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The Geriatric Cancer Experience in End of Life: Model Adaptation and Testing

by

Harleah G. Buck

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy College of Nursing University of South Florida

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Keywords: symptom severity, symptom distress, quality of life, structural equation modeling, spiritual needs

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Dedication

This dissertation is dedicated to the people who were willing to speak with researchers during the end of their lives and describe what the experience entailed.

Acknowledgements

Thank you to the Dean, Faculty, and College of Nursing of the University of South Florida for creating an environment within which this work could take place. Thank you to my doctoral committee for the time and effort contributed to this process. Thank you to my family for all of the encouragement and steadfast belief that this was a survivable event. Table of Contents

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ABSTRACT

The National Institutes of Health recommends the development of conceptual models to increase rigor and improve evaluation in research. Validated models are essential to guide conceptualizations of phenomena, selection of variables and development of testable hypotheses. Structural equation modeling (SEM) is a methodology useful in model testing due to its ability to account for measurement error and test latent variables. The purpose of this study was to test a model of The Geriatric Cancer Experience in End of Life as adapted from Emanuel and Emanuel's framework for a good death using SEM. It was hypothesized that the model was a five-factor structure composed of clinical status, physical, psychological, spiritual and quality of life domains and that quality of life is dependent on the other factors. The sample was comprised of 403 hospice homecare patients. Fifty six percent were male, 97% were white with a mean age of 77.7. Testing of the model used AMOS statistical software. The initial five-factor model was rejected when fit indices showed mis-specification. A three-factor model with quality of life as an outcome variable showed that 67% of the variability in quality of life is explained by the person's symptom experience and spiritual experience. As the number of symptoms and the associated severity and distress increase, the person's quality of life significantly decreases (β -0.8). As the spiritual experience increases (the expressed need for inspiration, spiritual activities, and religion)

the person's quality of life significantly increases (β 0.2). This is significant to nursing because the model provides a useful guide for understanding the relationships between symptoms, spiritual needs, and quality of life in end of life geriatric cancer patients and suggests variables and hypotheses for research. This study provides evidence for a strong need for symptom assessment and spiritual assessment, development of plans of care inclusive of symptom control and spiritual care, and implementation and evaluation of those plans utilizing quality of life as an indicator for the outcome of care provided by nurses.

Chapter One

Introduction

In the early 1900's, the chief causes of death were infectious and parasitic diseases. Today, however, degenerative causes like cancer constitute the major group of life limiting illnesses ("Cancer Facts and Figures 2006," 2007). In 2004 (latest data available) the National Center for Health Statistics (NCHS) reported a total of 2,397,615 deaths in the United States, with cancer listed as the second leading cause of death after heart disease. ("Deaths: final data for 2004", 2007). The typical cancer patient is over 65 years of age with multiple existing co-morbidities (Extermann, Overcash, Lyman, Parr, & Balducci, 1998). Currently, the median age of cancer patients at time of death, across gender and tumor types, ranges from 71 to77 years. If incident rates remain stable, the total number of cancer cases is expected to double by 2050, due primarily to the aging of the United States population. (Yancik, 2005). Eighty percent of hospice patients are 65 years of age or older and 44% of them have a cancer diagnosis (NHPCO, 2008). There is a need for the establishment of a valid conceptual model on which to base nursing practice and research specific to the complex needs of the older cancer patient in end of life.

Cancer Experience

A diagnosis of cancer has physiologic, psychological and social implications. Aging interacts with each of these dimensions. Physiologically, the geriatric patient has older organ systems, decreased immune function, co-morbid conditions and the pharmacological needs associated with these processes (Balducci & Beghe, 2000; Rao & Cohen, 2004). The existence of geriatric syndromes and uncontrolled or poorly managed co-morbidities affect cancer treatment choices and outcomes (Balducci & Extermann, 2000). Psychologically, the geriatric patient is at risk for depression with a prevalence range of 17 -25% (Rao & Cohen, 2004). Separating the symptoms associated with cancer and those of depression for the purposes of making a definitive diagnosis is often a challenge to providers (Hurria, Lachs, Cohen, Muss, & Kornblith, 2006). Socially, in the normative aging process, social interactions are reduced due to retirement, relocation, or death. End stage cancer can exacerbate the process of social isolation by confining the individual to the home or by depleting the energy needed for social interaction. A lack of social ties has been found to be an independent predictor of mortality (Binstock, 2006; Nussbaum, Baringer, & Kundrat, 2003). Conceptualization of the cancer experience in older adults should be inclusive not only of the physiologic, but also the psychological and social domains.

End of Life

End of life largely refers to the physical, psychological, spiritual and social experience of living with a time limiting diagnosis. End of life care is a health care system issue that is receiving increasing amounts of attention as the population ages. Older adults report that quality end of life care is an integrated whole consisting of several elements – adequate pain and symptom management, avoidance of merely life prolonging treatment, self-determined decision making, relieving burdens on their loved ones while strengthening relationships with them (Singer, Martin, & Bowman, 2000). The hospice movement emerged in response to the depersonalized, technology-focused

health care models in use in the 1950's and 1960's (Krisman-Scott, 2003). In only one decade (1991-2000) the number of adult hospice patients tripled, with those 85 and older increasing five-fold (Han, Remsburg, McAuley, Keay, & Travis, 2006). The average daily census of patients in hospices has only increased since that time.

Older adults are reported to view quality of life holistically and define it as a subjective experience of that which makes life worth living, encompassing: 1) relationships with others; 2) inconsistency and ambiguity; and 3) personal choice and control (Hendry & McVittie, 2004). Conceptually, quality of life and quality of dying for end of life patients can be viewed as anchors on a continuum. Quality end of life should continue through to a good death, conceptualized by many older people as quick, painless, without suffering, without knowledge of that impending death (in their sleep was preferred), and at peace with God and man (Vig & Pearlman, 2004). A bad death was described as prolonged, painful, suffocating, and filled with suffering and being a burden to others. Reported self-care behaviors used to improve quality of life include distraction with enjoyable activities, ignoring treatment regimens until symptoms increase, and thinking about dying at times but not being consumed by the thought. Planning for death ("getting their affairs in order") improves quality of life by relieving the perception that the person is a burden on their loved ones. While death is openly spoken of and acceptance voiced, unique goals, wishes, and concerns remain (Vig & Pearlman, 2003, 2004). Due to the importance of quality of life to the individual, conceptualization of the end of life experience for geriatric patients should include quality of life as a measureable outcome.

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Models in End of Life

MacCullum and colleagues (MacCallum, Wegener, Uchino, & Fabrigar, 1993) define a model as the mathematical expression of the relationships and processes arising from the observation of phenomena. The National Institutes of Health (NIH) recommend the development of conceptual models and standardization of operational definitions to increase the rigor of research and improve evaluation in current end of life research (NIH State-of-the-Science Conference Statement on improving end-of-life care, 2004). George (2002), in a state of the science review of design issues in end of life research, notes that limitations in this area are often conceptual in origin. George contends that clarity, design, and implementation issues are all linked and limited by the conceptual frameworks upon which a study is built. A systematic review of empirical literature related to symptoms in lung cancer found that only 3 studies out of 18 explicitly cited a theoretical framework (Cooley, 2000). A review of National Cancer Institute symptom management trials specifically recommends the development of conceptual frameworks that 1) have quality of life as a primary end point and 2) hypothesize the linkages between symptoms, symptom management, and different domains of quality of life (Buchanan, O'Mara, Kelaghan, & Minasian, 2005). Taxonomic issues related to whether the terms conceptual or theoretical, framework or model are used, complicates any discussion. A further limitation of current conceptual frameworks is the lack of testing with empiric data. This highlights the need for validated conceptual models.

Structural Equation Modeling

Structural equation modeling (SEM) is a statistical methodology that builds upon the general linear modeling methods. In classical linear modeling approaches, models are made to fit raw data and errors in the independent variables are considered negligible. SEM, however, is considered more powerful in that measurement error is explicitly accounted for, latent variables are allowed, and interactions, nonlinearities, correlated error terms and multicollinearity are taken into account. The analysis of the covariance structures of the observed variables allows for explanations of the relationships between the unobserved or latent variables. The assumption is that the unobserved variables generate the structure among the observed variables. The study of complex models and the effects (direct, indirect, and total) of variables are strengthened with the use of SEM (Byrne, 2001; Garson, n.d.; Lee, 2005; Long, 1983; Raykov, 2006).

SEM is primarily used for confirmatory rather than exploratory data analysis (Raykov, 2006). Relationships between variables, and their error terms, are specified a priori. This allows for testing of hypotheses related to those relationships. SEM has been recommended when theoretical testing is not well developed and ethical concerns exist concerning manipulation of variables. Multiple disciplines, from economics to medicine, make use of SEM due to these very strengths (Byrne, 2001; Garson, n.d.; Raykov, 2006). The overall purpose of covariance structure analysis, as in SEM, is to answer the question as to whether the model being tested fits the data well and whether this fit is impacted if the model is either simplified or made more complex (MacCallum, Roznowski, & Necowitz, 1992). There are three approaches to SEM in current use. In a strictly confirmatory approach the model is developed and tested using goodness-of-fit indices to determine whether the theorized patterns of variance and covariance are consistent with the sample data. One weakness to this approach is that while the model may be accepted, other alternative models cannot be ruled out. Also, it can only be stated

that the model is not disconfirmed. In the alternative models approach, two or more models may be tested and once again fit indices used to determine a best fitting model. A limitation in this method is that, once again, there may be plausible models not explored by the researcher. A third method, sometimes referred to as model development or model generating approach, is more commonly used. In this method an initial model is specified, tested, and then modified until better fit indices are obtained. A limitation of this method is that the model may so fit the sample data that it no longer fits the population data. (Garson, n.d.; Raykov, 2006). Due to the underlying mathematical structure, data driven strategies risk capitalization on chance problems. Cross validation strategies have been developed to address this limitation. One in current use makes use of a calibration sample to generate the model and then a unique sample is used to confirm the analysis. However, care must be taken as model modification and cross-validity results have been shown to be unstable across repeated sampling (MacCallum, Roznowski, & Necowitz, 1992)

Problem Statement

While validated models are recommended as essential to guide the conceptualization of phenomena, the selection of the variables to be studied and the hypotheses to be tested, none were found that adequately explicate the geriatric cancer experience in end of life.

Conceptual Framework

The Framework of a Good Death developed by Emanuel and Emanuel (1998) is an example of a conceptual framework that may be used in end of life research and will serve as the framework for this model adaptation and testing. Emanuel and Emanuel's model includes four components: 1) fixed characteristics of the patient (clinical status, sociodemographic features); 2) modifiable dimensions of the patient's experience (symptoms, relationships, economics, perceived needs); 3) potential interventions provided to patients, families, friends, healthcare providers, and others, and 4) outcomes (Figure 1). The framework was developed as part of the Commonwealth-Cummings project as a means to both understand and evaluate what constitutes a good death.



Figure 1. The Framework for a Good Death. Used by permission (Emanuel, E.J. & Emanuel, L.L. (1998). *Lancet*, *351 (suppl II)*, 21-20).

The developers tested the construct validity and stability over time of the framework in a later study. General concordance was reported between measured

variables and the portion of the conceptual framework explored. The variables were found to account for 46% of the variance in the end of life experience, thus providing enhanced empiric support for the importance of the multidimensional, subjective experience in end of life and the need for an interdisciplinary approach to care planning (Emanuel, Alpert, Baldwin, & Emanuel, 2000).

However, Emmanuel and Emanuel's (1998) framework, as originally conceptualized, suffers from several limitations. First, there is a lack of linear flow of domains across the model – one does not know when or where to enter the model. Second, the outcome, which is identified only as the "overall experience of the dying process" (p.23) does not provide a measureable outcome variable. Without a measurable outcome, we are unable to test any hypotheses. The limited use of the framework in research from the time of publication would seem to support this contention. While the developers noted the difficulty in transferring conceptual models to bedside practice, this lack of a measurable outcome variable limits the very empiric research that they recommend.

For this reason, an adaptation of the model was conducted with a focus on nursing's holistic ethos. McMillan (R01 NR008252) adapted Emanuel's framework to clarify the flow of the model from left to right. The structure of the four critical components identified by Emanuel and Emanuel were retained: the fixed characteristics, the modifiable characteristics, the interventions, and the outcomes. However, the sub-domains were modified and the direction made more linear. The constructs of clinical status, functional and cognitive status replaced disease and prognosis as indicators. Physical symptoms include a fuller conceptualization of the symptom experience –

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exploring both number of symptoms and severity/distress levels experienced. The psychological symptom sub-domain was expanded to include the patient's and caregiver's experience. The sub-domains of social support, hopes and expectations, economic and caregiving needs, and spiritual and existential beliefs were subsumed into a social/spiritual need of the dyad (patient and caregiver) sub-domain (Figure 2).



