.5	84.9						
7	.5	4.2	89.1						
8	.3	2.8	92.0						
9	.3	2.7	94.7						
10	.3	2.2	96.8						
11	.2	1.7	98.5						
12	.2	1.5	100.0						

Extraction Method: Principal Component Analysis.

Table 6. ZBI Exploratory Factor Analysis Table for White Respondents

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.8	40.3	40.3	4.8	40.3	40.3	4.2	35.4	35.4
2	1.8	15.3	55.6	1.8	15.3	55.6	2.4	20.2	55.6
3	1.0	8.2	63.8						
4	.8	6.4	70.2						
5	.7	6.1	76.3						
6	.6	5.3	81.6						
7	.5	4.4	86.0						
8	.5	3.8	89.7						
9	.4	3.3	93.0						
10	.3	2.8	95.8						
11	.3	2.3	98.1						
12	.2	1.9	100.0						

Extraction Method: Principal Component Analysis.

Figure 4. ZBI scree plot for African American respondents.

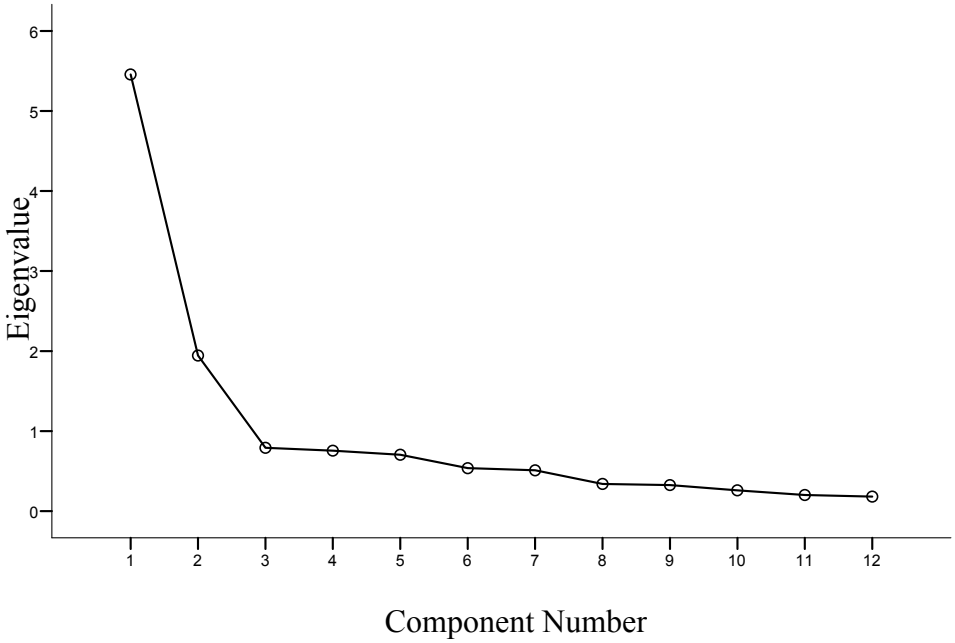


Figure 5. ZBI scree plot for White respondents

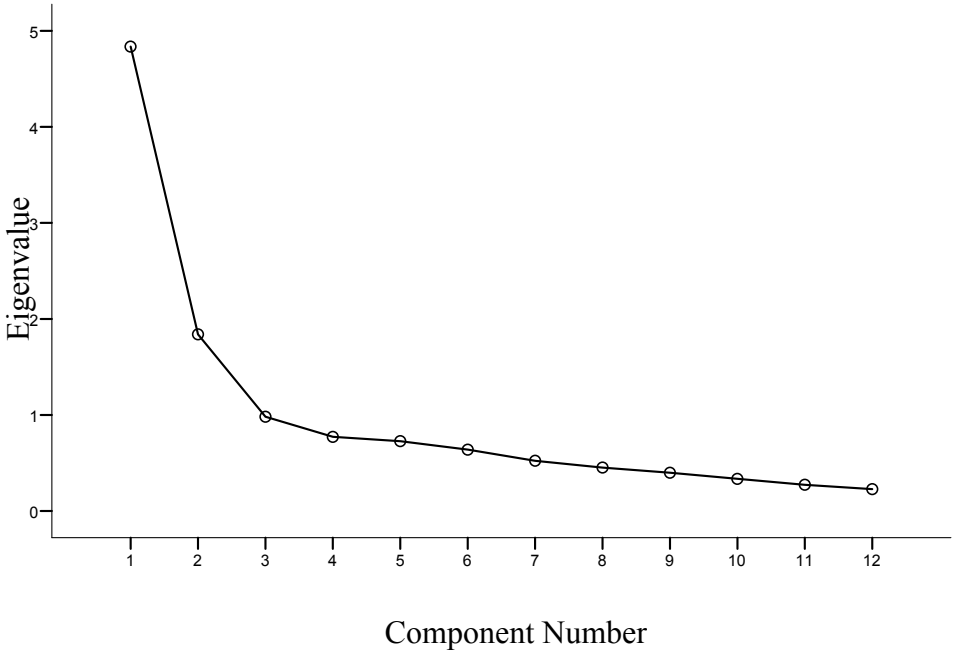


Table 7. ZBI Component Matrix for Total Sample

Item	Components 1 – personal strain	2 – role strain
Q15a	**.75**	-.31
Q15b	**.78**	-.27
Q15c	**.63**	.06
Q15d	**.66**	-.01
Q15e	**.71**	.15
Q15f	**.68**	-.32
Q15g	**.65**	-.20
Q15h	**.79**	-.23
Q15i	**.81**	-.15
Q15j	.59	**.50**
Q15k	.50	**.73**
Q15l	.38	**.77**

Extraction Method: Principal Component Analysis.
2 components extracted.

Table 8. ZBI Component Matrix for African American Respondents

Item	Components 1 – personal strain	2 – role strain
Q15a	**.71**	-.35
Q15b	**.77**	-.32
Q15c	**.64**	.11
Q15d	**.65**	.20
Q15e	**.73**	.14
Q15f	**.76**	-.20
Q15g	**.64**	-.31
Q15h	**.81**	-.30
Q15i	**.77**	-.26
Q15j	.59	**.54**
Q15k	.52	**.72**
Q15l	.39	**.74**

Extraction Method: Principal Component Analysis.
2 components extracted.

Table 9. ZBI Component Matrix for White Respondents

Item	Components 1 – personal strain	2 – role strain
Q15a	**.76**	-.28
Q15b	**.75**	-.22
Q15c	**.60**	.04
Q15d	**.65**	-.25
Q15e	**.67**	.18
Q15f	**.53**	-.50
Q15g	**.64**	-.06
Q15h	**.73**	-.17
Q15i	**.81**	-.05
Q15j	.52	**.51**
Q15k	.47	**.71**
Q15l	.35	**.76**

Extraction Method: Principal Component Analysis.
2 components extracted.

The Cronbach's α for ZBI for the total sample was 0.88, and Cronbach's α for factor one (personal strain) was 0.89 and for factor two (role strain) was 0.80. The two factors were significantly correlated, $r = .65$, $p < .001$. These results are consistent with prior research (Bédard et al., 2001). Item-to-total correlations for the total sample and for each racial subgroup were presented in Tables 10, 11 and 12. All individual items had an item-to-total correlation about greater than 0.35 for the total sample and 0.31 by racial subgroup, which was considered acceptable (Netemeyer, Bearden, & Sharma, 2003). These results indicated that the factor structure did not vary significantly across the two racial subgroups. Based on these results, all 12 items of the short version ZBI should be included to construct total scores for analysis. The ZBI scores were utilized to account for the perceived burden levels of caregivers.

Table 10. ZBI Item-to-Total Correlation Table for Total Sample

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15a	.66	.87
Q15b	.67	.87
Q15c	.55	.88
Q15d	.57	.87
Q15e	.63	.87
Q15f	.57	.87
Q15g	.56	.87
Q15h	.70	.87
Q15i	.73	.86
Q15j	.54	.88
Q15k	.46	.88
Q15l	.35	.89

Table 11. ZBI Item-to-Total Correlation Table for African American Respondents

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15a	.61	.87
Q15b	.67	.87
Q15c	.56	.88
Q15d	.58	.88
Q15e	.66	.87
Q15f	.67	.87
Q15g	.54	.88
Q15h	.71	.87
Q15i	.68	.87
Q15j	.55	.88
Q15k	.49	.88
Q15l	.36	.89

Cultural Justification for Caregiving Scale (CJCS)

To explore the underlying constructs of CJCS, an exploratory factor analysis was conducted with the current study sample. More specifically, principal components extraction with varimax rotation was used to estimate the number of factors.

Table 12. ZBI Item-to-Total Correlation Table for White Respondents

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15a	.66	.84
Q15b	.64	.84
Q15c	.49	.85
Q15d	.54	.85
Q15e	.58	.85
Q15f	.41	.86
Q15g	.54	.85
Q15h	.63	.84
Q15i	.73	.83
Q15j	.46	.85
Q15k	.43	.85
Q15l	.31	.86

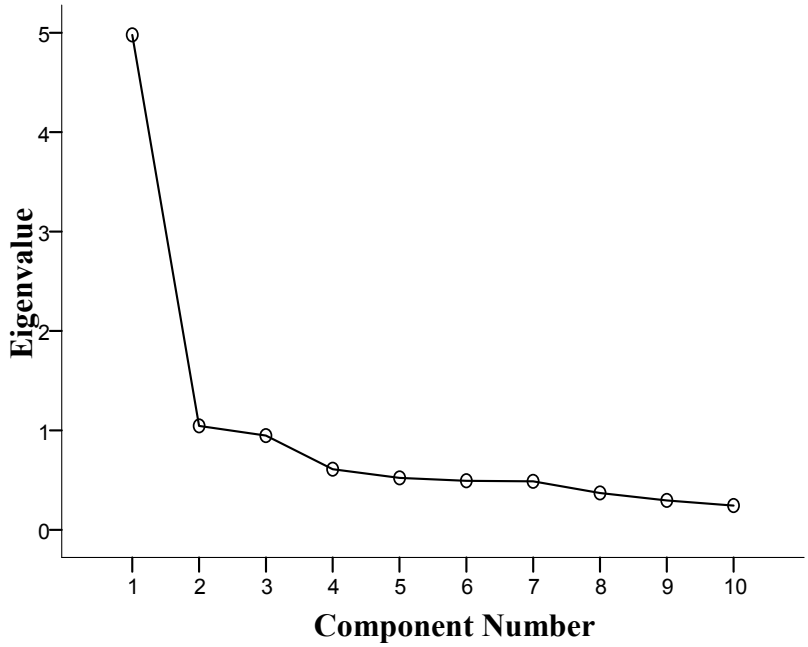
Although eigenvalues for the first two factors were greater than 1 (see Table 13), the eigenvalue for the first factor was close to 5 while the eigenvalue for the second factor was just above 1. This could be taken as evidence that there could be either one or two factors. The scree plot (Figure 6) visually showed that the point of inflexion of the curve was 2, indicating there was one factor.

Table 13. CJCS Exploratory Factor Analysis Table for Total Sample

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	5.0	49.8	49.8	5.0	49.8	49.8	3.2	31.8	31.8
2	1.0	10.5	60.2	1.0	10.5	60.2	2.8	28.4	60.2
3	1.0	9.5	69.7						
4	.6	6.1	75.8						
5	.5	5.2	81.1						
6	.5	4.9	86.0						
7	.5	4.9	90.9						
8	.4	3.7	94.6						
9	.3	3.0	97.6						
10	.2	2.4	100.00						

Extraction Method: Principal Component Analysis.

Figure 6. CJCS scree plot for total sample



Tables 14 and 15 and Figures 7 and 8 show the results by race. The same pattern for the total sample was observed for the African American respondents. For White respondents, the eigenvalues for the first three factors were greater than 1. The first factor was greater than 4, while the other two were just above 1. Both scree plots (Figures 7 and 8) visually showed that the points of inflexion of the curve were 2, suggesting one factor. Therefore, a one-component solution was forced and the component matrix results are shown in Tables 16, 17 and 18. The one-component solution explained nearly 50% of the variances for both the total sample and the African American respondents and explained about 40% of the variances for the White respondents. These results were consistent with prior research suggesting one factor on the CJCS (Dilworth-Anderson et al., 2005).

Table 14. CJCS Exploratory Factor Analysis Table for African American Respondents

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.8	47.7	47.7	4.8	47.7	47.7	3.0	30.3	30.3
2	1.2	12.5	60.2	1.2	12.5	60.2	3.0	29.8	60.2
3	1.0	9.5	69.7						
4	.8	8.2	77.9						
5	.6	6.1	84.0						
6	.5	4.7	88.7						
7	.4	3.7	92.4						
8	.3	3.2	95.6						
9	.2	2.4	98.0						
10	.2	2.0	100.0						

Extraction Method: Principal Component Analysis.

Table 15. CJCS Exploratory Factor Analysis Table for White Respondents

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.0	40.0	40.0	4.0	40.0	40.0	2.4	23.6	23.6
2	1.3	13.0	53.1	1.3	13.0	53.1	2.1	20.5	44.1
3	1.2	11.6	64.6	1.2	11.6	64.6	2.1	20.5	64.6
4	.7	7.5	72.1						
5	.6	6.3	78.4						
6	.6	6.0	84.4						
7	.5	5.3	89.7						
8	.4	4.2	93.9						
9	.4	3.7	97.6						
10	.2	2.4	100.0						

Extraction Method: Principal Component Analysis.

Figure 7. CJCS scree plot for African American respondents

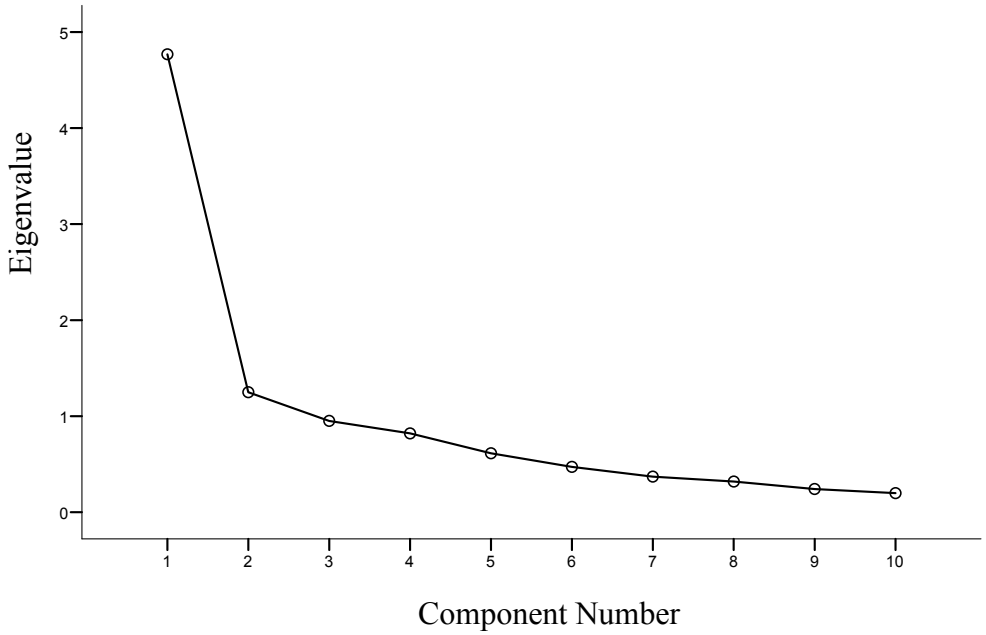


Figure 8. CJCS scree plot for White respondents

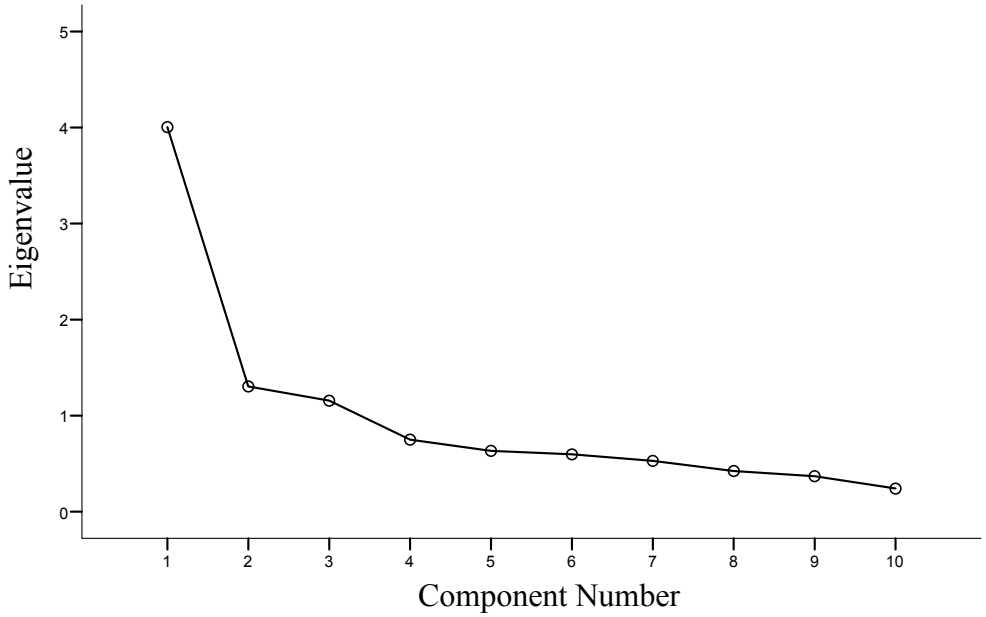


Table 16. Component Matrix for CJCS for Total Sample

	Component
Question	1
Q15m	.62
Q15n	.71
Q15o	.77
Q15p	.70
Q15q	.70
Q15r	.58
Q15s	.78
Q15t	.79
Q15u	.77
Q15v	.62

Extraction Method: Principal Component Analysis

Table 17. Component Matrix for CJCS for African American Respondents

	Component
Question	1
Q15m	.65
Q15n	.70
Q15o	.72
Q15p	.77
Q15q	.67
Q15r	.72
Q15s	.65
Q15t	.77
Q15u	.77
Q15v	.42

Extraction Method: Principal Component Analysis.

Table 18. Component Matrix for CJCS for White Respondents

	Component
Question	1
Q15m	.51
Q15n	.59
Q15o	.69
Q15p	.56
Q15q	.66
Q15r	.47
Q15s	.75
Q15t	.70
Q15u	.75
Q15v	.58

Extraction Method: Principal Component Analysis.

The Cronbach's α for CJCS was 0.88. Item-to-total correlations for the total sample and by racial subgroup are presented in Tables 19, 20 and 21. All individual items had an item-to-total correlation greater than 0.48 for the total sample and 0.35 by racial subgroup, which was considered acceptable (Netemeyer, Bearden, & Sharma, 2003). These results suggested that the factor structure did not vary significantly across the two racial subgroups. Based on these results, all 10 items of the CJCS should be included to construct total scores for analysis.

Table 19. CJCS Item-to-Total Correlation Table for Total Sample

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15m	.55	.88
Q15n	.63	.87
Q15o	.68	.87
Q15p	.61	.87
Q15q	.61	.87
Q15r	.48	.88
Q15s	.69	.87
Q15t	.70	.87
Q15u	.69	.87
Q15v	.54	.88

Table 20. CJCS Item-to-Total Correlation Table for African American Respondents

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15m	.58	.84
Q15n	.61	.84
Q15o	.63	.84
Q15p	.69	.83
Q15q	.54	.84
Q15r	.60	.84
Q15s	.54	.84
Q15t	.67	.83
Q15u	.68	.83
Q15v	.35	.88

Table 21. CJCS Item-to-Total Correlation Table for White Respondents

Question	Corrected Item-Total Correlations	Cronbach's (α) if item deleted
Q15m	.42	.82
Q15n	.50	.81
Q15o	.56	.81
Q15p	.46	.82
Q15q	.54	.81
Q15r	.36	.83
Q15s	.63	.80
Q15t	.57	.81
Q15u	.65	.80
Q15v	.48	.82

Actual Level of Burden Index

The mean level of the Actual Level of Burden Index for the whole sample was 4.1 (SD = 1.0). While African American caregivers appeared to have lower levels (M = 4.0, SD = 1.0) than their White counterparts (M = 4.1, SD = 1.1), the difference was not significant t (234) = -0.8, $p > .05$. These results are presented in table 23.

Bivariate Correlation

Table 22 shows the bivariate correlation between the three focus variables: ZBI, CJCS and the Actual Level of Burden Index. As shown in Table 22, while there was a significant correlation between ZBI and CJCS, the correlation was not significant between the Actual Level of Burden Index and ZBI or the Actual Level of Burden Index and CJCS.

Table 22. Bivariate Correlations between ZBI, CJCS, and Actual Level of Burden Index

		(1)	(2)	(3)
ZBI (1)	Pearson Correlation		-.14(*)	.12
	Sig. (2-tailed)		.02	.07
	N		253	235
CJCS (2)	Pearson Correlation			.10
	Sig. (2-tailed)			.14
	N			235
Level of Burden Index (3)	Pearson Correlation			
	Sig. (2-tailed)			
	N			

* Correlation is significant at the 0.05 level (2-tailed).

Overall Group Comparisons

The mean score are computed and means greater than or equal to 17 reflect high perceptions of burden while means less than 17 reflected lower perceptions of burden. Table 23 reveals that the mean ZBI score for the whole sample was 15.6 (SD = 9.9), while African American caregivers had significantly lower scores (M = 12.4, SD = 9.8) than their White counterparts (M = 18.5, SD = 9.0), t (251) = -5.2, $p < .001$.

The higher the score on the CJCS, the higher the cultural justification made for serving and accepting the role of caregiver. Also reflected in Table 23 was the mean CJCS score for the whole sample, which was 32.8 (SD = 6.9). African American caregivers had significantly higher scores (M = 36.6, SD = 5.5) than their White counterparts (M = 29.3, SD = 6.3), t (250.6) = 9.9, $p < .001$.

Table 23. Group Comparisons by ZBI, CJCS, and Actual Burden Index

Variable value	N	Mean	*SD*	*t*	*df*	*p*
Perceived Burden (ZBI)	253	15.6	9.9	251	-5.2	< *.001*
African American	120	12.4	9.8			
White	133	18.5	9.0			
Cultural Justification (CJCS)	253	32.8	6.9	250.6	9.9	< *.001*
African American	120	36.6	5.5			
White	133	29.3	6.3			
Actual Burden Index	236	4.1	1.0	234	-.8	> .05
African American	117	4.0	1.0			
White	119	4.1	1.1			

Research Question One

The first research question examines burden of caregiving across the two groups studied, African American women and white women. Specifically, the question was: Does the burden of caregiving present itself consistently across racial and ethnic subgroups of females caring for loved ones dying of cancer? The null hypothesis developed from this research question was: There will be no difference in caregiving burden amongst females caring for loved ones dying of cancer with respect to race and ethnicity. A multiple (OLS) regression analysis was conducted to answer research question one, using total ZBI score (perceived burden) as dependent variable, and race, age, education, income, relationship to the patient and CJCS as independent variables. Table 24 presents the regression results. The regression results indicated that there was a significant association between race and ZBI score (perceived burden). The significant association remained after controlling for age, education, income, relationship to the patient and CJCS. The regression results also indicated that none of the other variables

included in the model was significantly associated with ZBI score. These results indicated that the null hypothesis should be rejected.

Table 24. Summary of Regression Analysis for Variables Predicting Perception of Burden

Variable	*B*	SE *B*	β	*t*	*p*
Constant	6.14	7.51		.82	.42
Race	4.76	1.80	.24	2.64	.01
Age	-1.47	1.03	-.10	-1.43	.15
Education	1.32	1.47	.07	.90	.37
Income	1.62	1.58	.08	1.03	.31
Relationship	-.82	1.74	-.04	-.47	.64
Cultural Justification	.09	.12	.06	.73	.47

Note. $R^2 = .09$

In addition, a multiple (OLS) regression analysis was conducted, using the Actual Level of Burden Index (actual burden) as the dependent variable and race, age, education, income, relationship to the patient and CJCS as the independent variables. Table 25 presents the regression results. The regression results indicate that there was no significant association between race and the Actual Level Burden Index (actual burden), after controlling for age, education, income, relationship to the patient and CJCS. The regression results also indicated that none of the other variables included in the model was significantly associated with the Actual Level of Burden Index. These results indicated that the null hypothesis should be accepted.

Table 25. Summary of Regression Analysis for Variables Predicting Actual Level of Burden

Variable	*B*	SE *B*	β	*t*	*p*
Constant	2.67	.84		3.20	.00
Race	.30	.20	.15	1.53	.13
Age	.06	.11	.04	.55	.59
Education	-.08	.16	-.04	-.47	.64
Income	.10	.17	.05	.58	.56
Relationship	.06	.19	.03	.31	.76
Cultural Justification	.02	.01	.16	1.75	.08

Note. $R^2 = .03$

Research Question Two

The study's second research question focused on the influence of culture on the behaviors and perceptions of female caregivers. Specifically, the research question was: Can cultural influences and values be used to describe any differences in racial and ethnic subgroups of caregivers? The null hypothesis developed from the research question was: There will be no difference in the cultural justifications of caregiving with respect to race and ethnicity? A multiple (OLS) regression analysis was conducted to answer research question two, using total CJCS score as dependent variable and race, age, education, income and relationship to the patient as independent variables. Table 26 presents the regression results. The regression results indicated that there was a significant association between race and CJCS score, and the significant association remained after controlling for age, education, income and relationship to the patient. The regression results also indicated that caregiver's relationship to the patient (spouse or not) was significantly associated with CJCS, but age, education and income was not. These results indicated that the null hypothesis should be rejected.

Table 26. Summary of Regression Analysis for Variables Predicting Cultural Justification for the Role of Caregiving

Variable	*B*	SE *B*	β	*t*	*p*
Constant	39.84	3.38		11.78	.00
Race	-6.12	.97	-.45	-6.29	.00
Age	-.21	.61	-.02	-.35	.73
Education	-1.27	.86	-.09	-1.47	.14
Income	.30	.94	.02	.32	.75
Relationship	2.43	1.02	.17	2.38	.02

Note. $R^2 = .34$

Potential Mediating Effect of CJCS on Relationship Between Race/Ethnicity and Burden

As described in data analysis plan, an exploration of the potential mediating effect of CJCS on the relationship between race/ethnicity and caregiver burden (both perceived burden and actual burden) was conducted. With respect to perceived burden, CJCS and ZBI were significantly related (see Table 22), and race was significantly associated with both CJCS and ZBI (see table 23). The test for potential mediation of CJCS on the race and ZBI relationship can be found in Table 24. As shown in Table 24, when both race and cultural justification were entered simultaneously in the regression model, race remained significantly related to perceived burden (ZBI) but cultural justification (CJCS) was not significantly associated with perceived burden (ZBI). Therefore, CJCS should not be considered as a mediator of the relationship between race/ethnicity and caregiver perceived burden. With respect to caregiver actual burden, the results from bivariate analysis indicated that there was no significant association between CJCS and Actual Level of Burden Index (see Table 22) and the association between race and Actual Level of Burden Index was also non-significant (see Table 23). Based on the methodological framework specific by Baron and Kenny (1986), the statistical requirements for testing CJCS as a potential mediator of the association between race and actual burden were not

met, and no further analyses are warranted. Taken together, these results suggest that CJCS did not mediate the relationship between race and caregiver burden (neither actual nor perceived).

In summary, analyses for the study's first two research questions indicated that for this population of women caring for loved ones with advanced stage cancers, the differences with respect to the actual burden were not significant. However, white women perceived that their burden was significantly greater than African American women, even when controlling for multiple factors such as race, age, education, relationship to patient and cultural justification. Nonetheless, perception of burden did not correlate with actual burden. In addition, when cultural background provided meaning to their role as an informal caregiver, their perceptions of burden were lower. Finally, overall women who were caring for spouses were able to justify their roles more than those caring for other types of family members or close friends.

Phase II Analysis & Findings

The third research question was addressed through Phase II of the study which involved a qualitative analysis. Phase II of this study consisted of a qualitative analysis that was intended to provide answers to the question:

> *Are there constructs specific to African American women caring for loved ones with terminal cancer that might support interventions aimed at changing specific caregiving related behaviors?*
>
> *If so, do these constructs align with other constructs commonly used in health behavior change and if not, do they serve to support an explanatory model for specific caregiving behaviors?*

For this study, the specific explanatory model used is the Pinquart and Sorensen Conceptual Model for Caregiving (Pinquart & Sorensen, 2005) discussed earlier on page 54.

For this phase of the study, twenty-two African American women were interviewed. While the structured interview protocol for these interviews did not include the capturing of demographic information, often the participants provided such in their narratives. Table 27 provides an accounting of the age of the participants, their relationship to the cancer patient for whom they were caring, and the patient's type of cancer. The average age of the Phase II participants was 56.27 years.

Table 27. Information Captured on Phase II Participants

Participant	Caregiver Age	Relation to Patient	Type of Cancer
1	65	husband	stomach
2	58	sister	liver
3		father	esophageal
4		mother	lung
5	48	mother	cervical
6		father	
7	57	first cousin	breast
8	57	husband	prostate
9	60	husband	myeloma
10		husband	throat
11	67	best friend	metastatic breast
12	50	sister	metastatic colon
13	54	mother	lung
14	43	sister	
15	71	husband	
16	54	uncle	melanoma
17	68	niece	
18	62	husband	prostate
19	57	uncle	
20	62	husband	colorectal
21	41	husband	throat
22	39	mother	Brain

Across the participants, their loved ones had sixteen types of cancer and Figure 9 lists them. However, for various reasons, five participants were uncertain as to the specific type of cancer. Figure 10 indicates that the majority of the phase II participants (8) were caring for their spouse while the next largest group was caring for a parent (6). The balance of the participants was caring for or had cared for another type of relative or a close friend.