Figure 2. McMillan's adaptation of the Framework for a Good Death. Used with permission of author.

In McMillan's adaptation of the model, a structured assessment and report of the patient and caregiver with validated instruments served as the care-system interventions listed by the original framework. McMillan strengthened the model by placing measurable outcome variables – patient symptom distress, patient quality of life, patient

and caregiver depression, and patient and caregiver spiritual well-being and hypothesized a change in caregiver depression levels as a long term outcome. This adaptation of the framework guided the design of the original study from which this project derives its data.

Purpose

The overall purpose of this study is to test a conceptual model of the geriatric cancer experience in end of life as adapted from Emanuel and Emanuel's Framework for a Good Death (1998), using structural equation modeling (Figure 3). The fixed and modifiable domains of the patients (clinical status, physiological, psychological, and spiritual domains) will serve as the antecedents. For this study there are no mediating processes. Quality of life is the outcome variable of choice. If evidence for the validity of the model is obtained, future work will explore the effects of mediating processes (health care interventions) on quality of life in this population. Because the data used in this study was collected at the beginning of the hospice experience, the patient/family/health care provider interventions cannot be assessed. Thus, they are presented in a box with a dotted line.

A measurement model was first developed from the conceptual model followed by the testing of the psychometrics properties of the fit of observed to unobserved variables. A validation of a full structural model was then attempted using baseline data from a large sample of geriatric hospice cancer patients.

Research Question

Does the Geriatric Cancer Experience in End of life model accurately represent the self-reported experience of the geriatric cancer patients newly admitted to a hospice home care setting?



Figure 3. The Geriatric Cancer Experience in End of Life Conceptual Model.

Specific Aim 1

To establish the fit of the measurement model of the Geriatric Cancer Experience in End of Life.

Hypothesis 1. The Geriatric Cancer Experience in End of Life is a five-factor structure composed of clinical status, physical, psychological, spiritual and quality of life latent variables as proposed in the conceptual model.

Hypothesis 2. The variability in older adult's responses in the end of life cancer experience can be explained by these five factors.

Hypothesis 3. Consistent with the literature, the five factors are correlated but the error terms of the measured variables are not.

Specific Aim 2

To confirm the full structural model of the Geriatric Cancer Experience in End of Life.

Hypothesis 4. The full structural model of the Geriatric Cancer Experience in End of Life is a five-factor structure composed of clinical status, physical, psychological, spiritual, and quality of life latent variables and quality of life is dependent on the other factors, as proposed in the conceptual model.

Hypothesis 5. The variability of the older adult end stage cancer patients in the experience can be explained by the relationships between the five factors.

Hypothesis 6. Consistent with the literature, the four factors (clinical status, physiological, psychological, and spiritual) are correlated but the error terms of the measured variables are uncorrelated.

Hypothesis 7. There is a statistically significant pathway from the four factors (clinical status, physiological, psychological, and spiritual) to quality of life in the older adult end stage cancer population.

Significance of the Study

The proposed significance of this study is twofold. Testing the Geriatric Cancer Experience in End of Life model will provide evidence for its validity as a conceptual model to guide end of life research. If the model is supported it will strengthen future studies by providing a useful guide for understanding the phenomena of the geriatric experience in end of life cancer patients. It will also guide the selection of variables and hypotheses, once again strengthening the science (Cooley, 2000; George, 2002; *NIH State-of-the-Science Conference Statement on improving end-of-life care*, 2004). Second, if the model is supported it will provide a framework for the development of nursing processes for geriatric end of life care. Assessment and interventions based on conceptual frameworks have been recommended as essential to the professional identity of nursing (Peterson, 2004).

Definition of Terms

The following terms have been defined for the purposes of this study:

- Geriatric While definitions vary widely on the "geriatric population", 65 years
 of age is used as the lower limit of the category. Han and colleagues have shown
 that the Medicare hospice benefit, accessed at age 65, influences hospice
 utilization patterns (Han et al., 2006).
- Cancer experience Borrowing from the symptom literature, the cancer experience is defined as the subjective perception that clinical status, physiological, psychological, spiritual and quality of life domains are influenced by the diagnosis of cancer (Dodd et al., 2001; Kroenke, 2001; Parker, Kimble, Dunbar, & Clark, 2005).

- 3. End of life Once again using the hospice benefit regulation, end of life is defined as that period of time when a person is determined to have a life expectancy of six months or less based on the clinical judgment of his or her health care provider (CMS, 2004).
- Model A schematic representation of theoretical or hypothetical constructs and the assertions about their potential relationships and interrelationships (Raykov, 2006).
- 5. A good death To die peacefully, free from discomfort or turmoil (Kring, 2006).

Chapter Two

Review of Literature

The purpose of this chapter is to review what is known about end of life and the experience of geriatric patients with cancer. Multiple searches of Medline, CINHAL, and ISI databases were conducted for each of the measured and latent variables in the model (functional status, cognitive status, symptoms, depression, spirituality, and quality of life) with the additional keywords of hospice, end of life, geriatric and cancer. Interviews with content experts elicited additional references and bibliographic searches of published literature yielded further studies. These peer-reviewed publications were analyzed for content validity, scientific rigor, and applicability to the current study. In this chapter the theoretical framework is reintroduced and the current literature for the variables of interest for use in the model testing – clinical status, physiological, psychological, spiritual, and quality of life are reviewed, noting areas of progress and those areas where additional research is needed. Preliminary conceptual and empirical work by the investigator is then presented and discussed. An integration of the literature at the end of this chapter provides the summary statement.

Theoretical Background

Emanuel and Emanuel's (1998) Framework for a Good Death served as the conceptual framework for the parent study from which this study data was taken, as mentioned in the previous chapter. A structural adaptation, focusing on the clinical status, physiological, psychological, spiritual, and quality of life domains was developed.

Theoretical support for this adaptation was then explored from the original framework and the literature.



Figure 3. The Geriatric Cancer Experience in End of Life Conceptual Model.

Factors in the Geriatric Cancer Experience in End of Life Model

The Geriatric Cancer Experience in End of Life Model, as currently conceptualized, includes five latent variables: clinical status, physiological, psychological, and spiritual domains as the predictor variables and quality of life as the outcome variable (Figure 3). Indicators for these five latent variables were selected based upon the conceptual framework, the literature and the original study variables.

Clinical Status Domain

Functional status. Functional status is the level at which the individual is able to perform typical daily activities of self and social maintenance. It is an integral feature of the end of life cancer experience and has been shown to be an independent predictor of both morbidity and mortality in the geriatric cancer population (Hurria et al., 2006). Functional status can be defined on two planes: 1) the ability to conduct activities of daily living, and 2) the ability to maintain a homeostasis or functional reserve (Balducci, 2003; Balducci & Beghe, 2000; Katz, Downs, Cash, & Grotz, 1970; Lawton & Brody, 1969). Functional status has been shown to decline with aging, mediate the relationship between fatigue and depressive symptoms, decrease with lower caloric intake and weight loss, be related to the number of unmet needs experienced by the cancer patient, suffer degradation with an increase in number of symptoms, and be affected by perceived control over the symptom experience (Barsevick, Dudley, & Beck, 2006; Cooley, 2000; Hwang, Chang et al., 2004; Miaskowski et al., 2006; Vallerand, Hasenau, Templin, & Collins-Bohler, 2005).

Cognitive status. Cognitive status is the level at which the individual is able to perceive stimuli and reason. Dementia (loss of intellectual functions related to organic changes) and delirium (confusion state related to sensory or metabolic changes) may both be present in this population. However, overall cognitive functioning in end of life is similar to that of the general population, and cognitive slowing is viewed as a part of the normal aging process (Hansen-Kyle, 2005; Sahlberg-Blom, Ternestedt, & Johansson, 2001). Type of cancer and site of metastases can decrease cognitive functioning. New cognitive deficits can imply electrolyte imbalances, infection, or cytokine induced

sickness behavior. Families report that approximately 40% of their loved ones suffered from a decline in cognition in the last week of life. However, little objective data has been collected during end of life. While earlier conceptualizations of quality of life did not include cognitive status, since 2001 there has been a growing awareness of the impact of this construct (Barsevick, Whitmer, Nail, Beck, & Dudley, 2006; Brown et al., 2006; Buchanan et al., 2005; Hurria et al., 2006; Klinkenberg, Willems, van der Wal, & Deeg, 2004; Moryl, Kogan, Comfort, & Obbens, 2005).

Physiological Domain

Number of symptoms. The symptom experience includes the subjective perceptions of alterations in homeostasis, including the dimensions of distress. Distress is understood to be the level of mental, emotional, physical or mental upset experienced by the individual, while severity is the degree to which something is undesirable or hard to endure. Eighty-six per cent of the geriatric population report experiencing at least one severe symptom and 69% experience two or more (McMillan & Small, 2002; Miller, 2006; Walke, Gallo, Tinetti, & Fried, 2004). The concept of symptoms in cancer in end of life incorporates the side effects from treatments or medications and also symptoms related to both the cancer and any co-morbidity. End of life studies specific to cancer populations have shown that fatigue, pain, lack of appetite, dry mouth, and shortness of breath are the most commonly reported symptoms. Dyspnea, pain, and fatigue are reported to cause the most distress consistently during and after treatment for lung cancer. Age, gender, and type of cancer does not change this pattern (Bradley, Davis, & Chow, 2005; Cooley, Short, & Moriarty, 2003; McMillan & Small, 2002; Tishelman et al., 2005).

The presence of multiple symptoms has been shown to complicate the control of individual symptoms (Meuser et al., 2001). While early theorizing and research focused on single symptoms, more recent work has explored the apparent clustering of symptoms and their etiology and effect on quality of life. Symptom clusters are defined as three or more concurrent symptoms that are related but not required to have the same etiologies (Dodd et al., 2005). Symptom clusters research has shown the importance of recognizing the common etiologies and patterns of association, as well as the interactions of symptoms (Barsevick, Dudley et al., 2006; Gift, Stommel, Jablonski, & Given, 2003; Walsh & Rybicki, 2006). The development of a concept of symptom clusters is in the early phases of exploration and clarification. Pain, sleep disturbance and fatigue were found to be significantly related to each other and predicted 48.4% of the variance in functional status in patients being treated for cancer (Dodd et al., 2001). Pain, dyspnea and constipation occur commonly in the hospice cancer population and have been shown to be related to quality of life (McMillan & Small, 2002).

Severity of symptoms. Understanding the symptom experience is complicated by the issues of whether the prevalence, severity, or the distress that the symptom causes best explains the relationship with quality of life. Intensity (or severity) and distress have been shown to be distinct phenomena, while frequency and intensity are highly correlated. Fatigue and pain are most frequently reported as troublesome when severe. The perception of symptom severity has been shown to be affected by age, gender, performance status, and to be reflective of prognosis (Chang et al., 2003; Hoekstra, Vernooij-Dassen, de Vos, & Bindels, 2006; Tishelman et al., 2005; Walsh & Rybicki, 2006).

Significant recent research has been conducted on symptom burden. Cancer has been found to contribute significantly to symptom burden, with only nine percent of cancer patients living symptom free in the last week of life. Older patients suffer greater symptom burden over a longer period of time (Klinkenberg et al., 2004; Kutner, Kassner, & Nowels, 2001; Silveira, Kabeto, & Langa, 2005). The symptom experience construct has been extensively studied by nurse researchers. The symptom experience encompasses the totality of symptoms in a person's life. It is made up of the perception, evaluation, and response to the symptom and has been found to be disease specific (Doorenbos et al., 2005; Miaskowski et al., 2006; Tranmer et al., 2003). Current symptom management research has shown that symptoms occur from both the disease and the treatment. Incomplete effectiveness of treatment, lack of knowledge about management strategies, and belief that symptoms are normative and must be tolerated all contribute to the lack of adequate symptom management (Chang, Hwang, & Kasimis, 2002; Given et al., 2004; Johnson, Kassner, Houser, & Kutner, 2005; NIH State-of-the-*Science Conference Statement on improving end-of-life care*, 2004).

Psychological Domain

Distress. Knowledge about the role that symptom distress plays in end of life is a gap in the current understanding of dying (Tennstedt, 2002). A comprehensive review of the literature in symptom management notes that symptom distress is one of the three major concepts (with occurrence and severity as the other two) in the symptom experience (Fu, LeMone, & McDaniel, 2004; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle et al., 1994). Distress motivates the one experiencing it to act to relieve, decrease, or prevent the symptom. The perception and meaning assigned to

symptoms by the person has been found to be a function of how they interpret the symptom (Goodell & Nail, 2005; Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Some symptoms are more likely to cause distress. Multiple disciplines such as psychology, medicine, and nursing are currently conducting research with distress as an outcome in symptom cluster research (Kim, McGuire, Tulman, & Barsevick, 2005). Studies exploring the relationships with dignity in end of life have found that those experiencing symptom distress also report concerns with loss of dignity (Chochinov et al., 2002). Measures of functional status have been found to be inversely related to distress – patients experience greater distress as their functional status declines. Distress has been reported in 40-80% of patients with metastatic cancer and hospice patients report an average of four highly distressing symptoms on admission (Cartwright, Hickman, Perrin, & Tilden, 2006; Cooley et al., 2003; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle et al., 1994). The number of symptoms experienced is highly associated with heightened distress. However, suffering has been reported in the setting of low symptom distress (Abraham, Kutner, & Beaty, 2006). Distress level has been shown to provide the most information about quality of life in patients experiencing symptoms (Hwang, Chang et al., 2004). Survival times and satisfaction with care have also been shown to be related to distress (Hwang, Scott et al., 2004).

Depression. Depression is a mental state exhibited by the symptoms of sadness, lethargy, and a lack of enjoyment. Rates of depression in the geriatric population range from approximately 3% in a baseline sample of community patients to 17-25% in cancer patients. Gender, age, morbidity, symptom distress and functional decline all have been shown to increase the risk of depression (Given et al., 2004; Radloff, 1977; Rao &

Cohen, 2004). Common end of life symptoms such as fatigue and pain have been shown to independently predict depression. Site of care affects reported depression. Depression is reported by patients in hospitals and inpatient hospices at a higher level than those in outpatient palliative care clinics. Depression has been found to be associated with hopelessness and a heightened desire to die (Barsevick et al., 2004; Bradley et al., 2005; Chochinov et al., 2002).

Spiritual domain

Kring (Kring, 2006) in an analysis of the literature from four disciplines (sociology, theology, medicine, and nursing) explored the common determinants of a "good death". Out of 31 determinants reported in this analysis, only four were common to three or more of the disciplines – one of these determinants was meeting spiritual needs. The literature from sociology, theology, and medicine were reported as supporting the need for spiritual needs to be met. A lack in the nursing literature in this area was noted. This may be a limitation of the study itself, or support the need for additional work. Taxonomic issues, social desirability, the plurality of belief and practice in current Western society, the need for interdisciplinary collaboration, and lack of valid and reliable instruments have all been noted as limitations by researchers in studying spirituality (Pargament, Magyar-Russell, & Murray-Swank, 2005; Stefanek, McDonald, & Hess, 2005).

Spiritual needs are something that the individual wants or needs in order to find purpose and meaning in life (Hermann, 2000). Whether spiritual needs are being met or are unmet has been used as an indicator for the larger spiritual experience of the patient. Sixty-two percent of an end of life geriatric cancer population reported religion or

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spirituality was very important (Vig & Pearlman, 2004). Patients have been shown to be able to identify particular spiritual needs, but to have difficulty in distinguishing between psychosocial and spiritual needs and also between religiosity and spirituality (Hermann, 2001; Stefanek et al., 2005; Taylor, 2003b). Patient-identified needs fall into two categories: 1) existential (purpose or meaning) or 2) overtly religious categories. Existential needs encompass the need for companionship, involvement and control, the need to finish business, to have a positive outlook, the need for hope and gratitude, the need to give and receive love, create meaning and find purpose, and prepare for death. Overtly religious needs encompass the need for religion or religious practices, a particular faith community, to experience nature, to relate to the Ultimate Other, and the need to review beliefs (Hermann, 2001; Taylor, 2003b).

In a hospice cancer population, it was found that common spiritual needs identified were to be with family, see the smiles of others, think happy thoughts, and laugh. Overtly religious behaviors such as using religious phrases, inspirational materials, and religious texts were identified as the lowest needs. Prayer was reported by 50% of the patients as frequently or always a need (Hampton, Hollis, Lloyd, Taylor, & McMillan, 2007). It has been reported that religious beliefs and spiritual practices promote coping in end stage cancer patients. Individuals who use positive religious coping strategies such as forgiveness, direction, helping, seeking support of clergy, surrender, benevolent view of religion, and connecting report less depression, anxiety and distress (Ano & Vasconcelles, 2005; Weaver & Flannelly, 2004). Cues for identifying unmet spiritual needs may include the patient's expressions of frustration, fear, despair,
worthlessness, isolation or relationship problems (Murray, Kendall, Boyd, Worth, & Benton, 2004).

Quality of Life Domain

Quality of life is a construct measured in economics, medicine, and the social sciences. Conceptualization and measurement issues reflect the differing viewpoints of these disciplines. The medical model is portrayed as focusing on disability or pathology. The social sciences are seen as more holistic and humanistic, focusing on social roles, normalization, and empowerment (Cummins, 2005). Problems in standardization of language and measurement revolve around the differences in these models. In 2005, an examination of how quality of life was conceptualized, defined, and measured in the National Cancer Institute funded symptom management trials found that quality of life was most frequently conceptualized as a secondary end point to symptom management and defined and measured as a specification of the instrument chosen. In an analysis of 130 Community Clinical Oncology Program trials, a little over half measured quality of life, using 22 different instruments, but quality of life was a primary end point in only seven studies (Buchanan et al., 2005).

A review of the nursing literature from 1990-2004 looking at the international standards of quality of life assessment in palliative care found an escalation during this time period in both interest and instrument development with quality of life as an outcome in the cancer population. Conceptual and methodological limitations were noted related to the lack of a standardized definition and the multiplicity of measurement instruments (Jocham, Dassen, Widdershoven, & Halfens, 2006). Theoretically, definitions of quality of life tend to fall into one of two groups – the first is a global,

holistic understanding of the concept, and the second is a more health related understanding, inclusive of deficit based, disease based, or health promotion frameworks (Register & Herman, 2006).

Terms in current use when defining quality of life are: multidimensional, dynamic, subjective, objective, having positive and negative aspects, global or domain specific, essential, physical, psychological, social, functional, spiritual, financial, happiness, and life satisfaction (Bruley, 1999; Buchanan et al., 2005; Donnelly, Rybicki, & Walsh, 2001; McMillan, 1996a; McMillan & Mahon, 1994a; McMillan & Weitzner, 1998; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu et al., 1994). A synthesis of the current conceptualizations could define quality of life as a subjective, multidimensional concept inclusive of the physical, psychological, functional, social, and spiritual domains.

Quality of life and suffering have been found to be inversely related. There is a direct relationship between functional status and quality of life in the geriatric population. Reducing patient distress and functional interference has been found to improve quality of life. The variance in quality of life scores has been accounted for by sets of symptoms. In older adults it also has been found to be dependent on maintaining relationships. Pain relief has been found to be only one dimension that enhances quality of life. Relieving burden, strengthening relationships, satisfaction with care, and achieving control also improve quality of life (Abraham et al., 2006; Barsevick, Whitmer et al., 2006; Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000; Nuamah, Cooley, Fawcett, & McCorkle, 1999; Vig & Pearlman, 2003). One study found such a high correlation between a physical functioning scale and a quality of life index in a palliative care cancer population

that they theorized that both were measuring the same construct (Donnelly et al., 2001). Quality of life has also been shown to be stable over time and higher than expected in hospice populations (Donnelly et al., 2001; McMillan, 1996b; McMillan & Mahon, 1994a, 1994b).

Preliminary Studies

Conceptual

Buck (Buck, 2007a) developed the model of the Geriatric Cancer Experience in End of Life retaining the structure of Emanuel and Emanuel's (1998) conceptual framework (fixed domains, modifiable domains, interventions, outcomes) and the domains (clinical status, physiological, psychological and spiritual) from McMillan's adaptation (pg. 16, Figure 3). The social domain and the dyadic involvement were removed for this conceptualization. The impact of the care-system interventions was beyond the scope of this project but the domain was retained. However, the outcome variable of interest was now patient quality of life. The indicators for the domains were taken from a larger RO1 study but were validated by an extensive review of the literature. Functional and cognitive statuses have been shown to be accurate indicators of the clinical status of geriatric cancer patients in end of life. Symptoms (frequency, severity, and distress), depression, and spiritual needs have also been shown to be both predictive of outcomes and amenable to interventions in this population and so are included in this adaptation. The Geriatric Cancer Experience in End of Life Model was both inductively and deductively informed. The patient's clinical data and self-reported experiences serve as the measured indicators for the domains, the patient, family and the interdisciplinary

team (IDT) symptom and care management interventions serve as the mediating processes, and quality of life is the outcome.

Antecedents of the Model. Two fixed and five modifiable indicators were supported from the literature. The indicators are ordered from more objective to more subjective. The two fixed indicators, functional status and cognitive status, are attested to by clinician rated scales. The five modifiable indicators explicated- number of symptoms, severity of symptoms, distress caused by symptoms, depression, and spiritual needs are highly subjective. Thus, the current distinction between signs and symptoms is respected. While signs are understood to be objective measurements of organic processes observable to the clinician, the concept of symptom is inclusive of the subjective experience of the patient and as such incorporates both the perception of the patient and the meaning assigned to the experience. In the end of life stage, functional status is no longer considered a modifiable antecedent because disease progression leads to an expected decrease in functional status. Cognitive status has been shown to be a fixed characteristic in some end of life patients and modifiable in others. Pre-morbid incidence of cognitive impairment is also another area where cognitive status is fixed. However, some studies have shown that there are also reversible causes of delirium in this population related to either symptoms or treatment modalities. Due to the preponderance of fixed causes of cognitive levels the decision was made to include cognitive status with the fixed domains at this time.

Outcome of the Model. A conceptualization of a good death from the viewpoint of multiple disciplines (sociology, theology, medicine, and nursing) concluded that the goal of humankind is to die peacefully, free from discomfort or turmoil (Kring, 2006).

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Because the dying experience incorporates every aspect of the human being – mind, body, and spirit - the more limited concept of health related quality of life was set aside. The curative concept of health as an absence of disease is no longer appropriate. Instead, quality of life is seen as a more meaningful and measurable outcome.

Buck's structural adaptation was augmented using Fawcett's (2000) theory

formalization process to develop the definitions and relationships (Table 1). Then using

Walker and Avant's (2005) method of theory derivation, new propositions were

developed for the adapted model using Emanuel and Emanuel's (1998) propositions

(Table 2).

Table 2

Geriatric Cancer Experience in End of Life Model Propositions							
Emanuel & Emanuel's (1998)	Buck's Derivation						
Propositions About a Good Death							
Dying is a multifaceted but integrated experience including physical, psychological, spiritual, economic, and interpersonal concerns – some are fixed, but some are modifiable.	The geriatric cancer experience is multi- factorial but holistic. It is inclusive of fixed domains – clinical status and modifiable domains –physiological, psychological, and spiritual.						
Dying is not just a medical experience - interventions are the responsibility of the health care providers and the full social network and the institutions which interact with the dying patient.	Health care providers partner with the patient, family, and their institutions to provide symptom management and care management that honor the patient's wishes and uphold community, clinical, and ethical standards.						
The outcome of a good death is freedom from avoidable suffering, honors the patients' and families' wishes, and is consistent with established standards.	The outcome of geriatric cancer patients experiencing care according to the framework is increased quality of life in end of life.						

Table 1

Name of the Concepts	Classification of Concepts according to	Propositions – definitions	Propositions – relationships
Indicator variable	Dubin's Schema		
Patient	Associative	A patient is a person between the ages of 65 and death who is admitted to hospice care with a terminal diagnosis of cancer.	The fixed and modifiable domains of the patients are interrelated.
Family	Associative	A family member is whomever the patient identifies as such.	
Interdisciplinary team (IDT)	Summative	The IDT is the basic unit of care management of hospice. It is a group of professionals made up of medicine, nursing, psychosocial, chaplaincy, and volunteers. It is regulated by Medicare criteria.	
Patient, Family, and IDT	Relational		The patient, family, and IDT form a collaborative partnership of equals
Clinical Status of the Patient	Enumerative	The clinical status of the patient is the present state of the person in life as it relates to their functional and cognitive	The patient's clinical state is related to their physiological, psychological, spiritual domains and their quality of life.
Functional status Cognitive status		processes. This is an unmodifiable domain.	
Physiological Domain of the Patient	Relational	The physiological domain of the patient encompasses the number of symptoms and their severity level. This is a modifiable domain.	The physiological domain is related to the patient's clinical status, psychological, spiritual domains and quality of life.