Each interview was conducted via telephone and the duration ranged from 65 minutes to 110 minutes with the average duration being 92 minutes. These interviews occurred as soon after the eligible African American participants were identified within the Phase I portion of the study. They were conducted between May 21, 2007 and February 29, 2008. One eligible participant was scheduled twice and cancelled twice. No additional follow-ups were made to secure this one interview. Interviews were recorded then transcribed verbatim. The transcriptions resulted in a dataset comprised of 22 primary documents that ranged between 38 and 74 double-spaced pages of text. Hence forth, the term "primary documents" when used refers to unique transcripts.

Figure 9. Phase II caregivers' patient's cancer diagnosis

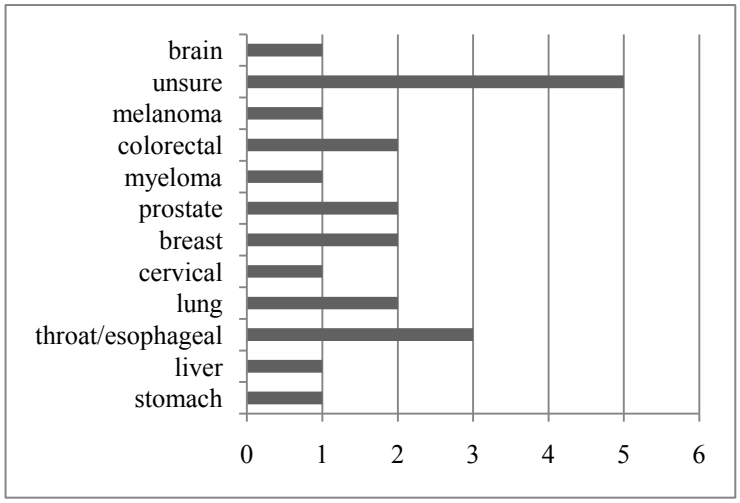
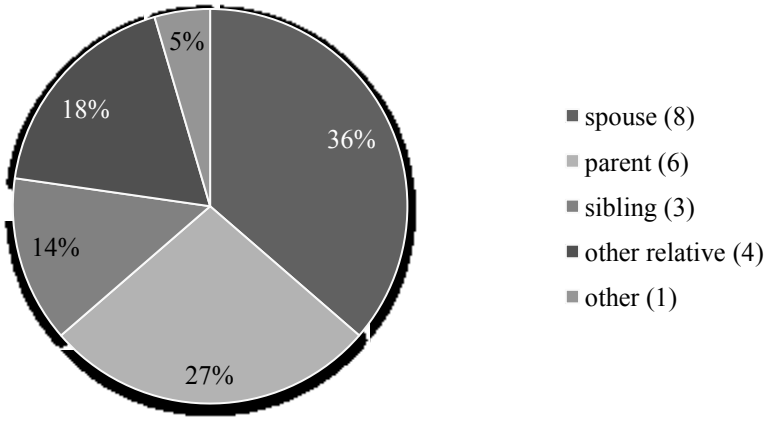


Figure 10. Phase II caregivers' relationships to patient



Coding & Analysis

The analysis process was performed using the analytic tool, *Atlas ti* in accordance to the analysis plan which was described in chapter 3. Initially, 8 primary documents were reviewed and noted (or memo'ed). This review led to an *a priori* set of broad codes that were utilized for the initial coding. Upon first pass through of all 22 primary documents, 61 codes were generated. The coding process suggests that saturation was reached after about 10 interviews. Table 28 shows the codes generate with each primary document coded, the number of unique codes attributed that that document as well as the total number of codes linked to each primary document. While Figure 11 indicates that saturation was likely reached after about 10 interviews (new codes), it is also recognized that the refinement of these codes occurred throughout the dataset (unique codes used), and that all codes were utilized robustly throughout (total codes used). Because of their co-occurrences and the relationships across the codes, the 61 codes were grouped into 10 categories or "families". Three codes were omitted because of their lack of co-occurrence within the dataset. These codes while interesting were seen as anomalies in

the data. These included, "no regrets", "wonders of race", and "financial matters" all of which were initially expected in the initial review of the primary documents to be more prevalent issues but after coding were either not mentioned or were more appropriately aligned with other stronger codes. For example, a quote coded to "no regrets" was, *"I don't regret anything. I just – well, yes, I do. I regret going to the bathroom. You know I had been sitting there with (Joyce).....I had to go to the bathroom and I was holding it in for about two hours and so I finally went… I almost missed her dying. When I came back, she gave her last breath and then all the blood and everything came out of her."* Additional coding subsequently linked this passage to a stronger code, "die while away" which is more appropriate in capturing specific constructs being sought. In another case, the participant said, *"I have no remorse about my father. No guilt. I gave up a lot but all that came back, you know. But, and like I said; now everybody thinks I'm the family caregiver because I am back at it right now."* Because it was unclear whether being labeled as the "family caregiver" actually brings regrets. Given the lack of groundedness or density, this code as well as the other two, were omitted.

Table 29 is a representation of the Code Families generated from the dataset. Within the analysis, "grounded" or "groundedness" refers to the number of elements (quotes, notes or memos) that are linked to a specific code. The higher the number of links the more grounded a code. Given the nature of this inquiry, it is understandable that the most grounded code is "caregiver role" since this was the overarching topic of spoken narratives. Table 29 shows how the 61 codes align within 10 code families. The numbers in parentheses after each code within a code family block represents its degree

of groundedness within the dataset. Almost every code family possesses several codes representative of the most grounded concepts.

Table 28. Codes Generated and Utilized

Primary Document	New Codes	Unique Codes Used	Total Codes Used
1	20	20	54
2	9	20	29
3	10	28	50
4	8	31	89
5	5	28	49
6	0	20	33
7	0	7	8
8	1	24	43
9	2	32	72
10	0	19	38
11	0	10	16
12	0	12	39
13	1	30	50
14	1	29	46
15	1	34	69
16	1	31	79
17	1	31	51
18	0	23	90
19	1	33	70
20	0	22	29
21	0	25	46

Note. Total codes column is not a sum of new Unique because either could be used multiple times in one primary document.

Figure 11. Code use across primary documents (transcripts)

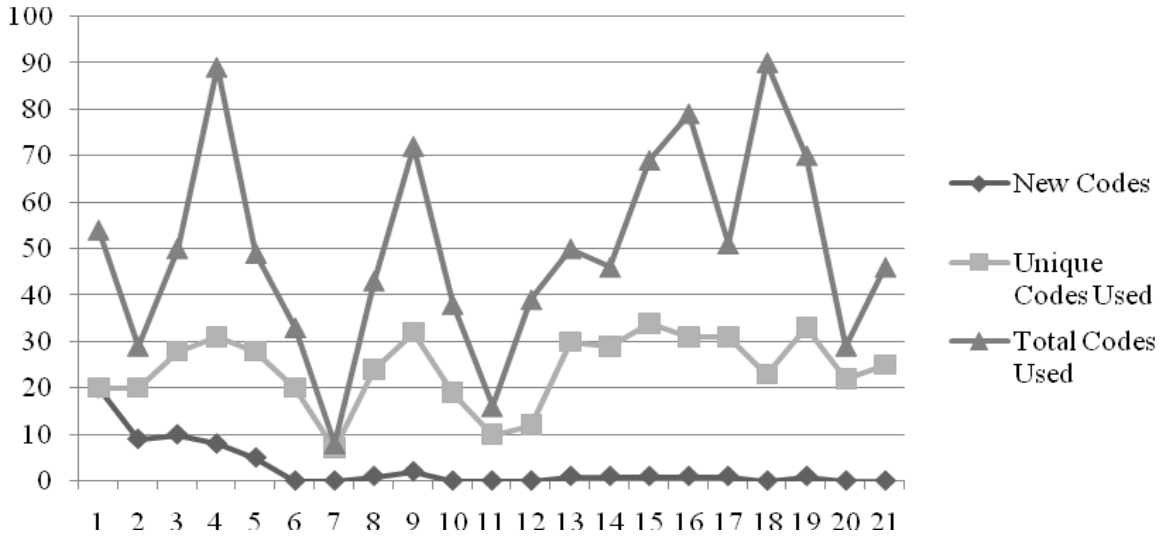


Table 29. Code Families Chart

Caregiver Issues (4) • caregiver's health challenge • caregiver's personal challenges • caregiver role • difficult role	Relationship to Patient (8) • continuation of care • maintaining dignity • no one can do like I do • no one would do but me • positives of the role • protector • pt-caregiver conflict • type of relationship	Spirituality & Religion (7) • coping • ministry • pulling from within • role of faith • strong spirituality • traditions of death • other source of strength	Emotionality (11) • die when away • difficult uncertainties • emotionality • getting it out • isolation • mental anguish • more emotional now than then • privacy warranted • pt change • regrets • self-sacrifice	Family Matters (7) • family conflict • family matters most • family roles • family talk • no one can do like I do • no one would do but me • distance caring
Health & Physical Challenges (7) • caregiver health challenges • in harm's way • more than one to care for • perceived burden • physical burden • self-care • working outside home continued	Patient's Health Issues (1) • patient's multiple health issues	Advice (2) • advice for caregivers • lessons learned	Perspectives About Death & Dying (5) • traditions of death • difficult discussions • house in order • preparing for death • privacy warranted	Support Systems (7) • doc talk • hospice duration • hospice referral • privacy warranted • unhelpful advice • social networks • unhelpful advice

Note: Unlinked codes: "no regrets", "wonders of race", "financial matters"

The study's third research question will be addressed in two ways. First by examining the code families and the relationships within those families, we can expose potential concepts that could and should support theoretical constructs with additional exploration. In addition, the study's guiding model can be assessed with respect to its alignment with the findings of this study in order to support further development of that model which is the Pinquart and Sorenson conceptual model for caregiving (Pinquart & Sorensen, 2005). Of the ten code families, two only have minimal linkages and will not be explored except in their links or co-occurrence within other families. These two families include; "patient's multiple health issues", which is pronounced in other families, and "advice", which was included in direct response to an item on the structured interview instrument and uniquely coded as such.

The networks that exist within the Code Families will be presented in order of strength or groundedness. This is determined by the number of segments or objects (quotes from narratives) that are attached to the codes within the networks (grounded). There are some networks that are quite interesting and important in the analysis because they have more codes linked within them (dense). The distinction between these two levels is the groundedness (more quotes within the narratives that point to these codes) and the density (more codes within a specific code family).

Due to the nature of the study, it is expected that one of the most grounded or strongest concepts is that which addresses the actual experience of someone in the caregiving role. Five codes align directly with the role of caregiver with the strongest

code representing quotes from the caregivers' narratives that specifically speak to their role. A few of the most explicit quotes within the code, "caregiver role" are:

"when I think of my role, I actually think of it as my purpose……whatever time that he lives, my purpose is to help take care of him"

"once she went to the hospital I never left her alone, from that point she never spent another moment alone."

"I cooked and cleaned and washed – I did everything in the house and just totally interacted with my Mom. Me and her were pretty much the only ones together, every now and then someone would visit but it was usually just she and I."

"I never pictured me in 100% realization even taking care of my father. Never thought that would be bestowed upon me but for some reason, the day my mother came out of outpatient surgery on life support, I knew I would have to because, I knew it. I just knew it. I wasn't prepared at the time to step into her shoes [as my father's caregiver], so it was challenging from day 1….I wasn't prepared to do all that she did, she would have done it for anybody. She would have bought you into her house and took care of you, you know. That's so who she was. But I wasn't who she was and I stepped into her shoes and they were too big. I could not fit them."

"People try to understand but they really don't. Like caregiving is an extremely hard job to do. And, I really would like to do something to help caregivers because I know, you know, what it entails. And nobody can imagine. You stay up at night, you know. You make all these sacrifices. And then not only are you dealing with the person's illness, you're dealing with their ego, is this a man and their -- just everything. There is a lot that goes with it. It's not an easy thing."

"My husband would get a little better but the energy that it took out of me I never regained. I never, you know, recouped ever. I don't feel like I ever recouped. And, I am trying to recoup but I can't."

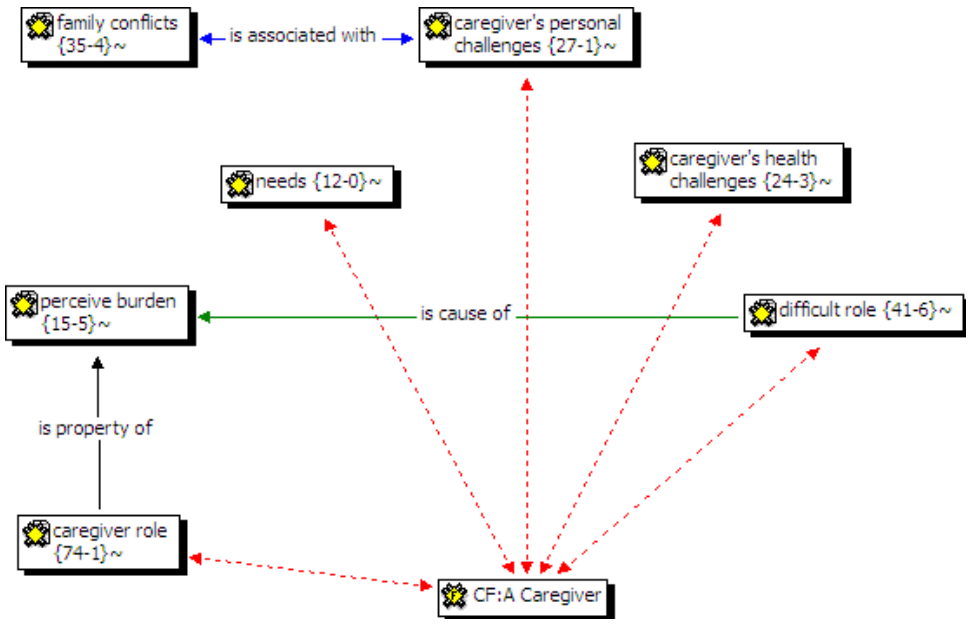
"so, you can't falter or fall, because if you do, then that person is just going to really – because you're their only hope, you know, that they're going to get through it…….if they're not feeling well or sick and frustrated, it's going to reflect to the person that you're caring for. When you care for someone else, you want – you don't want them to think like, I mean, or make, let them think that they are a burden."

Within the code family, “Caregiver Issues”, there are several linkages and codes that are linked to other code families. These linkages are of varied types and used throughout the analysis. The linkages (or associations) include:

- is associated with (= =)
- is a part of ()
- is cause of (⇒)
- contradicts (< >)
- is a (isa) –
- is property of ({*})

Figure 12 contains a network view of the code family for caregiving and within that network we find five codes are directly positioned within the code family, “caregiver issues”.

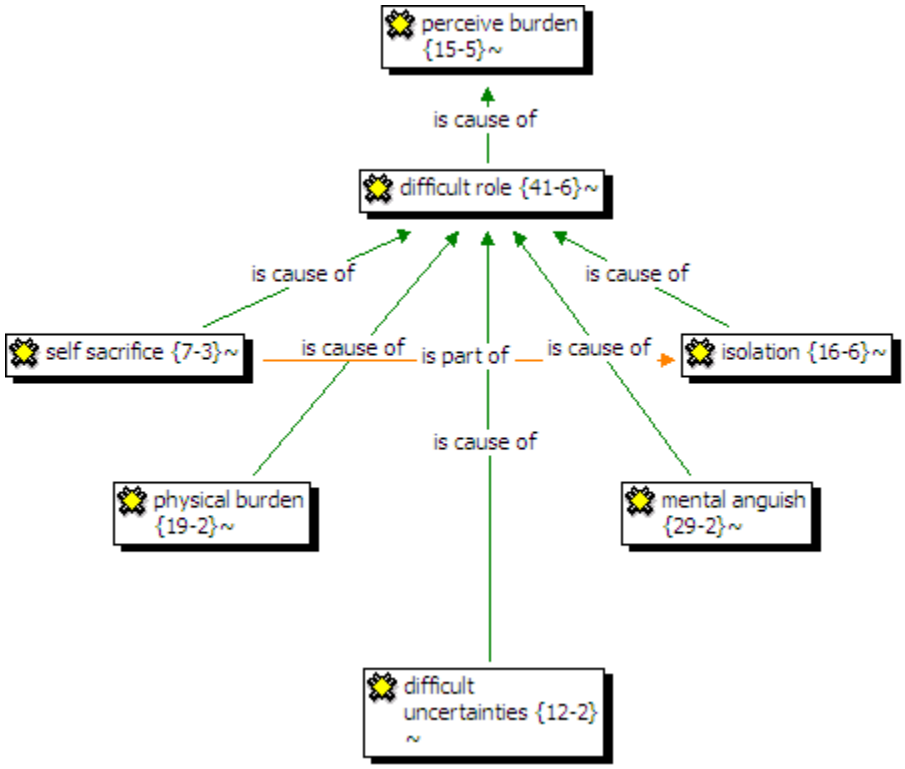
Figure 12. Caregiver issues network of concepts



The five codes included in this family of codes are; 1) caregiver's health challenges, 2) caregiver's personal challenges, 3) caregiver role (the strongest code in the dataset), 4) difficult role, and 5) needs. The links between the codes are determined by an analysis of code neighbors (quotes in close proximity) and co-occurrences (when a quote can be coded to more than one code). In this network, the analysis shows that the code "perceived burden" is caused by the "difficult role" code. This means that those items that were linked to one (perceived burden) were expressed within the context of the other (difficult role). In addition to being linked to "perceived burden", five other codes are linked to difficult role. All of these concepts contribute in some way to making caregiving a "difficult role". Figure 13 lists those associated codes which show that all are causes of "difficult role", and one, "self-sacrifice", is a part of another, "isolation". However of greatest interest in this network is the concept of "isolation", which is networked with the code family of emotionality, along with other codes, linked to difficult role to be discussed later. These relationships are appropriate and to be expected given that the caregiver role and the challenges associated with it certainly contain a great deal of psychosocial implications. The second most grounded network is "Family Matters" (see figure 14). In this code family, there are seven associated codes; 1) family roles, 2) no one can do like I do, 3) family talk, 4) distance caring, 5) family conflict, 6) family matters most, and 7) no one would do but me. There are three associations between these codes. Expressions of family matters most contradict those that speak toward family discord. The other two associations are aligned to the code, "no one would do but me." This code, and the associations, are of interest because they suggest how the

perceptions of these women that they are the only ones who would perform the tasks associated, their perceptions of family members, and the caregivers' perception of their role as caregiver are derived. In some cases, a woman is the one in the family recognized as the "family's caregiver or helper". She is generally the one who always is available to help and support family members. As such, this code is associated with "family role". Another situation that the narratives reveal is that the women are quite particular about how the support provided to a patient is performed.

Figure 13. Difficult Role network of concepts



So, particular, in fact, that they perceive others will not do it as well as they do. So, in one case, the perspective that "no one would do but me" is derived from the family's perception of the capacities of the woman. In the other case, it is derived from the woman's perceptions of the capacities (or lack thereof) of other family members. The

third most grounded network of codes in the dataset is that which speaks to the "Relationship to Patient." As was seen in Phase I of the study, those women caring for their spouses seemed to be most vulnerable to the implications of caregiving.

Figure 14. Family Matters network of codes

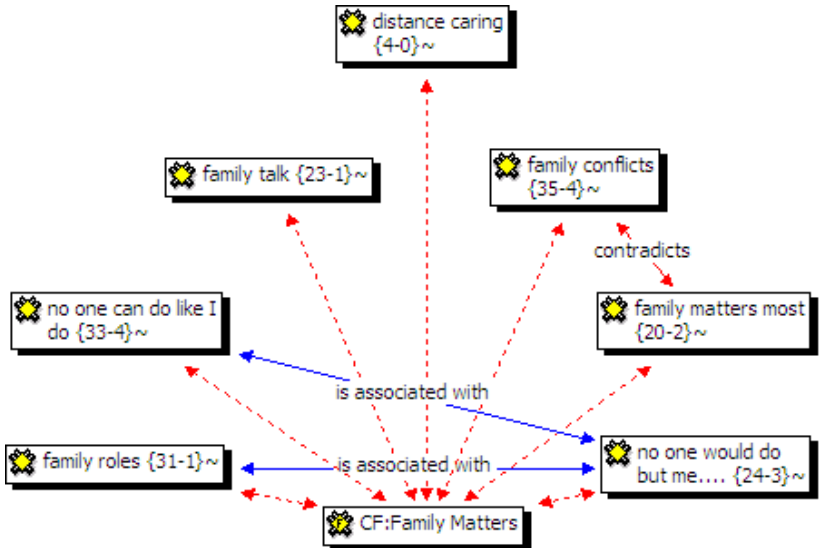
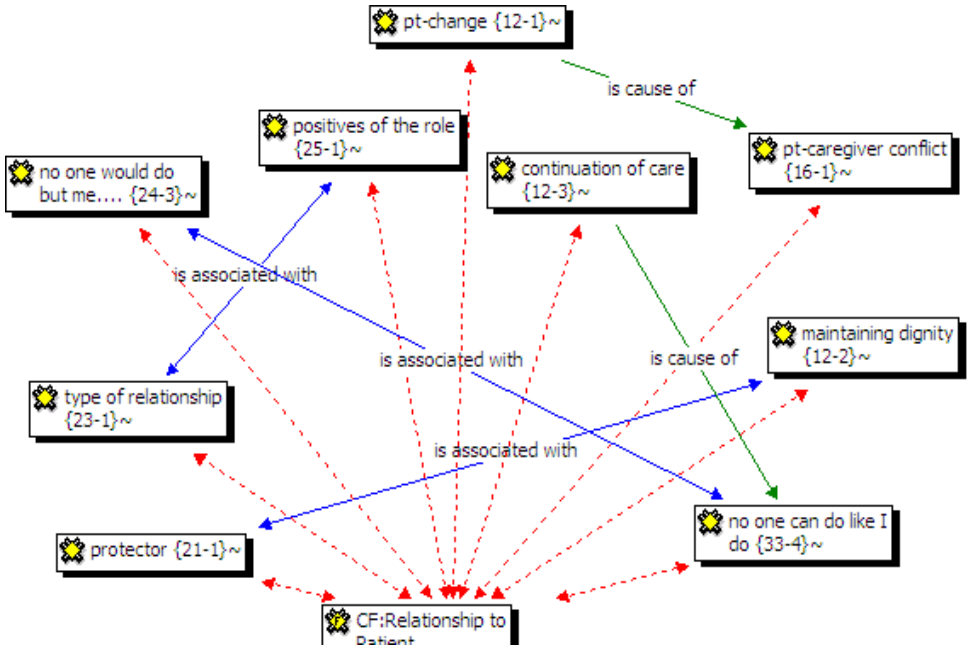


Figure 15. Relationship to Patient network of codes



The code family, Relationship to Patient, is comprised of a network of the following nine codes:

- no one can do like I do
- maintaining dignity,
- patient-caregiver conflict,
- continuation of care,
- patient change,
- positives of the role,
- no one would do but me,
- type of relationship, and
- protector.

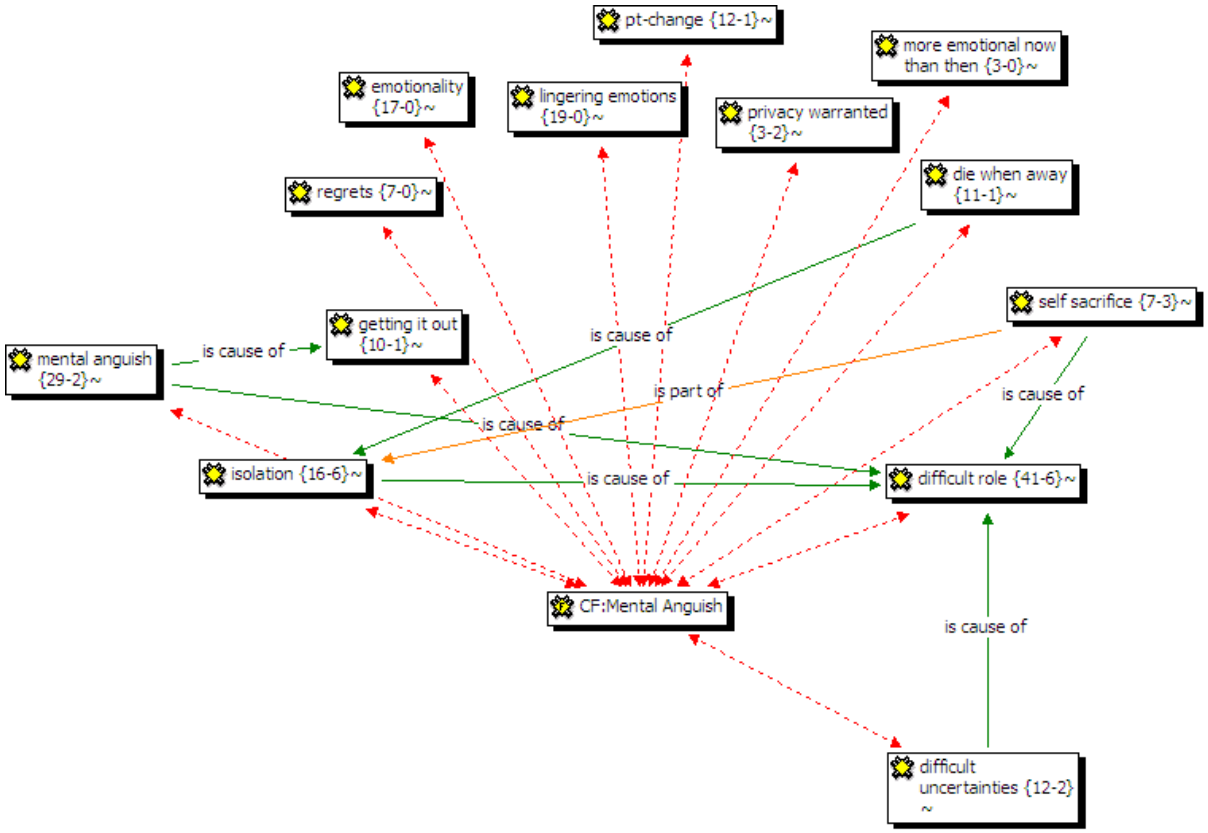
Within the network, there are two causal relationships between codes. Women express how the cancer changed the type of person they knew the patient to be. This change in personality or disposition, often leads to patient-caregiver conflict. Examples of this include quotes like, "*because normally he is a calm, easy-going guy. But when he tells me to get off his back, you know, stuff like that, I know it's not him. They told me it was because of the pills*" and "*the last two years he was – well the last year, anyway, he wasn't himself and I couldn't – I didn't handle it well. I was holding everything inside. I ended up having to go to the doctor because I told him – I said I need help. So, I ended up having to go to the doctor because I was having anxiety attacks*." In some cases, it appeared that along the way the patient became resistant to receiving care, "*one particular day he just kind of like – he had lost it. So, I was struggling trying to get the diaper under him and I kept telling him when I would push him over he was pushing back against me, you know, making more resistance. ……and that was one of the first times that I had ever gotten that agitated to him to whereas I knew I needed to just walk out of the room, settle down for a minute*."

In addition, within this code family network, the code, *continuation of care*, has a causal link with *no one can do like I do*. Because the primary caregiver was the interface between the medical team and the patient, the patient, and sometimes the caregiver, became dependent and insistent upon her sole provision of the patient's needs. One caregiver said, "*yeah, like I was a burden, you know. Even though I knew that the people that were there were there because they actually wanted to help me. And it felt like to ask for help was admitting that I couldn't do it, and I wanted to do it, you know."* Another quote, "*and I had a system, you know, I had a board indicating what medicines to give and what to look for and all of this. But anything, you know, he wouldn't let them. He'd be clogged until I got home. If he couldn't get himself up, he would never tell anybody what he needed really until I, you know, because he didn't trust anybody doing these things for him*." Another linkage is the association between the *maintaining dignity* code and the *protector* code. In some statements, the caregivers were reluctant to share the burden of care because they were protecting the patient by maintaining his or her dignity. "*You know because he was peeing on himself, and you know – you know, you don't want people to see, you know, your father in that state. So, I took people up on it [their offers to help] maybe once, and that actually worked well, but I still wasn't as comfortable and he wasn't either*" was one caregiver's rationale for refusing support. Another caring for her niece said, "*Well I felt like I was invading her privacy, because she was a very independent young woman. And having to give her bath and feed her, dress her, and – well, she kind of let me know that it felt like she was being her – how do I say? That she was being stripped of her independence*." Two other well grounded codes that were linked by association were *positives of the role* and *type of relationship*. Depending on

the type of relationship that existed between the caregiver and the patient, there were times when the dynamic between them serves to make the experience more positive. One carer stated, "*I'm so grateful that my mother and I got a chance to bond with each other because we had a situation where she was angry with me. I the one that always made my mother, insisted that my mother do the proper thing, because she did drink also…she would get away with everything with my brothers and sisters and I would always be the one, so she stayed more upset with me than anybody because of that. Given the chance to be with her on a daily basis and we got to talk and everything, that meant a lot to me. The fact that in my mind, if I hadn't did everything that I thought I could do for my mother before she passed, I feel like I would have many regrets and I have none now*." This statement and others like it, show how despite the nature of the relationship (good or bad), caring provided an opportunity to make that which was wrong, right and that which was good, all the more appreciated.

Another code family containing dense codes that are well grounded is that for the code family, Mental Anguish (figure 16). This code family encompasses 13 codes, the most grounded being *mental anguish*, and several linkages between the codes. A few quotes representing the code, mental anguish include:

Figure 16. Mental Anguish code family network



"I think I was feeling her pain and I don't know if that's possible. But I think that my system just shutdown. And I was doing all of the things she was doing. I was throwing up. I threw up for nine days straight. And, you know, they wanted me to talk to a psychiatrist. They wanted to put me on all these drugs. And I just, you know, but I've been fine ever since I got out of the hospital, I've been fine. There was nothing that they could find that was wrong with me."