Geriatric Cancer Experience in End of Life Model: Concept Identification and Classification

Symptoms –number and severity

Name of the Concepts	Classification of Concepts according to Dubin's Schema	Propositions – definitions	Propositions – relationships
Psychological Domain of the Patient	Relational	The psychological domain of the patient contains their perception and response to the experience as evidenced by their depressive symptomatology (sadness, lethargy, and anhedonia) and	The psychological domain is related to the patient's clinical status, physiological, spiritual domains, and quality of life.
Symptom distress Depression		distress in relationship to their symptoms.	
Spiritual Domain on the Patients	Enumerative	The spiritual domain of the patient encompasses all that the individual reports wanting or needing in order to	The spiritual domain is related to the patient's clinical status, physiological, psychological domains, and quality of
Spiritual needs		find purpose and meaning in life.	life
Quality of Life	Summative	Quality of life is defined as that which makes life worth living by the patient.	Quality of life is hypothesized to be related to the fixed (clinical status) and modifiable (physiological, psychological, and spiritual) domains of the patient.
Symptom and Care Management Interventions	Summative	Symptom and care management interventions are defined as both the gathering of data necessary for the developing of management strategies and the actual care given to alleviate or control symptom and care deficits. These interventions honor the patient's wishes and uphold community, clinical, and ethical standards.	It is hypothesized that these interventions moderate the relationship of the fixed and modifiable domains of the patient with the outcome – quality of life

Empirical

Buck (Buck, 2007b) explored the relationship between a set of symptom variables (pain, fatigue, dyspnea, and anorexia) and the subscales of geriatric cancer patients' quality of life scores, the relationship between the patient's global distress score and their quality of life score, and the relationship of age and gender with the patient's distress levels. Using canonical correlations, correlations, and factorial ANOVA it was found that there is a moderately strong relationship between this set of symptom variables (pain, fatigue, dyspnea, and anorexia) and the patient's quality of life subscales. Symptom severity explained 49% of the variance in quality of life, and symptom distress explained 42% of the variance in quality of life. It was also found that different symptoms associate differently with different subscales of quality of life, whether psychophysiological or functional. Communality coefficients showed that the social/spiritual well-being subscale of the quality of life index is problematic in this model, in both the severity and distress analysis. There is variance from the original variables not explained by the canonical variates. It was also found that there is a moderately strong, inverse relationship between the patients' quality of life and their global distress (R= -0.566, p<0.000). No relationship was found between age, gender and distress in this sample.

Chapter Summary

In summary, this chapter includes a focus on the literature related to end of life and the experience of geriatric patients with cancer, the conceptual framework is reviewed and the current literature for the variables of interest for this study – clinical status, physiological, psychological, spiritual, and quality of life is reviewed, noting areas of progress and those areas where future research is needed. Preliminary conceptual and empirical work is presented and discussed. The literature and the preliminary studies show need for an integrated analysis of the relationships between these domains. Little is known about the covariation of these variables in this population. In the next chapter, the design and methods of the study are discussed in depth with a description of the measured indicators used for the variables of interest.

Chapter Three

Methods

In the first part of this chapter the research question is reintroduced and an overview of the research design is put forward with the setting, sample, instruments used to measure the indicators, and procedures introduced. The conceptual model being tested is then reintroduced and discussion of the SEM model proposed. The final section summarizes the methodology proposed for this study.

Research Question

Does the Geriatric Cancer Experience in End of life model accurately represent the self-reported experience of the geriatric cancer patients newly admitted to a hospice home care setting?

Specific Aim 1

To establish the fit of the measurement model of the Geriatric Cancer Experience in End of Life.

Hypothesis 1. The Geriatric Cancer Experience in End of Life is a five-factor structure composed of clinical status, physical, psychological, spiritual and quality of life latent variables as proposed in the conceptual model.

Hypothesis 2. The variability in older adult's responses in the end of life cancer experience can be explained by these five factors.

Hypothesis 3. Consistent with the literature, the five factors are correlated but the error terms of the measured variables are not.

Specific Aim 2

To confirm the full structural model of the Geriatric Cancer Experience in End of Life.

Hypothesis 4. The full structural model of the Geriatric Cancer Experience in End of Life is a five-factor structure composed clinical status, physical, psychological, spiritual, and quality of life latent variables and quality of life is dependent on the other factors, as proposed in the conceptual model.

Hypothesis 5. The variability of the older adult end stage cancer patients in the experience can be explained by the relationships between the five factors.

Hypothesis 6. Consistent with the literature, the four factors (clinical status, physiological, psychological, and spiritual) are correlated but the error terms of the measured variables are uncorrelated.

Hypothesis 7. There is a statistically significant pathway from the four factors (clinical status, physiological, psychological, and spiritual) to quality of life in the older adult end stage cancer population.

Setting

The data were collected for a larger study funded by the National Institutes of Health (R01 NR008252) focusing on systematic assessment and hospice patient outcomes (S. C.

McMillan, P.I.). All data has been de-identified prior to analysis and entered into a SPSS, version 15.0 database.

Sample

The sample from this larger study consisted of cancer patients who were receiving hospice home care from one of two involved hospices. Participants were over the age of 65 and met the inclusion and exclusion criteria. The age 65 years of age was used to define the geriatric population due to the Medicare requirement of 65 years of age for access into the hospice benefit. Studies have shown different hospice utilization patterns in the under 65 and over 65 population (Han et al., 2006). Due to the need for informed consent and the use of self-report instruments by patients, the 10-item Short Portable Mental Status Questionnaire (SPMSQ) was used as a screening instrument for cognitive impairment. Patients had to score 7 or higher on the SPMSQ to be appropriate for the study. Patients were also screened for admission to the study using the Palliative Performance Scale (PPS) (Anderson, Downing, Hill, Casorso, & Lerch, 1996). Patients had to score 40 or higher on the PPS to be appropriate for the study. Inclusion criteria for the study included patients with a cancer diagnosis, were adults who were 65+ years old, male or female, able to read and understand English, and able to pass screening with the SPMSQ and PPS. Exclusion criteria included: patients who were confused, excessively debilitated, comatose or actively dying, or those who lacked a caregiver. All patients who met the criteria and consented to participate in the study were included in this analysis.

Instruments

Measures for Clinical Status Domain

Katz Activities of Daily Living Index. Activities of daily living are operationally defined as the ability to care for self in bathing, dressing, toileting, transfer, continence, and feeding. The Activities of Daily Living Index (ADLI) assesses these six activities of daily living (Katz et al, 1963). The assessment of these results in a seven-point grading with "A" being the highest (independent in all six functions) and "G" being the lowest (dependent in all six functions). The ADLI is one of the measured variables for clinical status (CS-1). The scale is provided in Appendix A.

The Palliative Performance Scale. Palliative performance is operationally defined as the physical/functional status of a patient no longer receiving curative treatment for a disease state. The interview about ADLs for the Katz instrument elicits the information needed to score the Palliative Performance Scale (PPS). The PPS (Anderson et al., 1996) was developed to measure physical status in palliative patients. Modified from the Karnofsky Performance Scale, it assesses five domains - ambulation, activity and evidence of disease, self-care ability, oral intake, and level of consciousness and assigns a value (100 - 0). It is a valid and reliable tool correlating well with survival time in cancer patients (Morita, Tsunoda, Inoue, & Chihara, 1999). The PPS was used in this study to screen the patients for inclusion (they must have scored 40 or higher) and as such suffers from a restriction of range in the data. The PPS is one of the measured variables for clinical status (CS-2). The scale is provided in Appendix B.

Short Portable Mental Status Questionnaire. Cognitive status is operationally defined as the level at which the individual is able to perceive stimuli and reason. (Sahlberg-Blom et al., 2001). While the SPMSQ is a brief instrument that may lack sensitivity to mild cognitive impairment, it has proven validity in detecting moderate to severe cognitive impairment (Lichtenberg, 1999). The total score on the SPMSQ (range 1-10) provides a measured variable for clinical status (CS-3). There is a restricted range limitation because patients with low (<7) scores are excluded from the study. The scale is provided in Appendix C.

Measures for Physical and Psychological Domains

Memorial Symptom Assessment Scale. The symptom experience is operationally defined as the subjective perceptions of alterations in homeostasis, and includes the dimensions of: 1) distress – the level of mental, emotional, or physical upset experienced by the individual and 2) severity – the degree to which something is undesirable or hard to endure. (McMillan & Small, 2002; Miller, 2006). The Memorial Symptom Assessment Scale (MSAS) is designed to differentiate among occurrence, intensity, and distress from symptoms. Separate five point Likert-type scales are used for two dimensions: (1) severity of the symptom and (2) the distress it produces. The items are scored by summing the items in each subscale (i.e., physical, psychological). The higher the score, the more severe or distressing the symptoms are for the patient (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu et al., 1994). Preliminary assessment of the validity of the score interpretations of the MSAS for use with cancer patients receiving hospice home care was conducted and included correlation with quality of life (HQLI) scores. The correlation between MSAS distress scores and HQLI scores

were moderately strong and negative (r= -0.72; p<0.001). In addition, reliability of the intensity and distress scores were acceptably high (r=0.73-0.74) using coefficient alpha (McMillan & Small, 2002). For the purposes of this study three composite variables were created from the information from the MSAS. The first variable (Phy-1) summed the total number of symptoms experience by the patient yielding a 0 -25 possible score. The second variable (Phy-2) summed the total severity experienced yielding a 0-100 possible score. The number of symptoms experienced and the MSAS subscale for severity provides the measured variables for the Physiological domain (Phy-1 and Phy-2). The third variable summed the total distress experienced yielding a 0-100 possible score. The MSAS subscale for distress provides a measured variable for the Psychological domain (Psy-1). The scale is provided in Appendix D.

Center for Epidemiological Studies – Depression (CES-D) Short Form.

Depression is operationalized as a mental state exhibited by the symptoms of sadness, lethargy, and a lack of enjoyment. The CES-D (Radloff, 1977) is a widely used 20-item scale that has proven useful to measure the symptoms of depression. Recently there have been efforts to develop and validate shorter versions of the CES-D for use in clinical settings and large scale survey research projects. A 10-item version of the CES-D has been developed to balance ease of administration and psychometric concerns. Items are scored as either present or absent, rather than rated for frequency as with the full CES-D. Irwin and colleagues (1999) assessed psychometric characteristics of this short form CES-D. Results showed that Cronbach's alpha was 0.92 for this short form, and testretest reliability was 0.83. Correlation of the short form and full CES-D was 0.88, suggesting that the short form is highly correlated with the lengthier and more widely validated full version. It was also determined that using a cutoff of greater than or equal to 4 on the scale, sensitivity, specificity, and positive predictive value of the scale were 97%, 84%, and 85% respectively when compared with clinical diagnosis of depression using the SCID. This provides evidence of validity for the scale. The CES-D provides a measured variable for psychological domain (Psy-2). The scale is provided in Appendix E.

Measures for Spiritual and Quality of Life Domains

Spiritual Needs Inventory. Spiritual needs are operationally defined as something that the individual wants or needs in order to find purpose and meaning in life. The purpose of the Spiritual Needs Inventory scale is to assess the extent to which patients have spiritual needs and whether those needs are met or unmet (Hermann, 2001). This 17-item questionnaire has two main parts. First the patient is asked to rate the items in response to the stem: "In order to live my life fully, I need to:" This stem is followed by items in column A such as "Sing/listen to inspirational music" and "Talk with someone about spiritual issues". The subject responds on a scale in column B from 1 (never) to 5 (always). Scores in this section may range from 17 to 85 with a higher score representing a greater spiritual need. In column C, the respondents indicate which of these needs remains unmet by marking yes or no. Validity was assessed by Hermann (Hermann, 2000) using factor analysis which confirmed the inclusion of all items. Reliability was assessed using Cronbach's alpha. This evaluation indicated a high degree of internal consistency (alpha=0.85). The five subscales from that study – outlook, inspiration, spiritual activities, religion, and community - were extracted using principle component

factor analysis. The subscales for the instrument provide the measured variables for spiritual needs (Sp-1, Sp-2, Sp-3, Sp-4, and Sp-5). The scale is provided in Appendix F.

Hospice Quality of Life Index-14. Quality of life is operationally defined as a subjective, multidimensional concept inclusive of the physical, psychological, functional, social, and spiritual domains (Cella, 2005; Cummins, 2005; McMillan & Small, 2002). The Hospice Quality of Life Index-14 (HQLI-14) is a shortened version of the previously used and validated Hospice Quality of Life Index (McMillan & Weitzner, 2000). Each item is scored on a 0 to 10 scale with 10 being the most favorable response and item scores are added to obtain a total scale score. Total scores can range from 0 (worst quality of life) to 140 (best quality of life). Mean scores in a group of 255 hospice patients with cancer were calculated for the total HQLI-14 and its subscales. The mean for the total was 101.2 (SD=19.2). Construct validity of the short form was evaluated by correlation with the original HQLI. The correlation between total scale scores was very strong at r=0.94 (p=0.000). This strong correlation provides evidence of the validity of the shortened HQLI. Reliability of the scores from the short form was estimated using Cronbach's alpha. Alpha for the total tool was strong (r=0.77). Psychometric analysis shows a three factor structure – psychologic/physiologic well-being, functional wellbeing, and social/spiritual well-being. The subscales of this instrument provide the measured variables for quality of life (QOL-1, QOL-2, and QOL-3). The scale is provided in Appendix G.