"It's like I had lost control. I couldn't control anything. I couldn't control what was happening to him or myself. I don't like that."

"after the cancer had metastasized to her brain and she would get so disoriented looking for her, looking for her mother. You know what I'm saying. And that was really hard, makes me want to tear up now, that was really hard seeing her go through that because I visualized me, like that was me, you know, looking for my mother."

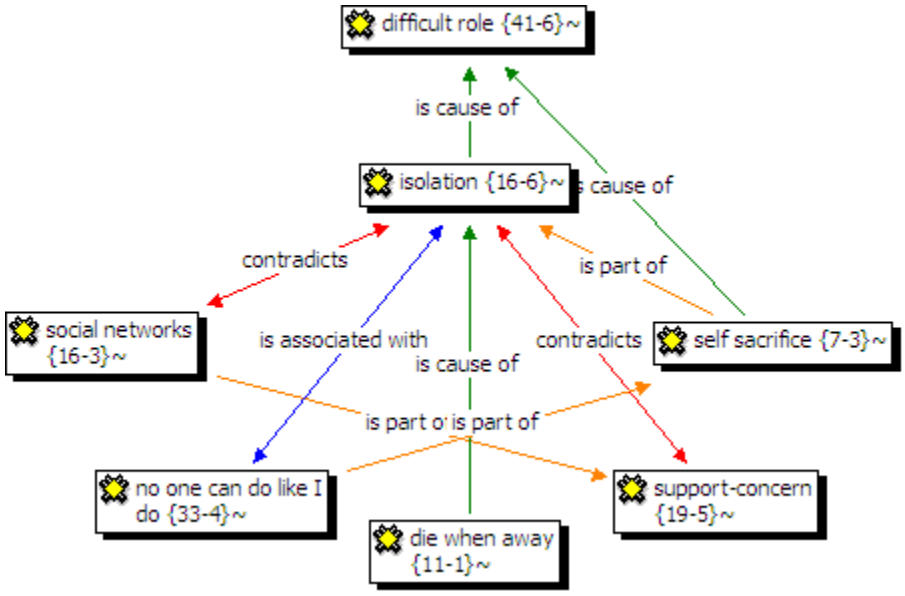
"it's really hard watching someone that you care about just dwindle away in front of your eyes. My husband was 6'1" and in his prime he weighed about 260. And he had – by the time he passed I know he was around 140……it's something I wouldn't wish on

my worst enemy. So, it does take a toll on you. I got to the place where I couldn't sleep."

Of the codes linked to this code family, Mental Anguish, several linkages can be found and in figure 16, we see that several of the linkages are causal in that the mental anguish experienced yield a difficult role with difficult uncertainties and an occasional need to "get it out" whether directly by speaking strongly to others (namely other family members) or physically in varying types of symptoms.

One particular network, within this code family was worth extracting to stand alone as an interesting phenomenon within the dataset. That is the network for "*isolation*". This concept of *isolation*, while belonging to the code family, *mental anguish*, is the densest within that family and is linked to 6 other codes including a causal link to one of the most grounded concepts of "*difficult role*". Figure 17, the isolation network, illustrates that while these women speak to their *social networks* of support, this is contradicted by an equally grounded concept of isolation. Also, Support and Concern, a code which represents the references to those who provide *support and concern* to the carer, is part of *social networks*. The code "*self-sacrifice*" is part of isolation in this network just as "*no one can do like I do*" is part of self-sacrifice. Likewise, "*no one can do like I do*" is associated directly with *isolation*. Of greatest interest, however, is that which causes *isolation*, which is "*die while away*". It was quite clear that women were afraid to leave the care of their loved one for others for varying reasons but a direct link to isolation as causal

Figure 17. Network for concept of Isolation



is the notion that the loved one might die when the carer steps away. Examples of expressions of this concept are:

"it was a weird feeling being around somebody – most people you know, they die, you know, you know they're going to die or they're in a car accident, something like that but to know that a person is going to die and you know you're waiting for them to die, you want to be with them, those precious moments, be with them."

"I had been sitting there with Joyce and I had to go to the bathroom and I was holding it in for about two hours and so I finally went to the bathroom and when I came back Joyce gave that -- I almost missed her dying. She had – gave her last breath and then all the blood and everything came out of her body. I feel if I hadn't gone to the bathroom I probably would have seen her been right with her to hold her hand or whatever, but you know"

"My worse fear was that he would call for me and I wouldn't be there. That he would, you know, take a turn for the worst or pass on or something and I wouldn't be there."

"My biggest fear during this whole time is that I am going to go up them steps or else come out of that bedroom and go in there again and he was going to be gone. That was my biggest fear."

"I had already pre-arranged it [a trip] and I really didn't want to go. But at any rate I had to leave town. So, of course, I was calling all the time to see – check on his status. And in the evenings I would always call. It was a blessing that I was able to come back home. Actually, I was really stressing at first not being there. Here I was thinking about him dying and I'm not here. You know, it was bothering me. But with me able to come back home – that made me feel better."

Seven codes make up the code family, Role of Faith. Figure 18 shows that within this code family, the most grounded concepts are that of *strong spirituality* and *role of faith*. The concept of strong spirituality has a causal link to four of the codes; "pulling from within", "other source of strength", "coping", and "ministry" and the first three mentioned are linked by direct association. Examples of quotes coded to ministry include:

"I think the caregiving that you do whether it's nothing but a smile or whether it's just stopping by to helping somebody that it becomes a ministry for caring."

"It may be a challenge for us to accept, but we know we can't do anything about it. And I feel that, you know, I've had other people come to me and say that this apparently was my calling in life.." Calling", here refers to a spiritual calling or command.

"I don't know how people characterize me, but I think I'm a very compassionate person, because I give from the heart. And what I'll do for anyone, not only my little sister, if a person needs me, I'm going to try to be there for them…..that is my thing – that is why I am put here."

Some examples of quotes coded to "strong spirituality" include:

"And I guess through it all I was prayerful that she could, you know, get well or, yes, I had hope for her. And I guess the other side of it, I felt like my prayer life is a source of strength."

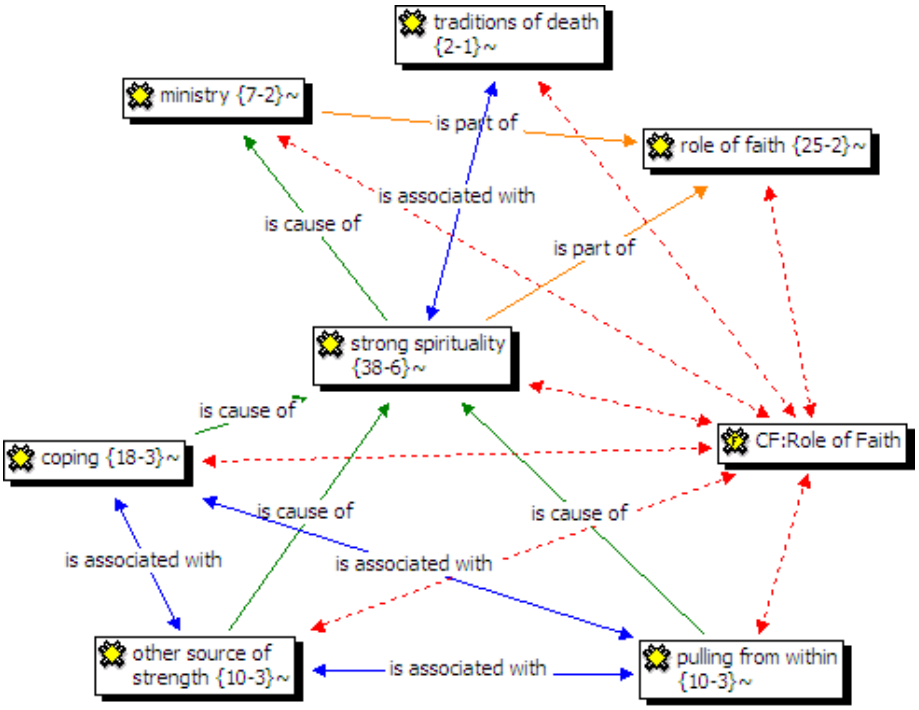
"….you know I could be hurt, or depressed, or sad and, you know, I could cry a little bit and let it out or give it to someone else like the release of sharing with someone else. And the, you know, I sort of get myself back together and say, come on Sharlitta, let's go. Got to get back on , got to get going. So I think it's more of an inner strength and, you

know, strength from God that, you know, just allows me to, you know, keep plugging on. It has to be done, somebody has to do it."

"What really helped me get through it basically was that I know – I know in my life I wanted God's blessings. I hope you believe in Him. I want – I truly wanted God's blessing in my life at that time."

Several of the quotes made reference to God not putting more on anyone than they could bear so that if they were burdened, it was a burden they could handle. One example is, "*You know, I feel that I have been truly blessed, you know? And so, you know, like He says, He doesn't put any more on you than He thinks you can bear. So I guess my shoulder must be a lot stronger than I think it is."*

Figure 18. Code network for Role of Faith



The seven code family networks presented and examined were to gain insight into potential area of intervention as well as behavioral constructs upon which interventions might be built. While the concepts that evolved through the qualitative assessment are

preliminary and while additional research is needed to move toward refining these concepts toward useful theoretical constructs, they do reveal critical areas upon which additional research might prove to be instrumental to behavioral interventions for caregivers aimed at addressing and perhaps reducing physical and psychosocial morbidity.

The study's total analysis supports a better understanding of the Pinquart-Sorenson Conceptual Model for Caregiving (Pinquart & Sorensen, 2005) and shown earlier in figure 1 on 54. The model surmises that ethnic differences amongst caregivers present themselves contextually at several levels. Evidence already indicates a difference in the health outcomes (Schulz et al., 1977) with White women experiencing greater psychological morbidity from caregiving and African American experiencing greater physical health morbidity as an outcome of caregiving. With respect to background (d), African American women in this study were younger, had less education, and lower incomes. This study also showed no difference for actual burden with respect to race but a significant difference in perceived burden with African American women having lower perceptions of burden thus supporting the element of caregiver burden and gain in the model. The Phase I findings of the study add insight into the following areas of the Pinquart-Sorenson Conceptual Model for Caregiving; Background, Care Recipient Health and Functioning, and Amount of Care Provided while Phase II findings from the qualitative assessment of African American women in the study, provide the greatest insight into the Personal Resources & Cultural Norms element of the model as well as some for family related issues that are also part of the model's Background element. All in all, this model does capture elements that seem to be inherent and strongly represented,

through this study, as part of the caregiving experience. It does not, however, sufficiently account for the extreme complexities of these elements nor the robust interactions that likely exist amongst them.

There were findings in Phase II of this study that lend an understanding to some of the differences that were found in Phase I findings. As mentioned, African American women perceived their caregiver burden to be lower than did White women. In addition, White women were more likely to be caring for a spouse than were African American caregivers in this study. Two strong concepts arising from the Phase II analysis of the narratives of Black women were "family matters" and "relationship to patient". The more closely related the caregiver was to the patient the more positive the role was perceived. In addition, there were family related issues that either supported or affirmed the caregiver's role identity or the degree to which they felt the role was either put upon them (no one would but me) or chosen (no one could but me). It could be that White women caring for long term spouses, who do not differ with regard to cultural justification of the role of caregiving, experience similar family related issues or similar feelings and attitudes identified in the construct of "relationship to patient". In addition, the caring role in the lives of African American women yield them rather familiar with the role and perhaps less burdened by it. Many of the participants expressed having cared for and lost a loved one prior to the episode of record. In fact, there were two participants who were actually caring from more than one person at the time of the interview. Such familiarity and internalization of the role perhaps contributes to a lower perception of burden as well. Finally, participants in Phase II often credited religion as the source of

strength and the reason for their acceptance of the role and its associated challenges. If one deems a role as a spiritual "calling", they may be reluctant to label it a burden.

Chapter Five

Discussion and Conclusions

This study, specifically focused on understanding potential distinctions between White and Black female caregivers as such relates to the burden of caregiving and the influence of culture in their perceptions of burden. The health and well-being of the caregiver is critical for patients being cared for at home (Ramirez et al., 1998). Unlike other types of caregivers, the role of family caregivers at the end of life and the demands this period brings are accompanied by the distress of an ensuing negative outcome of a sick loved one's death. Informal caregivers, particularly those whose loved ones have advanced cancer, are not likely to express their own needs and it is unlikely that health care professionals will perceive them as clients or potential recipients of care services (Northouse & Peters-Golden, 1993; Northouse et al., 2000). Rather, they are seen as an extension of the health care team without the preparation or training.

Caregivers of patients at the end of life experience high levels of psychological distress (Higginson et al., 1990), overwhelming anxiety (Higginson et al., 1997), and low marital satisfaction (Toseland et al., 1995). As demonstrated by the seminal study, Caregiver Health Effects Study (Shultz & Beach, 1999), there is also sufficient evidence addressing impact related to the potential health risks that accompany the responsibility of caregiving. At the end of 4 years, the study found mortality risks for participants who were providing care and experiencing caregiver strain were 63% higher than those whose spouse was not disabled (RR, 1.63; 95% CI, 1.00-2.65). Similarly, older participants, males, African Americans and those with at least 1 prevalent disease at baseline had

higher 4-year mortality rates (Schulz & Beach, 1999). Thirty three percent (33%) of the study's sample who were strained caregivers with prevalent disease died within the 4-year follow-up period. Findings revealed that strained caregivers compared with non-caregiving controls had significantly higher levels of depressive symptoms, higher levels of anxiety, and lower levels of perceived health. They also reported less time for exercise, adequate rest or self-care when sick. Caregivers of patients at the end of life experience high levels of psychological distress (Higginson et al., 1990), overwhelming anxiety (Higginson et al., 1997), and low marital satisfaction (Toseland et al., 1995).

A number of findings in the Phase I portion of this study are worth noting. First, the results of this study indicate that the factor structure of perceived burden scale (ZBI) as well as the cultural justification of caregiving scale (CJCS) did not vary significantly across the two racial subgroups of caregivers. That is, validity as well as reliability of these measures remained adequate for both African American and white woman caregivers. In this study, the Cronbach's α for ZBI for the total sample was 0.88, and Cronbach's α for factor one (personal strain) was 0.89 and for factor two (role strain) was 0.80. These findings demonstrate that ZBI was a reliable measure of perceived burden for caregivers caring for loved ones with advanced stage cancer. Previous research showed that reliability for ZBI among caregivers of patients with Alzheimer's disease, memory or behavior problems and produced Cronbach's of 0.88 (Bedard et al., 2001). As such, Bedard et al's (2001) suggestion that ZBI could be a reliable measure for most caregivers of older adults with cognitive impairment (Bedard et al., 2001) seem reasonable.

The Cultural Justification of Caregiving Scale (Dilworth-Anderson et al., 2004) assesses caregivers' cultural reasons and expectations in providing care. The reliability of the CJCS, determined by Cronbach's α levels for primary, secondary, and tertiary caregivers are reported to be 0.84, 0.87, and 0.94 respectively (P. Dilworth-Anderson, personal communication, June, 2006). For its use in this study, the CJCS had a Cronbach's α of 0.88 for the total sample. Results from this study also suggested that the factor structure did not vary significantly across the two racial subgroups. Based on these findings, the reliability and validity of the two scales (ZBI and CJCS) used to measure caregiver burden and cultural reasons for expectations in providing care are quite consistent with previous studies (Bedard et al., 2001; Dilworth-Anderson et al., 2004).