Demographic Data

Standard demographic data were collected from the patients and the patient's records in order to describe the sample. The data included age, race, gender, education,

religion, marital status, relationship to caregiver, home setting, most recent job, and diagnosis. The form is provided in Appendix H.

Procedures

The larger project was approved by the administrators of the two involved hospices prior to data collection. In addition, the proposal was approved by the USF Institutional Review Board for the Protection of Human Subjects. Informed consent and data collection for all subjects was obtained on admission to the study. The Informed Consent Form is provided in Appendix I. As this is a secondary data analysis on deidentified data, minimal risk to human subjects was expected. All data was kept in a locked cabinet and no data manipulation occurred with the original database. Syntax was used to create temporary data sets and analysis was conducted on these data sets.

The research design was non-experimental and cross sectional using baseline data, collected within 24 to 72 hours of admission to hospice. The use of trained research assistants, valid and reliable instruments, and strict inclusion and exclusion criteria were intended to minimize threats to the validity of the study.

Models

The Original Conceptual Model

The Geriatric Cancer Experience in End of Life conceptual model (Figure 3), as developed, retains the structure of Emanuel and Emanuel's (1998) conceptual framework (fixed domains, modifiable domains, interventions, outcomes) and the domains (clinical status, physiological, psychological and spiritual) from McMillan's adaptation (Figures 1 and 2). The outcome variable of interest is patient quality of life. The measured indicators for the domains were taken from the larger RO1 study, but evidence for their validity is presented by an extensive review of the literature in Chapter Two.



Figure 3. The Geriatric Cancer Experience in End of Life Conceptual Model.

Proposed Structural Equation Model

The measurement portion of the model (Figure 4) analyzes the psychometric properties of the relationships between the observed and the latent variables. The full structural model (Figure 5) tests a structural adaptation of the measurement model, with quality of life as an outcome (endogenous) variable. Symbol notation in current use with SEM is utilized. Circles or ellipses represent unobserved, latent factors (clinical status, quality of life, physiological, psychological, and spiritual domains, also the error/disturbance terms). Rectangles represent observed variables (CS-1 through Sp-5). Single-headed arrows represent the impact of the exogenous variable on the endogenous variable (path coefficients). Double-headed arrows represent the correlations or covariances between variables (Byrnes, 2001). The measured variables (CS-1 through Sp-5) are operationally defined and the instruments used to measure them were introduced in the previous paragraphs.



Figure 4. The Geriatric Cancer Experience in End of Life Measurement Model



Figure 5. The Geriatric Cancer Experience in End of Life Structural Equation Model

Data Analyses

Purpose

The overall purpose of this study was to test a conceptual model of the geriatric cancer experience in end of life using structural equation modeling (Figure 3). To accomplish this, a full structural equation model (inclusive of a measurement and structural components) was developed. Fitting the measurement model (Figure 4)

involved analyzing the psychometric properties of the interactions between observed variables and hypothesized latent variables. The parameters of the model were estimated from the links between variances and covariances of the observed variables and parameters, since the latent variables are not observed (Long, 1983). The full structural model (Figure 5) tested a structural adaptation of the measurement model, with quality of life as an outcome variable. In this early stage of model development and testing, cross sectional data was considered appropriate to examine and isolate the relationships among the variables of interest. Procedures for the consistent application of data preparation and analysis were developed to ensure the reliability of the findings.

Structural Equation Modeling

Structural equation modeling (SEM), with its ability to account for measurement error in observed variables and test models with latent variables (either theoretical or hypothetical constructs), was used for this project. In SEM, relationships between variables are specified a priori (as in Figures 3 and 4). SEM is recommended when theoretical testing is not well developed, due to its ability to estimate all parameters simultaneously, allowing for changes in more than one parameter. In SEM causal processes are represented by a series of regression equations that are pictorially represented, presenting a clearer conceptualization of the theory being tested. The overall purpose of this method is to answer the question as to whether the hypothesized model being tested fits the data well and that this fit is impacted if the model is either simplified or made more complex (Byrne, 2001; Garson, n.d.; Lee, 2005; MacCallum, Roznowski, & Necowitz,1992; Raykov, 2006).

The steps involved in conducting SEM analysis consist of:

- 1) specification of the model
- 2) screening and preparation of the data
- 3) iterative estimation processes
- 4) evaluation of the overall fit, including modifications
- 5) interpretation (Ferron, 2007)

In model specification, the researcher asserts, a priori, which effects are null, fixed, or vary. This is usually accomplished by developing a pictorial representation of the model from either theory or the literature. This specified pictorial model is then translated into a mathematical model using the notation specific to the statistical software in use. A full SEM model has both measurement and structural components. Before estimation can occur, assessment of whether there is a unique solution of the model parameters must be determined. An over-identified model, one in which there are more unique data points than estimable parameters, yields positive degrees of freedom allowing for hypothesis testing (Byrne, 2001). The measurement model is first fitted. Then using confirmatory factor analysis, the structural model is validated. After specifying the model and before data testing, the data needs to be screened for linearity, multivariate normality, outliers, and missing data. The estimation process finds the best parameter estimates (structural or path coefficients) for the model. The maximum likelihood estimation (F_{ML}) method is most commonly used by the current modeling software. Before the model can be interpreted, evaluation of the model fit should be conducted. The overall goodness of fit index is based on the assumption that the covariance matrix implied by the model is equal

to the covariance matrix of the sample. The further apart these two matrices are, the poorer the fit index. However, a good fit says nothing about the strength of the relationships nor does it imply good specification of the model. It states only that the two covariance matrices are not significantly different (in a χ^2 distribution). While there are multiple fit indices in use, most methodologists recommend the use of three to four indices from differing categories - both absolute fit indices (for example the root mean square error of approximation [RMSEA]) and incremental fit indices (for example the comparative fit index [CFI]). MacCullum and colleagues (1996) also recommend the use of confidence intervals to assess the precision of estimates. Areas of misfit can be identified from the inspection of residual and modification indices. If the model fit indices meet a priori set cut points, the interpretation can proceed. Parameter estimates (both standardized and unstandardized) and R² values are examined. Hypotheses tests and causal statements are based upon these findings. The analysis concludes with a transparent reporting of both the processes and findings (Byrne, 2001; Ferron, 2007; Garson, n.d.).

A priori Decisions

The reliability of the study was ensured through the consistent application of procedures developed a priori. Using the recommendations of MacCallum and colleagues (1999), as large a sample as is available was used and the level of communalities of the variables and the degree of over-determination of the factors was reported. As the model is currently conceptualized, there is a ratio of 15 variables to 5 factors. This equates most closely to the 20:7 ratio tested by MacCallum for which a sample size of at least 400 was shown in a Monte Carlo study, as needed to reach

communalities in the 0.92 to 0.98 range. Also, post hoc power analysis was conducted as issues related to loss of power in the presence of non-normal data were assessed (Curran, West, & Finch, 1996).

Analysis of MOment Structures (AMOS) version 7.0 (SPSS, 2006) makes use of the maximum likelihood method of parameter estimation. In maximum likelihood estimation (F_{ML}) the log likelihood, which are the odds that the observed value of the outcome variable may be predicted from the observed predictors, is maximized through an iterative process (Garson, n.d.). Four assumptions must be met with F_{ML} : 1) large sample; 2) multivariate normal distribution; 3) valid model; and 4) continuous variables. Using Byrne's (2001) recommendations, the likelihood ratio tests, factor loadings, and factor correlations were interpreted carefully in the presence of categorical variables with less than five categories and a high degree of skew. Both univariate and multivariate normality was assessed and reported.

As the sample is made up of subjects from two different agencies, using SPSS 15.0, univariate differences between sites were assessed using χ^2 tests on categorical variables and *t* tests on continuous variables. Bivariate correlations of the indicator variables by site were analyzed for differences and reported. As nonsignificant differences are found between the two groups the data were aggregated. In the preliminary stages of this study the data were first analyzed for descriptive statistics, once again, using SPSS 15.0. Values found to be outside the range of permissible responses and missing data were deleted using a listwise deletion. Patterns of missing data were assessed for using a Mahalanobis' distance. Then assessment of compliance with the assumptions of the method chosen (normality, linearity,

independence) was conducted and reported. Adhering to Curran, West, and Finch's (1996) recommendations, skew of less than two and kurtosis of less than seven was accepted. Bivariate relationships between the measured variables were examined using scatterplots and a correlation matrix. Using AMOS, the measurement of each latent variable (to its observed variables) was tested for psychometric soundness prior to testing the measurement model. Per the recommendations of Byrne (2001) this determines whether the items measure the factor they purport to measure.

Multicollinearity was assessed for and model modification was conducted and reported. However, due to the small sample size cross-validation was not feasible. *The Measurement Model*

Model specification. Byrne's (2001) analytic strategy was followed, making use of the AMOS graphic interface, to test the factorial validity of a first order confirmatory factor model (measurement model). It was important that psychometric soundness be validated because the relationships being tested in the full model involved latent variables. After the measurement model was found to be operating adequately, the full structural equation model was tested for validity using the strategies recommended for testing a causal structure. The model was specified from the conceptual framework, translating the theoretical model into mathematical model. AMOS Graphics works from a path diagram created by the user instead of equation statements, allowing for visualization of the relationships hypothesized. The drawing tools available in the software were developed taking SEM conventions into account (Byrne, 2001).

In the measurement model it was postulated that the geriatric cancer experience in end of life is a five-factor structure composed of clinical status, physical, psychological, spiritual, and quality of life latent variables as proposed in the conceptual model. It was also postulated that: 1) responses of subjects in the experience can be explained by these five factors, 2) each item-pair (measured variable to factor) has a nonzero loading on the factor that it purports to measure and a zero loading on the other five factors, 3) consistent with the literature, the five factors are correlated, and 4) the 15 measured variable error terms are uncorrelated. There were at least two measured variables for each latent variable.

Identification status was determined by first calculating the number of parameters to be estimated and comparing this to the number of data points. Bentler and Chou's (1987) formula of:

of parameters $\leq (\frac{1}{2} \# \text{ variables } x \# \text{ variables } + 1])$,

yielded a calculation of:

 $40 \le (7.5 \text{ x } [15+1] = 120 \text{ data points})$

As this model is over-identified (one in which the number of data points from the observed variables exceeds the number of estimable parameters), this allows for 80 degrees of freedom for the χ^2 distribution and so hypothesis testing was tenable (Byrne, 2001).

Parameter estimation and evaluation of fit. Estimation of parameters and evaluation of overall model fit was conducted after the model was specified. SEM analyzes the covariance matrix implied by the model. This matrix is a function of the model parameters. Raykov's (2006) rules for determining model parameters were adhered to:

1. all variances of independent variables are model parameters

- 2. all covariances between independent variables are model parameters
- all factor loadings connecting latent variables with their indicators are model parameters
- all regression coefficients between observed or latent variables are model parameters
- variance of and covariances between dependent variables as well as covariances between dependent and independent variables are not model parameters
- 6. each latent variable in the model needs a metric scale set

Due to the χ^2 goodness of fit test's sensitivity to large sample size, several fit indices were examined (Byrne, 2001). For absolute fit indices, a non-significant χ^2 and a Root Mean Square Error of Approximation (RMSEA) of ≤ 0.05 was accepted and confidence intervals reported. For a Type III incremental fit index a Comparative Fit Index (CFI) of ≥ 0.95 was accepted (Byrne, 2001; Hu, 1998). Areas of misfit were indentified using the residual matrix. Standardized residuals are analogous to Z scores, so values greater than 2.58 were considered large. Modification indices produced by AMOS were then examined. When modification was indicated, the literature and theory was revisited and modifications were attempted and the model rerun. When the fit indices improved and parsimony maintained, the modification was retained and reported. (Byrne, 2001). Further analyses of fit indices and parameters were then conducted.

The Structural Model

Model specification. After the measurement model was found to be operating adequately, the structural portion of the model was tested for validity using the strategies recommended for testing a causal structure in Byrne (2001). The postulated structural relationships among the variables arise from the conceptual model and are grounded in theory and empirical research. The hypotheses tested argue for the validity of structural links between the five factors. There are four exogenous latent variables (ξ) and one endogenous latent variable (η) . In the model it was postulated, a priori, that the geriatric cancer experience in end of life is a five-factor structure composed of clinical status, physical, psychological, spiritual, and quality of life latent variables and that quality of life is dependent on the other factors, as proposed in the conceptual model. It was also postulated that: 1) responses of subjects in the experience can be explained by the relationships between the five factors (there is a relationship), 2) each item-pair (measured variable to factor) has a nonzero loading on the factor that it purports to measure and a zero loading on the other five factors, 3) consistent with the literature, the four factors (clinical status, physiological, psychological, and spiritual) are correlated, and 4) the 15 measured variable error terms are uncorrelated.

Identification status was determined by first calculating the number of parameters to be estimated and comparing this to the number of data points. Bentler and Chou's (1987) formula of:

of parameters $\leq (\frac{1}{2} \# \text{ variables } x \# \text{ variables } + 1])$,

yielded a calculation of:

 $34 \le (7.5 \text{ x} [15+1] = 120 \text{ data points})$

As this model is over-identified (one in which the number of data points from the observed variables exceeds the number of estimable parameters), this allows for 86 degrees of freedom for the χ^2 distribution and so hypothesis testing is tenable (Byrne, 2001).

Parameter estimation and evaluation of fit. Estimation of parameters and evaluation of overall model fit was conducted, once again using Raykov's criteria (2006). Several fit indices were examined. For absolute fit indices, a non-significant χ^2 and a Root Mean Square Error of Approximation (RMSEA) of ≥ 0.05 were accepted and confidence intervals reported. For a Type III incremental fit index a Comparative Fit Index (CFI) of >0.95 was accepted (Byrne, 2001). Areas of misfit were indentified using the residual matrix. Standardized residuals are analogous to Z scores, so values greater than 2.58 were considered large. Due to the confirmatory nature of this analysis, no modification was planned (Byrne, 2001).

Chapter Summary

In the first part of this chapter an overview of the research design was put forward with the research question reintroduced and the setting, sample, and procedures introduced. The conceptual model being tested was reintroduced and discussion of the SEM model proposed and the instruments used to measure the indicators was discussed. The final section summarized the methodology proposed for this study.

Chapter Four

Results

In the first part of this chapter the sample characteristics are reported. The preliminary analysis of the data and assessment of bivariate relationships are reported next. Assessment of the measurement model with assessment of fit and modifications and then the assessment of the full structural model are reported. In the next section the hypothesis testing is conducted. Post hoc power analysis is then reported. Finally, the results are summarized.

Sample Characteristics

Comparisons of the Sample from the Two Sites

The first a priori decision was to assess the differences between the data accrued from the two agencies to determine whether the data could be aggregated for analysis. A series of χ^2 tests were conducted on the categorical variables, and *t* tests were conducted on the continuous variables (Table 3). In Site 2 the sample has had more years of schooling, while in Site 1 the sample is more likely to live with people other than their family members and in a rural setting. These differences could be seen to enhance the generalizability of the sample. For example, aggregating the data from the two sites would allow for comparison with samples that were drawn from either single living arrangements or those dwelling with others in either a rural or suburban setting.

Table 3

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SIGNITICATI	Differences	Deiween	THE IN	O SUES
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	Site 1	Site 2	$\chi^2$ df	<i>t</i> ( <i>p</i> )
Years of School	11.9 (3.2)	13.16 (3.2)		-3.88 ( <i>p</i> =0.000)
	Frequency	Frequency		
Living Arrangement				
Lives alone	14	11	21.9 _{5df}	
Lives with spouse	136	132		
Lives with children	26	22		
Other	47	11		
Home setting				
Urban	3	1	17 124	
Suburban	167	160	<b>17.1</b> 2af	
Rural	53	15		
	Moon (SD)	Maan(SD)		
Kotz ADI I (CS 1)	2.70(2.2)	$\frac{\text{Mean}(SD)}{2.05(2.0)}$		2 12
Katz ADLI (CS-I)	2.19 (2.3)	2.03 (2.0)		(n=0.001)
$\mathbf{PPS}\left(\mathbf{CS}_{2}\right)$	5.06(1.2)	5 65 (0 7)		(p=0.001)
115 (CS-2)	5.00 (1.2)	5.05 (0.7)		(n-0.000)
HOL J-14 (OOL-3)	36 74 (4 1)	35 47 (4 9)		(p=0.000) 2.82
	50.74 (4.1)	55.47 (4.7)		(n=0.005)
SNI (Sn-1)	389(08)	3.61(0.7)		3 44
	5.05 (0.0)	5.01 (0.7)		(p=0.001)
<b>SNI (Sp-3)</b>	2.08(1.3)	2.39(1.2)		-2.48
	,	,		(p=0.01)
<b>SNI (Sp-5)</b>	4.11 (2.1)	3.78 (0.7)		2.06
				(p=0.04)
MSAS (Psy-1)	1.87 (0.7)	2.05 (1.0)		-2.10
× • /	× /			(p=0.04)

*Note:* CS = Clinical Status; QOL = Quality of Life; Sp = Spiritual; Psy = Psychological

When the differences between measured indicator variables are inspected seven of the variables show significance. However, further analysis of the means of these variables and size of the *t* statistic show a small amount of meaningful difference. The largest difference between the two sites is related to the Palliative Performance Scale (CS-2), with Site 1 scoring significantly lower on this scale than Site 2. Bivariate correlations of

the 15 measured variables (CS-1 through Sp-5) by site were then analyzed to assess for significant differences between the two sites (Table 4). From the two sites 98 significant correlations (at 0.05 or 0.01) were found. Sixteen of those correlations were at the 0.05 level and 82 of them were at the 0.01 level. At Site 1 - 52 correlations were found to be significant and at Site 2 - 46 of the correlations were found to be significant. In no instance of a significant correlation in both sites, was that correlation found to be in the opposite direction from the other site. However, in two instances (CS-1 by Sp-5 and Sp-5 by CS-3) it was found that one site was significant in one direction while the other site was neither significant nor in the same direction. It was concluded that the two agencies' data could be analyzed as reflecting one sample from this population.

Table 4

		CS-1	Psy-2	QOL-1	QOL-2	QOL-3	Sp-1	Sp-2	Sp-3	Sp-4	Sp-5	CS-2	Phy-1	Phy-2	Psy-1	CS-3
CS-1	Site 1	1														
	Site 2	1														
Psy-2	Site 1	0.043	1													
	Site 2	-0.025	1													
QOL-1	Site 1	-0.011	-0.39(**)	1												
	Site 2	0.063	046(**)	1												
QOL-2	Site 1	-0.18(**)	-0.40(**)	0.46(**)	1											
	Site 2	-0.046	-0.48(**)	0.55(**)	1											
QOL-3	Site 1	-0.079	-0.25(**)	0.27(**)	0.306(**)	1										
	Site 2	0.053	-0.25(**)	0.34(**)	0.275(**)	1										
SP-1	Site 1	0.024	-0.152(*)	0.035	0.167(*)	0.33(**)	1									
	Site 2	-0.006	-0.169(*)	0.136	0.178(*)	0.27(**)	1									
SP-2	Site 1	-0.046	-0.048	0.016	0.148(*)	0.30(**)	0.40(**)	1								
	Site 2	-0.035	-0.051	0.110	0.133	0.21(**)	0.47(**)	1								
SP-3	Site 1	-0.066	-0.006	0.002	0.112	0.24(**)	0.33(**)	0.81(**)	1							
	Site 2	-0.056	-0.055	0.071	0.133	0.175(*)	0.43(**)	0.79(**)	1							
SP-4	Site 1	-0.024	-0.114	0.006	0.120	0.30(**)	0.37(**)	0.70(**)	0.58(**)	1						
	Site 2	0.061	-0.079	0.070	0.089	0.21(**)	0.40(**)	0.70(**)	0.65(**)	1						
SP-5	Site 1	0.19(**)	-0.073	-0.038	0.068	0.20(**)	0.59(**)	0.42(**)	0.35(**)	0.26(**)	1					
	Site 2	-0.039	-0.060	-0.010	0.121	0.23(**)	0.57(**)	0.42(**)	0.36(**)	0.37(**)	1					

Bivariate Correlations of Measured Variables by Site

*Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual ;*Correlation significant at the 0.05 level (2 tailed). **Correlation significant at the 0.01 level (2 tailed)

Table 4 (continued)

Bivariate Correlations of Measured Variables by Site

		CS-1	Psy-2	QOL-1	QOL-2	QOL-3	Sp-1	Sp-2	Sp-3	Sp-4	Sp-5	CS-2	Phy-1	Phy-2	Psy-1	CS-3
CS-2	Site 1	0.52(**)	.131(*)	-0.072	-0.299(**)	-0.167(*)	0054	-0.22(**)	-0.19(**)	-0.2(**)	0.009	1				
	Site 2	0.43(**)	0.036	023	-0.125	-0.030	-0.018	0.131	0.113	0.139	-0.088	1				
Phy-1	Site 1	0.020	0.46(**)	-0.53(**)	-0.437(**)	-0.18(**)	-0.031	0.118	0.153(*)	0.038	0.047	0.078	1			
	Site 2	-0.132	0.33(**)	-0.52(**)	-0.520(**)	-0.30(**)	0.042	-0.004	0.025	-0.005	0.076	-0.046	1			
Phy-2	Site 1	0.075	0.46(**)	-0.54(**)	-0.497(**)	-0.18(**)	0036	0.087	0.111	0.022	0.076	0.121	0.88(**)	1		
	Site 2	-0.080	0.42(**)	-0.57(**)	-0.592(**)	-0.27(**)	-0.008	-0.021	0013	-0.048	0.038	0.006	0.88(**)	1		
Psy-1	Site 1	0.065	0.51(**)	-0.53(**)	-0.502(**)	-0.20(**)	0.000	0.113	0.162(*)	0.051	0.096	0.098	0.85(**)	0.93(**)	1	
	Site 2	-0.099	0.42(**)	-0.58(**)	-0.571(**)	-0.25(**)	0.007	0.000	-0.008	-0.019	0.066	-0.028	0.88(**)	0.94(**)	1	
CS-3	Site 1	0.122	-0.016	0.018	0.007	-0.020	044	-0.081	-0.115	-0.037	0.048	0.2(**)	-0.168(*)	-0.114	-0.132(*)	1
	Site 2	0.22(**)	-0.172(*)	0.155(*)	0.031	0.122	-00.051	0.003	-0.018	-0.079	-0.2(**)	0.4(**)	-0.164(*)	-0.151(*)	-0.161(*)	1

*Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual ;*Correlation significant at the 0.05 level (2 tailed). **Correlation significant at the 0.01 level (2 tailed)

# Comparisons of Completers vs. Non-completers

A further a priori decision was to use a listwise deletion for any subjects with missing data. Post hoc power analysis showed sufficient power in the sample of completers (N = 403), and so the decision was made not to impute data for the missing cells. A comparison of the two groups, completers and non-completers, was conducted to assess for any bias. The original sample included 428 subjects. Of that sample, 403 subjects (94%) completed all data points and 25 (6%) were missing some or many data points. Crosstabulations were conducted on the categorical variables – site, age, gender, relationship to caregiver, ethnicity, years of schooling, cancer diagnosis, living arrangement, job, and home setting by state (completer or non-completer) and a  $\chi^2$  statistic generated. Only home setting showed a significant difference ( $\chi^2_{df}$  = 7.21_{2df}). For the continuous variables (measured indicators) *t* tests were run. Only four of the 15 measured variables were significantly different between the two groups (Table 5).

Table 5

	Completers	Non-completers	<i>t</i> ( <i>p</i> )
	Mean (SD)	Mean (SD)	
Psy-2	2.90 (2.2)	4.0 (2.7)	2.08
			( <i>p</i> =0.04)
CS-2	5.33 (1.1)	6.04 (1.1)	3.13
			( <i>p</i> =0.002)
QOL-2	23.86 (8.3)	17.75 (9.3)	-2.06
			( <i>p</i> =0.04)
Phy-2	20.63 (11.0)	26.58 (16.9)	2.25
			( <i>p</i> =0.03)

Comparison of Completers vs. Non-completers

*Note*. Psy = Psychological; CS = Clinical Status; QOL = Quality of Life; Phy = Physical
Only depression (Psy-2), functional status (CS-2), functional well-being (QOL-2) and symptom severity (Phy-2) showed significant differences; with the non-completers more likely to have more depressive symptoms, suffer lower functional wellbeing, and more severe symptoms, but score higher on the Palliative Performance Scale (CS-2). However, inspection of the means and the size of the *t* statistic showed small differences. It was concluded that there were not meaningful differences between those who completed the study and those who did not. Further information on the 25 non-completers is presented in Table 6.