Second, this study showed that women's experiences in caring for loved ones are likely to differ by race. Findings show that while African American and White women's actual burden, measured by number and duration of activities of daily living and instrumental activities of daily living, was not significantly different. However, African American women perceived caregiving as significantly less burdensome than did their White counterparts. The significant racial difference in burden perceptions held true even after controlling for factors like age, education levels, income, or relationship to the patient. Even more interesting is the fact that the significant racial difference in burden perceptions remained even after factoring in the cultural justifications made for assuming the role of caregiver. This finding aligns with those of others examining the burden perceptions of caregivers (Dilworth-Anderson et al., 2004; White, Townsend, & Parris Stephens, 2000).

Third, this research showed that women's use of cultural influences to justify their caregiving role also varied by race. African American women were more likely than their white counterparts to culturally justify the experience of caregiving and the demands that such placed upon them. In other words, culturally speaking, African American women were more likely than their white counterparts to find meaning in their role as caregiver. The significant difference in cultural justification between these two racial subgroups remained even after controlling for factors like age, education, income and relationship to the patient. There appear to be some limitations, however, with respect to the ability of the CJCS to properly distinguish the experiences of caregiving that render differing perspectives with regard to cultural reasons and expectations of caregiving. For example women who are caring for spouses, whether White or Black, tend to be able to justify their roles more than those caring for other types of family members or close friends. Unfortunately, the CJCS was unable to help us distinguish whether the role justification was truly due to cultural influences or expectations inherent in the relationship.

From Phase II of the study, there are several indications as to why the perceptions of burden differ between the two subpopulations and why there may be greater acceptance of the role, as measured by the CJCS, for African American women. The role of faith and the possession of a strong sense of spirituality likely contribute greatly to the coping capacity of African American women when caring for a loved one at the end of life. This sense of spirituality, however, also prevents women from requesting assistance in their role as caregiver and from exhibiting frustrations with the role and all the challenges it brings as showing so is seen as having a lack of faith. The self-isolation

concept revealed through the narratives, which is due to several factors including a profound fear of not being at the bedside of a loved one when he or she dies, contradicts the premonition of these women have a strong social network and that such might lessen their burden. The study reveals that despite the resilient factors African American women possess (faith and family for example) that could serve to decrease the burden of caregiving, there are beliefs and attitudes that deter accessing or taking advantage of these supports. Some of these include role-identity within the family, perceptions of strength in the women themselves, and belief that failing to take it all on without complaint may be position them as having little or no faith.

Forth, findings from this study indicated that there was no significant association between actual (measured by number and duration of activities of daily living and instrumental activities of daily living) and perceived (measured by ZBI) burden among the study participants. However, it did find that cultural justification of caregiving was significantly associated with perceived burden, but not actual burden. As mentioned, women whose cultural influences, as measured by the cultural justification for caregiving scale, provide meaning in their role as a caregiver for loved ones perceived the burden of this experience to be lesser than those for whom similar meaning is not found. The women finding this greater meaning for the role of caregiving in this study were African American women and White women who were caring for long-time spouses.

A more comprehensive examination could reveal attributes of both groups of women that would greatly contribute to addressing and reducing the risks that the role of caregiving brings to both groups. Given that the majority of caregivers are women, it is important to consider the multiplicity of roles that women possess and the confluence or

interactions of these roles. Thoit and others (Thoits, 1995; Thoits, 1992)theorize that role-centricity plays a role in influencing the psychological well-being of those whose roles are perceived as important in their self-identity. Supposedly, individuals gain more meaning, purpose, and behavioral guidance as a result of enacting a role that is more central to their self-concept and that such gains contribute to greater psychological adjustment and less distress. For example, Martire and colleagues examined the "mother role" relative to other roles like wife and employee and found that the moderation effect for the mother role was that stress may not have negative effects on well-being when it occurs in a role that is highly central and in which there are expectations of high levels of stress (Martire, Parris Stephens, & Townsend, 2000). It could be that this construct of role-centrality may explain the shortcomings of the CJCS in distinguishing between African American and White women by examining the importance placed upon the distinct roles of caregiver (for African American women) and wife (for White women). In addition to role-centrality, for this study as well as others (Aranda & Knight, 1997; Siefert, Williams, Dowd, Chappel-Aiken, & McCorkle, 2008), African American women differed significantly in that they were providing care for an array of others. Just as women are natural caregivers for their families, historically, African American women have provided care to others since slaves were first brought to America to provide labor services. In a 1998 review of literature on the mental health and well-being of Black women, Gibbs and Fuery (Gibbs & Fuery, 1998) reveals two prominent views of Black women; one as victims of discrimination, economic exploitation, and social rejection for over 370 years, and the other as having overcome many of these barriers through the development of a set of cultural attitudes, a pattern of coping strategies, and a series of

help-seeking behaviors which have enabled them to survive and sometimes thrive in a frequently hostile, exploitive, and unsupportive environments. Epstein's argument that the apparent irony of the "multiple negative" effect (Epstein, 1973) for Black women professionals and Smith's "positive marginality" effect (Smith, 1986) may actually influence the self-perceptions of Black women in ways that enable them to transcend limitations and exceed expectations for particular tasks and social roles.

The study does contribute concepts that should be considered in developing interventions aimed at caregivers. For example, it is clear that family role plays a critical role in the identifying the "caregiver" in the family whether defined by family members or by the caregiver herself. Being able to identify whether or not one fits this role is key to being able to prepare women for greater self-efficacy in the role of the "family's caregiver". If women are able to identify themselves as natural or designated carers, they might be persuaded to engage in activities that would benefit their families and better prepare them for the caregiving role should it be realized. Likewise, this study indicates that when a woman is caring for her spouse, she is more likely to realize a greater meaning to her role than those caring for non-spouses.

We can assume that women who are caregiving will suffer a degree of "mental anguish" that could increase the meaning they append to the role but likely decrease their propensity to seek respite or support for it. These women assume the role of medical care provider at home without the full comfort and self-efficacy for this role. Some, in fact, even feel that the system has given up on the patient and have abandoned them in the role of caregiver. Interventions could also focus on the health care systems in order to avoid the perception that when there is no cure or treatment, one is abandoned by the health

care system. If the medical care team could be made to consider a cancer patient at the end of life a dyad where both the patient and his/her caregiver warrant and receive attention, care, and support, the caregiver might be made less vulnerable to the impact of their role as caregiver.

Despite the illuminations that speak to potential constructs that can be employed in intervention development such as isolation and faith contradiction, it is likely that interventions will have greater impact if they focused on those with the potential to support and influence the caregiver rather than the women themselves. Interventions aimed at families, friends, church members of caregivers and the medical teams of the patients they care for are likely to have greater results than those aimed at reaching extremely stressed women who are already so overwhelmed with the day-to-day management of a loved one whose life is threatened by cancer that they fear leaving their side for any period of time. Asking caregivers to temporarily step away from this situation to engage in an intervention is not likely to happen.

One quote that depicts and expresses the beliefs that accompany the role that resonates with this investigator is, "*I always felt that I could stand between him and dying and if I kept doing as much as I could for as long as I could he would live….but I just couldn't*." No one is able to stand in the space between life and death and believing that one can is an enormous burden in and of itself. Helping caregivers caring for loved ones with advanced or end-stage cancer is likely best aligned with interventions that provide an understanding that in some cases death is inevitable and the best gift to a loved one is less an attempt to prolong life, or prevent death than it, is a role to be a sherpa or shepherd that guides them sweetly toward it.

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Appendix A

OMB #0925-0046-21
Exp. Date: 10/31/06[1]

National Cancer Institute
Office of Communications and Education
Family Caregiver Needs Assessment Questionnaire

Date of call: _____/_____/_____ Staff Name: _____

FOR INTERNAL USE ONLY

INCLUDE IF:	EXCLUDE IF:
• Female • Between ages of 31-80 • African American; Hispanic or Latina; or White (non-Hispanic) (recruit 65 people per category) • Currently providing care for someone with cancer OR recently provided care (within last year) for someone within the last year of his/her life	• Male • Less than age 31 or over age 80 • American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander • Parent of child or young person with cancer (age 20 or less) • For living relative - Not currently providing care for living relative OR did not provide care during the last year of life for someone who is now deceased

Language for disqualification: I'm sorry, but we are currently looking for people who fit a different profile. Thank you for your time and interest in this research.

Language for stopped interview: Thank you very much for your time. Would you be willing for NCI to use the information you've already provided? [If not, inform respondent that the information will be shredded and not included in the analysis.]

Thank you for calling the National Cancer Institute Education Support Project. This is [insert name of the individual screening calls]. How may I help you?

[1] Instrument was approved under the 2006 OMB package, and research has approval from NCI to be conducted past OMB expiration date.

[If caller is interested in participating in caregiver research]

Thank you for your interest in participating in this study. I am going to ask you a few basic questions about yourself and your experiences as a family caregiver. First, I need to provide you with some background on the study and your rights and protections as a participant.

This research is being conducted by Lenora Johnson at the National Cancer Institute's Office of Communications and Education, in partial fulfillment of doctoral research at the George Washington University School of Public Health. Findings will help to expand the understanding of caregivers and support NCI's development of information for cancer caregivers.

Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed to anyone outside of this study, except as otherwise required by law. While every effort will be made to keep the information you share with me confidential, this cannot be guaranteed as there is always a slight possibility of loss of confidentiality. There will be close to 200 women interviewed. The data will be reported in aggregate form only, with any potentially identifying information removed. You may skip any questions that you prefer not to answer. You may stop the interview at any time. Your participation in this study involves a survey which will take about 15 to 20 minutes to complete. *Do I have your permission to continue?*

- ☐ Yes [Continue]
- ☐ No [Thank respondent and discontinue interview]

You are or have been providing care for a loved one with cancer. Since caregiving can cause both physical and emotional stress for many people, some of the questions I ask may bring up difficult emotions for you. If these feelings become too much, please let me know and we can either stop the interview and reschedule it or pause and give you some time. The information you provide will help us to develop resources for other family caregivers.

Finally, if you have any questions about participating; there are several places for you to call to get further information about your rights as a study participant. These include:

The Office of Human Research of George Washington University at (202) 994-2715
The ORC/Macro Institutional Review Board at (301) 572-0340
The Office of Communications and Education at NCI at (301) 496-6792

[I CERTIFY THAT I HAVE READ THE ABOVE PARAGRAPHS TO THE RESPONDENT.
SIGNATURE: _____]

GENERAL QUESTIONS – ALL CALLERS

1. Note gender [DO NOT READ]:
   - ❑ Male [*DISQUALIFY*]
   - ❑ Female [RECRUIT]

2. Are you: [READ CHOICES; SELECT ONE]
   - ❑ Age 18-20 [*DISQUALIFY*]
   - ❑ Age 21-30 [*DISQUALIFY*]
   - ❑ Age 31-45 [CONTINUE]
   - ❑ Age 46-60 [CONTINUE]
   - ❑ Age 61-70 [CONTINUE]
   - ❑ Age 71-80 [CONTINUE]
   - ❑ Age 81+ [*DISQUALIFY*]

3. Would you describe your race/ethnicity as [RECRUIT MIX OF CAUCASIAN, AFRICAN AMERICAN AND LATINAS]:
   - ❑ American Indian or Alaska Native [*DISQUALIFY*]
   - ❑ Asian [*DISQUALIFY*]
   - ❑ African American [CONTINUE]
   - ❑ Hispanic or Latino (please specify country of origin): _____ [CONTINUE]
   - ❑ Native Hawaiian or Other Pacific Islander [*DISQUALIFY*]
   - ❑ White (non-Hispanic) [CONTINUE]

4. How would you classify your relationship to the patient?
   - ❑ Spouse/partner
   - ❑ Parent of patient over age 21
   - ❑ Parent of patient age 20 or less [*DISQUALIFY*]
   - ❑ Sibling
   - ❑ Child of patient
   - ❑ Extended relative (example: aunt, uncle, cousin)
   - ❑ Friend
   - ❑ Other (specify): _____

5. What is the <u>treatment status</u> of your [<u>father's/mother's/brother's/etc.</u>] cancer?
   - ❑ In treatment
     - ❑ for getting rid of the cancer (“curative”)
     - ❑ for comfort care only (palliation)

     Type of treatment
     - ❑ Receiving chemotherapy
     - ❑ Receiving radiation therapy
     - ❑ Surgery
     - ❑ Other (specify): _____
   - ❑ Treatment completed with success

     Under 5 years (specify: _____)

- Over 5 years (specify: _____)

❒ Don't know
- Please describe what you do know about the treatment:

_____

_____

_____

- Deceased [SKIP TO Q7]

6. What is the stage of your [father's/mother's/brother's/etc.] cancer?
   - Stage I (i.e., "early stage") [*DISQUALIFY*]
   - Stage II (i.e., "early stage") [*DISQUALIFY*]
   - Stage III (i.e., "advanced") [SKIP TO Q8] [IF AFRICAN AMERICAN, RECRUIT FOR IN-DEPTH INTERVIEW—Q20]
   - Stage IV (i.e., "advanced") [SKIP TO Q8] [IF AFRICAN AMERICAN, RECRUIT FOR IN-DEPTH INTERVIEW—Q20]
   - Don't know (Please indicate whether you know whether the cancer is operable/treatable or not)

     _____

BEREAVED CAREGIVERS ONLY

7. Approximately how long ago did your [father/mother/brother/etc.] pass away?
   - ❑ Less than a month ago [CONTINUE]
   - ❑ 1-2 months ago [CONTINUE]
   - ❑ 3-4 months ago [COTINUE]
   - ❑ 5-6 months ago [CONTINUE]
   - ❑ 7-8 months ago [CONTINUE]
   - ❑ 9-10 months ago [CONTINUE]
   - ❑ 10-11 months ago [CONTINUE]
   - ❑ 1 year ago [CONTINUE]
   - ❑ More than 1 year ago [*DISQUALIFY*]

   a. Did you provide care in some form (providing emotional support, taking to doctor appointments, helping with day-to-day household or medical tasks) towards the end of his/her life?
      - ☐ Yes [IF AFRICAN AMERICAN, RECRUIT FOR IN-DEPTH INTERVIEW—Q20]
      - ☐ No [CONTINUE]

8. Did you provide unpaid care to your [Q4 response] to help him/her take care of him/herself within the last 12 months of his/her life?