Table 6

Variable	Number missing	Percent	
CS-1	2	8	
CS-2	1	4	
CS-3	2	8	
QOL-1	17	68	
QOL-2	17	68	
QOL-3	17	68	
Phy-1	0	0	
Phy-2	6	24	
Psy-1	7	28	
Psy-2	6	24	
Sp-1	15	60	
Sp-2	15	60	
Sp-3	15	60	
Sp-4	16	64	
Sp-5	15	60	
Mean (SD) number of missing data poir	nts per subject	6.	12 (3.85)
Median number of missing data points	per subject	8	
Range		0-	13*
Skew		-0.	19
Kurtosis		-1.	2

Patterns of Missing Data N = 25

*Note: Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual *One subject missing demographic data, not indicator variable data

# **Demographics**

Four hundred and three newly admitted hospice patients consented to participate in the study and had completed data. Table 7 shows the demographic characteristics of this sample.

Table 7

Demographic Characteristics

	Percent	Mean (SD)
Age		77.7 (12.5)
Years of School		12.53 (3.2)
Gender		
Male	55.9	
Female	44.1	
Relationship to Caregiver		
Spouse	64	
Parent	19.3	
Child	1.9	
Other	14.8	
Marital status		
Married	65.9	
Widowed	22.3	
Divorced	8.2	
Other	3.6	
Ethnicity		
Caucasian	97	
African American	1.4	
Hispanic	1.1	
Other	0.5	
Religion		
Christian	86	
Jewish	2	
Other	0.01	
None	12	
Cancer diagnosis		
Lung	37.1	
Pancreas	10.9	
Colon	7.1	
Prostate	6.5	
Liver	4.1	
Other	34.3	
Most Recent Job		
Professional	20.4	
Manager/administrator	12.3	
Service	12.0	
Other	55.3	
Home setting		
Urban	1.1	
Suburban	80.9	
Rural	18.0	

The sample reported an average of 10 symptoms, an average total symptom severity score of 21 (possible score 0-100), an average total symptom distress score of 20 (possible score 0-100), an overall quality of life index of 102.4 (possible score 0-140), with an average of one unmet spiritual need. Seventy one percent of the sample reported zero or one unmet spiritual needs (range 0-10 from a possible 0-17).

#### Preliminary Analysis

#### Data Quality

Prior to further analysis, the 15 measured variables (indicators for the latent variables) were then assessed for univariate normality. The range of actual data was compared with possible data for each scale and no findings were outside of the possible range for that scale. Due to the use of maximum likelihood estimation in SEM, the recommendation of Curran and colleagues (Curran, 1996) to reject any measured variable with a skew of two or greater and a kurtosis of seven or greater were used as criteria. Table 8 provides the descriptive statistics for the 15 indicator variables. None of the variables were found to have violated the recommendations of Curran for univariate normality (Curran, 1996). *Assessment of Assumptions of Method* 

*Multivariate normality*. After assessing the indicator variables for univariate normality, the data were assessed for multivariate normality. While univariate normality is a necessary condition, it is not sufficient for determining multivariate normality (Stevens, 2002). AMOS reports a multivariate kurtosis value (Mardia's coefficient) with its associated critical ratio. Values ranging from > 1.96 to 10 are considered moderately non-normal (Ekland-Olson, 2007; Garson, n.d.). The critical ratio in AMOS represents

the statistic divided by its standard error and is comparable to a Z test, testing the

difference between the statistic and zero (Byrne, 2001).

Table 8.

Descriptive statistics	jor the matcator v	unubies		
Variable	Mean (SD)	Minimum-	Skewness	Kurtosis
		Maximum		
CS-1	2.45 (2.2)	0-8	1.35	0.48
CS-2	5.33 (1.1)	1-8	-0.75	1.32
CS-3	1.87 (.99)	1-4	0.84	-0.46
QOL-1	42.47 (9.3)	18-60	-0.26	-0.54
QOL-2	23.84 (8.3)	5-40	-0.02	-0.69
QOL-3	36.16 (4.5)	19-40	-1.34	1.38
Phy-1	9.75 (4.1)	1-25	0.43	0.08
Phy-2	20.62 (11.)	1-66	0.70	0.48
Psy-1	19.85 (13.)	0-74	0.92	1.11
Psy-2	2.90 (2.17)	0-9	0.58	-0.49
Sp-1	18.71 (4.1)	5-25	-0.51	-0.13
Sp-2	9.85 (4.7)	1-20	0.50	-0.64
Sp-3	6.59 (3.7)	2-15	0.78	-0.53
Sp-4	6.27 (2.9)	0-10	-0.19	-1.35
Sp-5	11.64 (2.5)	3-15	-0.65	0.29
Mardia's coefficient				8.11
Critical ratio				3.60
<i>Note:</i> CS = Clinical Stat	us; Phy = Physical; Psy	v = Psychological; Q	OL = Quality of Life;	Sp = Spiritual

Descriptive Statistics for the Indicator Variables

Multivariate non-normality of the data tends to inflate the  $\chi^2$  fit statistic while deflating the standard errors. The inflation of the  $\chi^2$  could lead to a greater likelihood of rejection of the model being tested, while deflation of the standard errors will lead to regression paths and factor/error covariance being found statistically significant more often than they are. However, violations of this assumption are rarely assessed for or reported in current SEM literature (Byrne, 2001; Garson, n.d.). While this multivariate kurtosis (Mardia's coefficient 8.11) indicates moderately non-normal data, due to the use of multiple fit indices the analysis was continued (Hu, 1998). Multivariate normality was also assessed using the Mahalanobis' distance. The greatest Mahalanobis' distance for this data was 45.185. The larger the Mahalanobis' distance the more improbable the centroid of the multivariate solution under normal distribution (Garson, n.d.). However, it was decided, a priori, to retain outliers. Inspection of all of the Mahalanobis' distances for the data set show a gradual increase in the distance with no extreme values noted.

*Linearity*. The second assumption of SEM, as a type of general linear model, is that there is a linear relationship between the measured variables. Scatterplots of the variables were analyzed. The scatterplots showed a normal shape and direction for all of the bivariate relationships except for the three clinical status indicators. Figure 6 presents the scatterplot for CS-1 by CS-3. The restricted range caused by the screening of the subjects by these instruments is visible in the data. The decision was made to retain these variables, as no other indicators of cognitive/functional status were available.



*Figure 6*. Bivariate scatterplot of CS-1 by CS-3.

Stevens (2002) recommends assessing bivariate correlations of the indicator variables and notes that, ideally, the independent variables should be significantly correlated with the dependent variables and uncorrelated (or weakly correlated) with each

other. A correlation matrix of the indicator variables was constructed (Table 9) and analyzed. Initial assessment of the bivariate correlations shows significant relationships between all the indicator variables that had been grouped together a priori reflecting the latent construct. The three quality of life indicators were also found to be significantly correlated to the other constructs, seeming to support the hypothesis that it was a dependent variable. However, some of the correlations, though significant at both the 0.05 and 0.01 level, were still weak to moderate in magnitude. The correlations show 0.17 to 0.43 for the clinical status indicators, 0.29 to 0.50 for the quality of life indicators, 0.47 for the psychological variables, 0.88 for the physiological variables, and 0.30 to 0.80 for the spiritual variables. Further analysis also showed significant, strong relationships between the Psy 1 and 2 and Phy 1 and 2 variables (from 0.40 to 0.93), indicating multicollinearity (an unacceptably high level of intercorrelations between the measured variables, making assessment of the effect of the variables unreliable). In the presence of the multivariate non-normality of the measured variables, the moderate Mahalanobis' distance, and multicollinearity, further analysis was needed.

Correlations	of the	Indicator	Variables
Correlations	0 ine	maicaior	variables

	Sp-1	Sp-2	Sp-3	Sp-4	SP-5	Psy-1	Psy-2	Phy-1	Phy-2	QOL-1	QOL-2	QOL-3	CS-1	CS-2	CS-3
Sp-1	1	1	1	I		,	5	5	2						
Sp-2	0.42(**)	1													
Sp-3	0.35(**)	0.80(**)	1												
Sp-4	0.38(**)	0.70(**)	0.61(**)	1											
Sp-5	0.59(**)	0.42(**)	0.33(**)	0.30(**)	1										
Psy-1	0.004	0.070	0.091	0.023	0.085	1									
Psy-2	-0.16(**)	-0.049	-0.026	-0.098(*)	-0.069	0.47(**)	1								
Phy-1	0.005	0.070	0.095	0.020	0.062	0.862(**)	0.40(**)	1							
Phy-2	-0.011	0.048	0.053	-0.006	0.072	0.93(**)	0.44(**)	0.88(**)	1						
QOL-1	0.078	0.053	0.029	0.033	-0.024	-0.55(**)	-0.42(**)	-0.53(**)	-0.55(**)	1					
QOL-2	0.17(**)	0.14(**)	0.119(*)	0.107(*)	0.089	-0.53(**)	-0.44(**)	-0.47(**)	-0.53(**)	0.5(**)	1				
QOL-3	0.31(**)	0.26(**)	0.2(**)	0.26(**)	0.22(**)	-0.221(**)	-0.25(**)	-0.23(**)	-0.21(**)	0.31(**)	0.29(**)	1			
CS-1	0.040	-0.041	-0.079	0.005	0.13(**)	0.006	0.012	-0.030	0.035	0.020	-0.123(*)	-0.012	1		
CS-2	-0.074	-0.100(*)	-0.053	-0.077	-0.049	0.049	0.094	0.023	0.061	-0.056	-0.23(**)	-0.123(*)	0.43(**)	1	
CS-3	-0.027	-0.050	-0.090	-0.053	-0.035	-0.140(**)	-0.082	-0.16(**)	-0.116(*)	0.074	0.017	0.048	0.17(**)	0.22(**)	1
Mean	18.71	9.85	6.59	6.27	11.64	19.85	2.90	9.75	20.62	42.47	23.84	36.16	2.45	5.33	1.87
SD	4.09	4.69	3.69	2.91	2.50	12.65	2.17	4.10	10.98	9.28	8.29	4.53	2.18	1.07	.99

*Note.* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual *Correlation significant at the 0.05 level (2 tailed). **Correlation significant at the 0.01 level (2 tailed)

At this point the decision was made to conduct a principal factor analysis (PFA) on the 15 indicator variables to assess whether there was an inherent underlying structure in the data. If no underlying structure was found, further analysis would not have been conducted. PFA is recommended in model testing as it accounts for the covariation among variables, not the total variance, as in principal component analysis. PFA uses iteratively-derived estimates of the communalities between the variables in a set and seeks the least number of factors that accounts for the contention that there was a latent structure (SPSS, 2006). Communality, as reported the contention that there was a latent structure (SPSS, 2006). Communality, as reported in the SPSS output, is the sum of the squared factor loadings for the variables. Initial communalities are the proportion of the variance accounted for in each variable by the rest of the variables. Extraction communalities are estimates of the variance in each variable accounted for by the factors in the factor solution (SPSS, 2006). Table 10 shows both the initial and extraction communalities for the indicator variables.

Table 10

	Initial	Extraction
CS-3	0.096	0.113
QOL-1	0.416	0.417
QOL-2	0.434	0.477
QOL3	0.234	0.244
Sp-1	0.424	0.623
Sp-2	0.729	0.896
Sp-3	0.654	0.718
Sp-4	0.515	0.536
Sp-5	0.412	0.508
CS-1	0.247	0.388
CS-2	0.263	0.535
Psy-2	0.312	0.318
Phy-1	0.799	0.792
Phy-2	0.893	0.884
Psy-1	0.879	0.893

Communalities of Indicator Variables

*Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual

Small communality values in the extraction indicate variables that do not fit well with the factor solution. Inspection of the initial eigenvalues suggested that 4 latent variables were explaining 66% of the variability in the data. The extraction sums of squared loadings (variance explained by the extracted factors before rotation) suggested that the 4 latent variables were explaining 56% of the variability in the data. The loss of approximately 10% of the variation may be due to factors unique to the original variables or also variability not explained by the model (SPSS, 2006). Inspection of the scree plot suggested that a 5 factor solution might better explain the variability in the data, but the eigenvalue of Factor 5 was only 0.86, so the analysis continued on 4 factors. An oblique rotation was chosen due to the correlations between the original variables. SPSS generates 3 matrices in a PFA with an oblique rotation. The factor matrix (Table 11) are the factor loadings between the variables and the factors and is analogous to Pearson's R (note the cross loadings for Sp-1, 3, and 5). The pattern matrix (Table12) is the coefficient representing the unique contribution of the variable. The structure matrix (Table 13) is the factor loadings in an orthogonal rotation. It is recommended that both the structure and pattern matrices be used to label the factors (Garson, n.d.).