   - ❒ Yes
   - ❒ No [DISQUALIFY]

9. What type(s) of cancer was your [Q4 response] diagnosed with? [RECUIT MIX OF CANCER TYPES; IF DON'T KNOW PRIMARY SITE, PLEASE INDICATE SITE(S) IF KNOWN]

   _____

10. How long did you provide help to your [Q4 response] – best estimate of time? (SELECT ONE)

    - ❒ Less than 3 months
    - ❒ 3 to 6 months
    - ❒ More than 6 months

11. In what type of setting did your [father/mother/brother/etc.] last receive care?
    - ❒ Hospice
      - ❑ In Home
      - ❑ Residential/In Patient
    - ❑ Hospital
      - ❑ Inpatient
      - ❑ Outpatient

- ❑ Nursing home
- ❑ Home care
- ❑ Physician's Office/Clinic
- ❑ Other: _____

12. Thinking now of the things you did to help your [Q4 response], about how many hours did you spend in an average week, doing these things?

    [verbatim response]_____

    - ❒ Less than 1 hour per week
    - ❒ _____ hours per week
    - ❒ More than 40 hours per week [constant volunteered care provided]
    - ❒ Don't know

13. I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by himself/herself. For each, just tell me if you provided this kind of help. Did you help your [Q4 response] (check all with a 'yes' response):

    - ❒ Get in and out of bed and chairs (A)
    - ❒ Get dressed (A)
    - ❒ Get to and from the toilet (A)
    - ❒ Bathe or shower (A)
    - ❒ Deal with incontinence or diapers (A)
    - ❒ By feeding him or her (A)
    - ❒ By giving medicines, pills, or injections (A)
    - ❒ By managing finances, such as paying bills, or filling our insurance claims (I)
    - ❒ By grocery shopping (I)
    - ❒ With housework, such as doing dishes, laundry, straightening up (I)
    - ❒ By preparing meals (I)
    - ❒ By providing transportation, either by driving him/her or helping get his/her transported (I)
    - ❒ By arranging or supervising services given by others (I)

14. Did anyone else provide <u>unpaid</u> help to your [Q4 response] during the time you cared for him/her?
    - ❒ No
    - ❒ Yes

    [IF YES] Who else provided help? (Probe for relationship(s) to patient, and how many people total)

    _____
    ___

    About how many hours per week <u>total</u>? _____ [If respondent does not know exact amounts of time, probe as follows:]

Could you perhaps estimate if the time was more than, less than, or about equal to the time you spent providing care? [SELECT ONE]

- ❒ More than you
- ❒ Less than you
- ❒ About equal to you
- ❒ Still can't determine

15. Did anyone else provide paid help to your [Q4 response] during the time you cared for him/her (nurses aid, homekeeper, health aid, respite worker, etc.)?

- ❒ Yes If yes, about how many hours per week? _____
- ❒ No

Now I would like to read you several statements about providing care for your relative/friend, and ask you to respond to them. Please respond "never," "rarely," "sometimes," "quite frequently," or "nearly always." I'll remind you of the response choice when I read each statement.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
a. Did you feel that because of the time you spent with your relative that you didn't have enough time for yourself?					
b. Did you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
c. Did you feel angry when you were around your relative?					
d. Do you feel that your relative (when he/she was sick) affected your relationship with family members or friends in a negative way?					
e. Did you feel strained when you were around your relative?					
f. Do you feel that your health has suffered because of your involvement with your relative?					
g. Did you feel that you didn't have as much privacy as you would like because of your relative?					
h. Did you feel that your social life suffered because you were caring for your relative?					
i. Did you feel that you had lost control of your life during your relative's illness?					
j. Did you feel uncertain about what to do about your relative?					
k. Did you feel you should have been doing more for your relative?					
l. Do you feel you could have done a better job in caring for your relative?					

Now I'm going to read some additional statements about caregiving, to which I'd like to know how much you agree or disagree. Please respond "strongly agree," "somewhat

agree," "somewhat disagree," and "strongly disagree." I'll remind you of the response choice when I read each statement.

	I gave care to _____ because…..	Strongly Agree	Somewhat Agree		Somewhat Disagree	Strongly Disagree
m.	It is my duty to provide care to family members who is seriously ill.					
n.	It is important to set an example for the children in the family.					
o.	I was taught by my parents to take care of family members.					
p.	Of my religious and spiritual beliefs.					
q.	By giving care to family members, I am giving back what has been given to me.					
r.	It strengthens the bonds between me and them.					
s.	I was raised to believe care should be provided in the family.					
t.	It is what my people have always done.					
u.	I feel as though I am being useful and making a family contribution.					
v.	My family expects me to provide care.					

16. What is the highest level of education you have completed? [RECRUIT MIX]
    - ❑ Less than high school diploma [CONTINUE]
    - ❑ High school diploma [CONTINUE]
    - ❑ Some college/trade school [CONTINUE]
    - ❑ College (bachelor's degree) [CONTINUE]
    - ❑ Graduate school [CONTINUE]

17. Would you describe yourself as living in a:
    - ❑ Rural area

    (Defined as a town with less than 2,500 people, and more than 20 miles away from a city with a population of at least 50,000)

    - ❑ Suburban area

    (Defined as a town with more than 2,500 people, and within 20 miles of a city with a population of at least 50,000)

    - ❑ Urban area *(Defined as a city with population of at least 50,000)*

18. Is your combined household income: [RECRUIT MIX]
    - ❑ Less than $30,000 per year
    - ❑ $30,000-80,000 per year
    - ❑ More than $80,000 per year
    - ❑ Prefer not to answer

19. Are you employed or volunteer in a cancer-related medical setting (a place where cancer patients are seen and given physical and/or mental health care)?
    - ❑ No [CONTINUE]
    - ❑ Yes [CONTINUE]

    If yes, how would you best describe your job?
    - ❒ Administrative/clerical
    - ❒ Nurse
    - ❒ Nurse's aide
    - ❒ Physician assistant
    - ❒ Physician
    - ❒ Social worker or counselor
    - ❒ Hospice volunteer
    - ❒ Other (please describe: _____)

20. (FOR AFRICAN AMERICAN BEREAVED OR ADVANCED STAGE [III or IV] CAREGIVERS ONLY; THIS GROUP HAS GREATER MORBIDITY RATES RELATED TO CAREGIVING AND MAY REQUIRE MORE RESEARCH)
    We'd like to invite you to participate in an additional telephone interview within the next few weeks. This interview would be to talk about some of your experiences with caregiving and your sources of strength. We would schedule this at a time convenient to you and it would take about 45-60 minutes. You would also receive $50 for your participation. Would you be willing to participate?
    __ Yes [ADVISE RESPONDENT SOMEONE WILL CONTACT HER TO SET UP A CONVENIENT TIME, THEN CONTINUE TO Q21]
    __ No [CONTINUE]

21. Are you are interested in receiving a brief report about this study's findings when they are available? (We will send the report by email if you have an account; I will get your contact information in a minute.)
    - ❑ YES, PLEASE SEND [CONTINUE]
    - ❑ NO [SKIP TO CLOSE]

CURRENT CAREGIVERS

10. Are you providing unpaid care to your [Q4 response] to help him/her take care of him/herself now or within the past 12 months?

- ❒ Yes
- ❒ No [DISQUALIFY]

11. What type(s) of cancer was your [Q4 response] diagnosed with? [RECUIT MIX OF CANCER TYPES; IF DON'T KNOW PRIMARY SITE, PLEASE INDICATE SITE(S) IF KNOWN]

_____

12. How long have you been providing/provided help to your [Q4 response] – best estimate of time? [SELECT ONE]

- ❒ Less than 3 months
- ❒ 3 to 6 months
- ❒ More than 6 months

11. In what type of setting does your [Q4 response] currently receive care? [RECRUIT MIX]

- ❒ Hospice
  - ❑ In Home
  - ❑ Residential/In Patient
- ❑ Hospital
  - ❑ Inpatient
  - ❑ Outpatient
- ❑ Nursing home
- ❑ Home care
- ❑ Physician's Office/Clinic
- ❑ Other: _____

12. Thinking now of the things you do to help your [Q4 response], about how many hours did/do you spend in an average week, doing these things?

- ❒ Less than 1 hour per week
- ❒ _____ hours per week
- ❒ More than 40 hours per week [constant volunteered care provided]
- ❒ Don't know
- ❒ [verbatim response]_____

13. I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by himself/herself. For each, just tell me if you provide this kind of help. Do you help your [Q4 response] (check all with a 'yes' response):

- ❒ Get in and out of bed and chairs (A)
- ❒ Get dressed (A)
- ❒ Get to and from the toilet (A)
- ❒ Bathe or shower (A)
- ❒ Deal with incontinence or diapers (A)
- ❒ By feeding him or her (A)
- ❒ By giving medicines, pills, or injections (A)
- ❒ By managing finances, such as paying bills, or filling our insurance claims (I)
- ❒ By grocery shopping (I)
- ❒ With housework, such as doing dishes, laundry, straightening up (I)
- ❒ By preparing meals (I)
- ❒ By providing transportation, either by driving him/her or helping get his/her transported (I)
- ❒ By arranging or supervising services given by others (I)

14. Has anyone else provided unpaid help to your [Q4 response] during the time you've been caring for him/her?
    - ❒ No
    - ❒ Yes

[IF YES] Who else provides help? (Probe for relationship(s) to patient, and how many people total)

_____
_____

- ❒ About how many hours per week total? _____ [If respondent does not know exact amounts of time, probe as follows:]
  Could you perhaps estimate if the time is more than, less than, or about equal to the time you spend providing care? [SELECT ONE]
  - ❒ More than you
  - ❒ Less than you
  - ❒ About equal to you
  - ❒ Still can't determine

15. Has anyone else provided paid help to your [Q4 response] during the time you've been caring for him/her (nurses aid, homekeeper, health aid, respite worker, etc.)?

    - ❒ Yes If yes, about how many hours per week? _____
    - ❒ No

Now I would like to read you several statements about providing care for your relative/friend, and ask you to respond to them. Please respond "never," "rarely," "sometimes," "quite frequently," or "nearly always." I'll remind you of the response choice when I read each statement.

		Never	Rarely	Sometimes	Quite Frequently	Nearly Always
a.	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
b.	Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
c.	Do you feel angry when you are around your relative?					
d.	Do you feel that your relative currently affects your relationship with family members or friends in a negative way?					
e.	Do you feel strained when you are around your relative?					
f.	Do you feel that your health has suffered because of your involvement with your relative?					
g.	Do you feel that you don't have as much privacy as you would like because of your relative?					
h.	Do you feel that your social life has suffered because you are caring for your relative?					
i.	Do you feel that you have lost control of your life since your relative's illness?					
j.	Do you feel uncertain about what to do about your relative?					
k.	Do you feel you should be doing more for your relative?					
l.	Do you feel you could do a better job in caring for your relative?					

Now I'm going to read some additional statements about caregiving, to which I'd like to know how much you agree or disagree. Please respond "strongly agree," "somewhat agree," "somewhat disagree," and "strongly disagree." I'll remind you of the response choice when I read each statement.

I give care to _____ because…..	Strongly Agree	Somewhat Agree		Somewhat Disagree	Strongly Disagree
m. It is my duty to provide care to family members who is seriously ill.					
n. It is important to set an example for the children in the family.					
o. I was taught by my parents to take care of family members.					
p. Of my religious and spiritual beliefs.					
q. By giving care to family members, I am giving back what has been given to me.					
r. It strengthens the bonds between me and them.					
s. I was raised to believe care should be provided in the family.					
t. It is what my people have always done.					
u. I feel as though I am being useful and making a family contribution.					
v. My family expects me to provide care.					

16. What is the highest level of education you have completed? [RECRUIT MIX]
    - ❑ Less than high school diploma [CONTINUE]
    - ❑ High school diploma [CONTINUE]
    - ❑ Some college/trade school [CONTINUE]
    - ❑ College (bachelor's degree) [CONTINUE]
    - ❑ Graduate school [CONTINUE]

17. Would you describe yourself as living in a:
    - ❑ Rural area

    (Defined as a town with less than 2,500 people, and more than 20 miles away from a city with a population of at least 50,000)

    - ❑ Suburban area

    (Defined as a town with more than 2,500 people, and within 20 miles of a city with a population of at least 50,000)

    - ❑ Urban area *(Defined as a city with population of at least 50,000)*

18. Is your combined household income: [RECRUIT MIX]
    - ❑ Less than $30,000 per year
    - ❑ $30,000-80,000 per year
    - ❑ More than $80,000 per year

- ❑ Prefer not to answer

19. Are you employed or volunteer in a cancer-related medical setting (a place where cancer patients are seen and given physical and/or mental health care)?
    - ❑ No [CONTINUE]
    - ❑ Yes [CONTINUE]

    If yes, how would you best describe your job?
    - ❒ Administrative/clerical
    - ❒ Nurse
    - ❒ Nurse's aide
    - ❒ Physician assistant
    - ❒ Physician
    - ❒ Social worker or counselor
    - ❒ Hospice volunteer
    - ❒ Other (please describe: _____)

20. Are you are interested in receiving a brief report about this study's findings when they are available? (We will send the report by email if you have an account; I will get your contact information in a minute.)
    - ❑ YES, PLEASE SEND [CONTINUE]
    - ❑ NO [SKIP TO CLOSE]

So we can send you a report (if desired), or in case we need to ask you some additional questions, I'd like to find out some basic contact information.

CONTACT INFORMATION		
Name:		
Street Address:		
Apartment/Suite #:		
City:	State:	Zip:
Phone:		
Email:		

CLOSE:

Thank you very much for your time today. If you'd like additional information on cancer or caregiving, you can call 1-800-4-CANCER (1-800-422-6237) or visit www.cancer.gov.

We very much appreciate your interest and support in NCI's work.

Appendix B

In-Depth Interview Semi-Structured Guide
Female African American Caregivers of
Advanced Stage Cancer Patients
Duration: 1 Hour

I. Introduction [1 minute]

- ☐ Hello, my name is [_____]. Thank you for agreeing to speak with me today.
- ☐ We are talking with caregivers like yourself, who are caring for people with advanced cancer, in order to help understand your experiences and the issues you confront on a daily basis.
- ☐ We also want to find out what helps people cope, or what makes it difficult to cope, especially for people who are caring for people with advanced stages of cancer.
- ☐ This information will be used by the National Cancer Institute in helping other caregivers like you, for information or programs they develop in the future.

II. Informed Consent [2 minutes]

Before we begin, I need to let you know that this interview should last about 45-60 minutes. What we discuss today will be confidential and will not be disclosed to anyone outside of this study except as otherwise required by law. You may stop this interview at any time. You may also refuse to answer any question. If you do so, we'll still send you a gift card for $50. For note taking and report purposes only, I am recording our discussion so I can accurately report what you tell me. The tape will be destroyed after we analyze the data, and your name and other personal identifying information will not be used or connected in any way with the data in our final report. Do I have your permission to continue?

- ☐ Yes [Continue]
- ☐ No [Thank respondent and discontinue interview]

[I CERTIFY THAT I HAVE READ THE ABOVE PARAGRAPH TO THE RESPONDENT. SIGNATURE: _____]

Language for stopped interview: Thank you very much for your time. Would you be willing for NCI to use the information you've already provided? [If not, inform respondent that the information will be shredded and not included in the analysis.]

III. Questions to Guide the Discussion [30-45 minutes]

1. Tell me a bit about your loved one and his or her experience with cancer.

2. Tell me a little about what's most important to you in life.

3. What does the end-of-life stage of cancer mean to you personally?

4. Have you experienced this sort of loss before – meaning have you lost other loved ones who were close to you?

    a. If so, were you also providing care and support for them?

    b. How does this current caregiving experience differ from previous one (if it differs)?

    c. How is it similar to other losses?

5. Are there particular beliefs or activities that accompany your experiences related to death, dying and the end of life?

6. Regarding your role as a primary caregiver, how did it come to be that you filled this role?

    a. What was it like for you?

    b. Describe a very difficult time. How did you feel then?

    c. Describe a positive caregiving time.

    d. Have there been times you, personally, had someone providing care to you? How does this relate (if at all) to your experience as "caregiver"?

7. Let's talk about things that you do to support yourself in your role as caregiver.

    a. Were you able to discuss some of the more complicated issues that accompany end of life with your loved one, such as their wishes for life sustaining measures, living wills, etc.? Please tell me about those discussions and how you coped.

    b. What about your communications about these same issues with the health professionals who treat(ed) him/her? How comfortable were you with these discussions?

    c. What about your discussions about these complex issues with other family members? How did you cope with them?

d. How much time do you take each day to provide for your own needs (health care needs like keeping up with routine appointments, eating right, getting exercise and sufficient sleep/rest, finding time for self) while providing care to your loved one?

e. How do you go about obtaining additional help in providing care? Do you call upon others? Do you utilize services that might be available to you? What, if any, networks (like church, social groups, or Internet support groups) do you use to lean on when you need something?

f. How have those networks helped you?

g. If you were not currently providing care to your loved one, what are some things you would be doing with the time that caring now occupies?

IV. Life's Critical Events and Coping Strategies [10-15 minutes]

1. Consider your life. Think for a minute about what some of the most memorable experiences have been (the highs) and what some of the most difficult experiences have been. Please just think about them, don't tell me anything about them. [Respondent should not be asked to share this with the interviewer.]

2. In thinking of the difficult experiences, what are some things that helped you during that time?

    a. Explore spiritual and other coping strategies – cultural influences of such.

    b. How are those same things helping you now to cope with the stress of caregiving?

    c. What are some possible new sources of strength that you didn't have before?

    d. What kinds of stress are you under now that maybe you weren't under before?

3. In thinking about the most positive experiences, have those contributed in some way to how you find strength to provide care? How?

4. If you were to talk with someone else who is in a similar situation as yourself, what advice would you offer them?

V. Closing

I really appreciate how much you have shared with me today about your experiences with caregiving. As a token of our appreciation, you should be receiving a $50 gift card from us in the mail within the next few weeks. [Confirm mailing address.] If you think of anything else you would like to add, please feel free to contact me at [phone] or [email]. If you'd like additional information on cancer or caregiving, you can call 1-800-4-CANCER (1-800-422-6237) or visit www.cancer.gov. Thank you for all your time and support of this study.

Appendix C1

We'd Like To Hear From You

The National Cancer Institute (NCI), a federal agency that is part of the National Institutes of Health (NIH) and the George Washington School of Public Health, would like to talk to women who are providing care for a family member or friend with cancer. We'd like to learn about your caregiving experience and how you have coped.

If you are:

- Female
- Between the ages of 31 and 80
- Currently providing care for someone over the age of 20 with cancer, OR you provided care for someone over the age of 20 with cancer at end-of-life within the last year

Please call us toll-free at:

1-888-249-0029

(Monday to Friday, 9am-5pm EDT)

We will ask you some questions about yourself and your caregiving experience. Participating in this study involves a total of 15-20 minutes by phone. If they qualify, eligible participants may be asked to provide additional information about their caregiving experiences in a follow-up telephone interview that will last approximately 45-60 minutes.

Appendix C2

Are you an African American woman caring for a family member or loved one with cancer?

Cancer affects an entire family. Those with loved ones battling cancer often find themselves struggling right along side of them. African American women especially are impacted by the stress of caregiving.

The National Cancer Institute (NCI) and the George Washington University School of Public Health would like to talk to women who are caring for a family member or friend with cancer. We would like to learn about your experiences and how you cope.

If you are:

- ❑ **An African American woman**
- ❑ **Between 31 and 80 years of age, and**
- ❑ **Caring for and adult with cancer, OR you cared for an adult with cancer at the end of life within the last 12 months**

Please call us at **1-888-249-0029** (Mon-Fri, 8am-5pm EDT)

We will ask you some questions about yourself and your caregiving experience. This will take 15-20 minutes by phone. If you qualify, you may be asked to provide additional information in a follow-up telephone interview that will last approximately 45-60 minutes, for which you will be compensated $50.00 for your time.

Appendix D

Caregiver Research Study
Recruitment Contacts

Primary Recruitment Strategies
Outreach • Blast emails • Targeted calling and letters • Flyer distribution (conferences and insertion into newsletters) • Outreach through local physicians • Ads in targeted publications (African American & Hispanic/Latino) • Radio show promotion

Study recruitment was conducted through a variety of methods, including blast emails to intermediary organizations listed on NCI's Partnering on Educational Tools (POET) database; targeted calling to organizations with end-of-life and/or caregiving focus, hospitals and clinics, and churches; flyer distribution to conferences and pharmacies. Additionally, Lenora Johnson participated in radio shows with local radio stations as well as XM Satellite radio shows. Interested individuals contacted a toll-free number for screening. A detailed summary of recruitment outreach strategies appears below.

A total of 22 women were then invited to participate in additional in-depth telephone interviews lasting 60-90 minutes each.

A. OUTREACH

1. Email Distribution (April-December 2007)

- POET Categories Included (emails for "all contacts")
  - Patient Service Organizations (197)
  - Advocacy Organizations (261)
  - Professional Association (320)
  - Academic Institutions (81)
  - Insurance Company/HMO (5)
  - Hospital/Health Clinic (116)
  - Cancer Centers (97)
  - Community-based Organization (Health related) (196)
  - NCI Community Network Program (8)
  - CCOPs (13)

- 3 Blast emails to all POET contacts (2,790)
- Email to all Macro employees (1,200)

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2. Targeted Individual Contacts/ Flyer Distribution

Organization Name & Address	Newsletter? (Y/N)	Web site Announcement section? (Y/N)	Contact Person Name, Email, & Phone #	Date Called & Response
Aging with Dignity www.agingwithdignity.org PO Box 1661 Tallahassee FL 32302-1661 Office: 820 E Park Ave Ste D100 Tallahassee FL 32302-1661	N	Y	1-888-594-7437 fivewishes@agingwithdignity.org	Emailed a study flyer to fivewishes@agingwithdignity.org
American Cancer Society www.cancer.org	N	Y	1-800-227-2345	Discussed study on phone; Mailed letter and 200 copies of flyer
CancerCare www.cancercare.org 275 Seventh Avenue New York, NY 10001	Y	N	1-800-813-4673	Called three times, answered, transferred and disconnected
Family Caregiver Alliance www.caregiver.org 180 Montgomery Street STE. 1100 San Francisco, CA 94104	Y	Y	1-800-813-HOPE (4673) info@cancercare.org	Emailed Bonnie Lawrence with info and she said they will post it in on the site and in their newsletter for a fee of 50$ max of 50 words
Gilda's Club, Inc. www.gildasclub.org 322 Eighth Avenue, Suite 1402 New York, NY 10001	N	Y	1-888-445-3248 info@gildasclub.org	Sent an email with flyer info Swagner@Gildasclub.org Haven't heard
Hospice Foundation of America www.hospicefoundation.org			1-800-854-3402	Emailed Albert Lee flyer info. Rlee@hospicefoundation.org
Lance Armstrong Foundation www.livestrong.org PO Box 161150 Austin, TX 78716	N	Y	1-512-236-8820 (general number) 1-866-235-7205 (LIVESTRONG SurvivorCare	Talked to Brooke McMillan Mailed flyers with info to Andy Miller.

			Program)	
National Family Caregivers Association (NFCA) www.nfcacares.org			1-800-896-3650	Talked to Debbie Halpurn and said they would include an announcement in their June e-letter and send us a copy Deborah.Halpern@thefamilycaregiver.org Also repeated announcement in their November e-letter (8,000 people)
National Hospice and Palliative Care Organizations (NHPCO) www.nhpco.org 1700 Diagonal Road Suite 625 Alexandria, VA 22314	N	Y	1-703-837-1500 1-800-658-8898 (helpline) nhpco_info@nhpco.org	Gave recommendation to The Heartland Hospice & the Capital Hospice
The Well Spouse Foundation www.wellspouse.org 63 West Main Street, Suite H Freehold, NJ 07728	Y	Y	1-800-838-0879 732-577-8899 info@wellspouse.org	Emailed Donna info@wellspouse.org Said she would pass email around to board and try to put it on their site
The Heartland Hospice 12304 Baltimore Ave Beltsville, MD 20705			240-264-1692	Mailed flyers to Bernadette Wengert.
The Capital Hospice			800-869-2136	Left message about the study.

Personal Contacts (Lenora) – With Appropriate Networks & Broad Reach

Name	*E-Mail*	*Agency*
Pauline Sieverding	Pauline.sieverding@va.gov	VA
Marylou Guihan	Marylou.guihan@va.gov	VA
Barbara Kreling	bkreling@aol.com	Georgetown University
Nancy Campbell	Nancy.campbell2@va.gov	VA
Collins Airhihenbuwa	aou@psu.edu	Penn State University
Charlene Day	cadHolli@aol.com	Friend/Colleague
Carolyn Banard	luvnluci@yahoo.com	Friend/Colleague
Barbara Escorza	escorzab@aol.com	Friend/Colleague
Chanita Hughes-Halbert	chanita@mail.med.upenn.edu	Friend/Colleague
Yvonne Taylor	Yvonne.Taylor@NA.AMEDD.army.mil	Walter Reed AMC
Charles vonGunten	cvongunten@SDHospice.org	San Diego Hospice

Frank Ferris	fferris@sdhospice.org	San Diego Hospice
Mariela Alarcon-Yohe	malarcon@astdhpphe.org	DHPE
Daniel Betancourt	daniel.betancourt@revlon.com	Friend/Colleague
Gloviel Rowland	PastorGlovioell@aol.com	Friend/Colleague
Felicia Solomon	solomonf@mail.nih.gov	Friend/Colleague
Mark Clanton	mclanton@mac.com	For His Mother
Rochelle Rollins	RollinsR@mail.nih.gov	Friend/Colleague
Leslie Cooper	lcooper@mail.nih.gov	Colleague
B. Lee Green	greenbl@moffitt.usf.edu	Colleague/Moffitt
Troy Cooper	Tufts4@hotmail.com	Friend
Michael Thompson	MTHOMPSO@provhosp.org	Friend/Prov. Hosp
Letitia Presley-Cantrell	prescan@aol.com	Friend/Colleague
Johnny Chip Allen	2smoov4u@sprintmail.com	Friend/Colleague
Gloria Johnson	dgjohnson4@cox.net	Parents
Linda Harris	Linda.Harris@hhs.gov	Friend/Colleague

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3. Flyer distribution

- 200 flyers distributed by Prairie View A&M University at conference.
- 1,700 flyers inserted into Sunday program at Greater Mt. Calvary Holy Church.
- 200 flyers distributed to local Giant pharmacies.
- 2500 flyers to varying churches throughout the metropolitan area through network of friends and associates.

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4. Outreach through local physicians

- Referrals from nurse at Washington Hospital Center/Mt. Calvary Comfort Ministry.
- Referrals from a physician at a predominantly African American hospice (Washington Home).
- Howard University Cancer Center

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5. Courtesy Print Ad Placement in Minority Media Channels

Publication	Market	Circulation	Publication Date	Ad Size
African American Publications				
The Baltimore Times	Baltimore, MD	25k	8/30/07	¼ page
The New York Beacon	New York, NY		8/30/07	¼ page
The Birmingham Times	Birmingham, AL	16.5	9/6/07	¼ page

The Atlanta Voice	Atlanta, GA	61.7	9/6/07	¼ page
The Atlanta Daily World	Atlanta, GA	50k	9/6/07	1/8 page
The Afro-American	Washington, DC	50k	9/6/07	1/8 page
Trends Magazine	DC and Baltimore	120k	9/19/07	1/6 page
Praise Magazine	DC-area churches			¼ page
Hispanic Publications				
El Especialito-Hudson Edition	Hudson County, NY	198.5	9/7/07	¼ page
El Colombiano	Miami/Ft. Lauderdale	35k	9/6/07	¼ page
Notikitos Magazine[2]	LA/Orange County/Riverside	35k	9/15/07	¼ page
Orale Magazine	LA/Southern CA	100k	9/10/07	¼ page
La Información	Houston and surrounding counties	100k	9/6/07	¼ page
*Que Onda! Houston Edition**	Houston	100k	9/6/07	¼ page
*Que Onda! Dallas Edition**	Dallas/Ft. Worth	65k	9/13	¼ page
*Extra—Two languages Una Voz**	Chicago and surrounding areas	67.5k	9/6	¼ page
*Reflejos Bilingual Journal**	Chicago area	98.2	9/9	¼ page

6. Radio Show Promotions

a. Sara Lomax Reese, host
Healthquest Live (heard on WURD - AM in metro Philadelphia and Delaware Valley/African American station)
Topic: African American Women as Cancer Caregivers/End-of-Life care
Deadline: Today for Monday, February25 live broadcast @ 11:30 a.m.

Spokesperson: Lenora Johnson\, NCI Communications Director

To an African American audience that is heavily female, the expert will talk about some of the concerns and issues that African American women face as cancer caregivers that are different from other populations. Station wants to address this as part of Black History Month. She will cite NCI information and mention the 1-800-4CANCER number as well as the disparities information Website developed by NCI's Center to Reduce Cancer Health Disparities (crchd.cancer.gov).

[2] Bilingual Spanish/English publication.

At the end of the interview, the show's host will inform women in the audience about a number they can call to participate in a study about African American women as cancer caregivers.

Appendix E

Zarit Burden Index Scale

Patient ID:	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
***1) DO YOU FEEL that because of the time you spend with your relative that you don't have enough time for yourself?**	0	1	2	3	4
***2) DO YOU FEEL stressed between caring for your relative and trying to meet other responsibilities (work/family)?**	0	1	2	3	4
3) DO YOU FEEL angry when you are around your relative?	0	1	2	3	4
4) DO YOU FEEL that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
***5) DO YOU FEEL strained when you are around your relative?**	0	1	2	3	4
6) DO YOU FEEL that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) DO YOU FEEL that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) DO YOU FEEL that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) DO YOU FEEL that you have lost control of your life since your relative's illness?	0	1	2	3	4
***10) DO YOU FEEL uncertain about what to do about your relative?**	0	1	2	3	4
11) DO YOU FEEL you should be doing more for your relative?	0	1	2	3	4
12) DO YOU FEEL you could do a better job in caring for your relative?	0	1	2	3	4
***4- Screen questions. A score of 8 or higher reflects high burden. Needs followup.**					
12- Survey questions. A score of 17 or higher reflects high burden. Needs followup.					
Total screen score:					
Total survey score:					
Comments:					
Care Coordinator:					
Date:					