	Factor				
	1	2	3	4	
Phy-2	0.913	0.195	-0024	0.108	
Psy-1	0.913	0.224	-0.049	0.086	
Phy-1	0.855	0.213	-0.098	0.078	
QOL-2	-0.652	0.108	-0.172	0.102	
QOL-1	-0.644	-0.021	0.012	0.029	
Psy-2	0.548	-0.044	0.008	-0.128	
QOL-3	-0.362	0.299	0.005	0.154	
Sp-2	-0.111	.0894	0.010	-0.292	
Sp-3	-0.068	0.784	-0.021	-0.315	
Sp-4	-0.125	0.695	0.034	-0.190	
Sp-1	-0.164	0.612	0.139	0.450	
Sp-5	-0.050	0.566	0.188	0.386	
CS-2	0.133	-0.144	0.684	-0.171	
CS-1	0.037	-0.037	0.619	0.041	
CS-3	0118	-0.108	0.294	-0.033	

Factor Matrix of the 15 Indicator Variables

Note CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual: Bolded values 0.30 or greater (Ferron, 2007).

### Table 12

Pattern	Matrix o	f the	15	Measured	Indicators

		Fac	tor	
	1	2	3	4
Psy-1	0.949	0.016	-0.076	0.150
Phy-2	0.947	-0.025	-0.054	0.169
Phy-1	0.887	0.018	-0.123	0.128
QOL-1	-0.639	0.008	0.005	0.038
QOL-2	-0.623	0.031	-0.200	0.126
Psy-2	0.523	0.040	0.037	-0.164
QOL-3	-0.294	0.112	-0.046	0.286
Sp-2	0.005	0.937	0.003	0.020
Sp-3	0.026	0.871	-0.016	-0.054
Sp-4	-0.030	0.700	0.022	0.062
CS-2	0.110	0.068	0.721	-0.094
CS-1	0.052	-0.039	0.609	0.165
CS-3	-0.130	-0.028	0.304	-0.010
Sp-1	-0.012	0.070	0.010	0.751
Sp-5	0.088	0.086	0.074	0.673

*Note.* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual **Bolded** values 0.30 or greater (Ferron, 2007).

	Factor					
	1	2	3	4		
Psy-1	0.928	0.073	-0.086	0.035		
Phy-2	0.925	0.038	-0.059	0.032		
Phy-1	0.869	0.073	-0.132	0.025		
QOL-1	-0.644	0.047	0.000	0.128		
QOL-2	-0.641	0.145	-0.214	0.238		
Psy-2	0.544	-0.065	0.043	0.216		
Sp-2	-0.028	0.947	-0.141	0.494		
Sp-3	0.005	0.845	-0.145	0.385		
Sp-4	-0.061	0.729	-0.089	0.419		
CS-2	0.122	-0.093	0.717	-0.121		
CS-1	0.032	-0.051	0.604	0.098		
CS-3	-0.127	-0.076	0.309	-0.027		
Sp-1	-0.116	0.449	-0.049	0.787		
Sp-5	-0.005	0.413	0.018	0.700		
QOL-3	-0.336	0.274	-0.083	0.386		
N CO	C1 $1$ $C1$ $D1$	DI	D. 1.1.1.1.001	O 114 CT 10		

Structure Matrix of the 15 Measured Indicators

*Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual: **Bolded** values 0.30 or greater (Ferron, 2007).

Factor 1 would appear to capture a Symptom/Quality of Life discrepancy factor, Factor 2 a Spiritual/Religious factor, Factor 3 a Functional/Cognitive factor, and Factor 4, a Spiritual/Existential factor. This again would seem to support a four factor conceptual model over a five factor model.

*Independence*. The design of the study guaranteed the independence of the subjects. This is cross sectional data obtained on each unique subject at time of admission to the study.

## Assessment of the Measurement Model

## Assessment of Model Fit

With the preliminary analysis of the indicator variables completed, the model fitting phase began. The latent and measured variables for this model are summarized in Table 14.

Latent	Measured Indicators
Variable	
Clinical	
Status	CS-1, Katz Activity of Daily Living Index
	CS-2, Palliative Performance Scale
	CS-3, Short Portable Mental Status Questionnaire
Quality of	QOL-1, Hospice Quality of Life Index-14, total
Life	Psychologic/physiologic well-being subscale
	QOL-2, Hospice Quality of Life Index-14, total Functional well-being subscale
	QOL-3, Hospice Quality of Life Index-14, total Social/spiritual well- being subscale
Physical	Phy-1, MSAS, number of reported symptoms
i nysioui	Phy-2. MSAS, total severity score
Psychological	Psy-1, MSAS, total distress score
, ,	Psy-2, CESD total depressive symptomatology score
Spiritual	Sp-1, Spiritual Needs Inventory, total Outlook subscale
	Sp-2, Spiritual Needs Inventory, total Inspiration subscale
	Sp-3, Spiritual Needs Inventory, total Spiritual activities subscale
	Sp-4, Spiritual Needs Inventory, total Religion subscale
	Sp-5, Spiritual Needs Inventory, total Community subscale

Latent Variables and Their Measured Indicators

Per Byrne's (2001) recommendation, the fit of the indicators to their latent variables were first assessed using AMOS which provided both an  $R^2$  for the latent and measured variables and  $\chi^2$  statistic of the difference between the implied model and sample data (Table 15).

Latent variable	Measured variable	$R^2$ between latent and measured variable	$\chi^2$ test of difference between implied model matrix and sample matrix
Chinear Status	CS-2 CS-3	0.58 0.07	nonsignmean
Quality of Life	QOL-1 QOL-2 QOL-3	0.73 0.69 0.40	nonsignificant
Physiological	Phy-1 Phy-2	0.82 0.95	significant
Psychological	Psy-1 Psy-2	0.94 0.23	significant
Spiritual	Sp-1 Sp-2 Sp-3 Sp-4 Sp-5	0.21 0.90 0.70 0.54 0.20	significant

Latent to Measured Variable Fit

Weak covariances are noted between the clinical status measured variables and the latent variable but the model specification matrix is not statistically different from the sample matrix. Quality of life's model is also well fitted but once again, QOL-3 shows a weak to moderate covariance (0.40) with the latent variable. The physiological, psychological, and spiritual latent variables all show significant differences between the implied and sample matrices with Psy-2, Sp-1, and Sp-5 showing weak covariance with their latent variables (0.20-0.23). This continues to call into question the fit of these variables. The five factor measurement model was reproduced in AMOS utilizing the graphic interface.

Convergence was achieved and a  $\chi^2 = 307.361$  (df 80, p=0.000), CFI of 0.927, and a RMSEA of 0.084 resulted. These did not meet the levels for fit indices set a priori (nonsignificant  $\chi^2$ , CFI  $\ge 0.95$ , RMSEA  $\le 0.05$ ). Several reasons, besides specification error, have been found to complicate model fit: inadequate sample size, non-normal data, or missing data, for example (Boomsma, 2000). As has been previously noted, this particular sample has shown a moderate amount of multivariate non-normality. *Model Modifications* 

AMOS produces a modification index (M.I.) which is the expected drop in the overall  $\chi^2$  if a parameter is freely estimated, with an expected change in parameter statistic (Par Change) (Byrne, 2001). Inspection of these statistics showed that the largest M.I. was 95.73 (Par Change – 4.009) for a covariance of the error term for Sp-1 (e11) and Sp-5 (e15). This was supported by a correlation between these two error terms of 0.49. When e11 and e15 were allowed to covary and the analysis rerun, the  $\chi^2$  decreased to 198.014, the CFI increased to 0.96, and the RMSEA decreased to 0.061. These still did not meet the a priori standards. AMOS also produces a standardized residual covariance matrix which shows where the areas of misfit are occurring between the implied model and the sample model. The residual acts as an error term – it represents the difference between the observed data and the hypothesized model. These standardized residuals function as a *Z* score with 2.58 signifying a large misspecification (Byrne, 2001). Inspection of the standardized residual matrix (Table 16 ) shows that most of the misfit is occurring in Psy-2, QOL-3, Sp-1, Sp-5 and CS-1 and 3.

# Table 16.

Standardized Residual Covariance Matrix of Five Factor Measurement Model

	Sp-1	Sp-2	Sp-3	Sp-4	Sp-5	Psy-1	Psy-2	Phy-1	Phy-2	QOL-1	QOL-2	QOL-3	CS-1	CS-2	CS-3
Sp-1	0.000														
Sp-2	-0.09	0.000	0.000												
sp-s Sp-4	045	-0.02	0.000	0.000											
Sp-4 Sn-5	0.000	0.123	-0.51	-0.25	0.000										
Psy-1	-0.57	-0.01	0.592	-0.62	1.074	0.000									
Psy-2	-3.51	-1.67	-1.12	-2.49	1.683	0.000	0.000								
Phy-1	-0.35	0.433	1.056	-0.34	0.813	0.005	0.405	0.000							
Phy-2	-0.71	-0.09	0.146	-0.91	0.981	0.005	0.222	0.000	0.000						
QOL-1	0.372	-1.49	-1.64	-1.29	- 1.637	0.622	- 3.401	1.022	0.738	0.000					
QOL-2	2.151	0.100	0.010	0.067	0.551	0.253	- 3.289	0.537	0.159	-0.138	0.000				
QOL-3	5.483	3.631	2.652	3.997	3.688	1.468	2.102	0.783	1.678	0.579	-0.068	0.000			
CS-1	1.314	0.276	-0.64	0.940	3.125	- 0.287	0.042	- 1.042	0.220	2.015	-0.739	0.703	0.000		
CS-2	0.608	-0.11	0.585	-0.11	0.138	0.271	1.525	0.310	0.380	1.646	-1.617	-0.847	-0.019	0.000	
CS-3	-0.27	-0.43	-1.30	-0.63	0.438	3.034	- 1.745	3.448	- 2.573	2.320	1.245	1.462	0.831	-0.112	0.000

*Note.* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual; >2.58 **bolded** 

Returning to the bivariate correlation matrix and the PFA, it was decided to collapse the Psychological and Physiological factors into one factor that was named the "Symptom Experience". The four indicator variables (Phy-1, Phy-2, Psy-1, and Psy-2) showed significate correlations and had factor-loaded together supporting this decision. All four variables were also measuring some form of symptomatology (number of symptoms, severity of symptoms, distress of symptoms, and depressive symptomatology) supporting their aggregation theoretically. Figure 7 shows the new four factor model hypothesized (the error terms for Sp-1 and Sp-5 were still allowed to covary).

This model achieved a  $\chi^2$  of 204.099 (df 83, p= 0.000), a CFI of 0.961, and a RMSEA of 0.60, showing continued misfit. Inspection of the standardized covariance matrix (Table 17) shows where the greatest misfit occurs



Figure 7. The Geriatric Cancer Experience in End of Life (four factor) Model

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Table 17

	Sp-5	Sp-4	Sp-3	Sp-2	Sp-1	Phy-1	Phy-2	Psy-1	Psy-2	QOL- 1	QOL- 2	QOL- 3	CS-1	CS-2	CS-3
Sp-5	0.000														
Sp-4	-0.236	0.000													
Sp-3	0.000	1.005	0.000												
Sp-2	0.117	-0.027	-0.087	0.000											
Sp-1	-0.495	0.075	-0.414	0.015	0.000										
Phy-1	0.755	-0.437	-0.409	0.303	0.945	0.000									
Phy-2	0.921	-1.010	-0.775	-0.222	0.032	0.060	0.000								
Psy-1	1.187	-0.429	-0.452	0.239	0.810	-0.061	0.004	0.000							
Psy-2	-1.631	-2.399	-3.454	-1.557	-1.022	-0.520	-0.303	0.297	0.000						
QOL-1	-1.636	-1.290	0.373	-1.494	-1.637	0864	-0.618	-0.679	-3.382	0.000					
QOL-2	0.559	0.081	2.160	0.112	0.026	0.650	0.232	0.145	-3.298	-0.143	0.000				
QOL-3	3.691	4.003	5.487	3.635	2.659	0.856	1.728	1.411	-2.103	0.569	-0.048	0.000			
CS-1	3.117	0.927	1.306	0.261	-0.651	-1.022	0.243	-0.327	0.021	1.997	-0.767	0.689	0.000		
CS-2	-0.136	-0.105	-0.606	-0.099	0.588	-0.290	0.407	0.188	1.481	1.664	-1.612	-0.842	-0.02	0.000	
CS-3	-0.443	-0.635	-0.275	-0.437	-1.307	-3.437	-2.561	-3.055	-1.756	2.310	1.230	1.454	0.880	0109	0.00

Standardized Residual Covariance Matrix for the Four Factor Measurement Model

 $\frac{1}{1} \frac{1}{1} \frac{1}$ 

Most of the misspecification continued to appear to be arising from QOL-3, Psy-2, CS-1, CS-2, CS-3, Sp-1, and Sp-5. These were the same variables that showed a greater degree of non-normality, problems with bivariate linearity, covarying error terms and model misfit (Table 18). They were also the variables for which the PFA indicated smaller extraction communalities - estimating less of the variance in each variable accounted for by the factors in the factor solution (SPSS, 2006).

Table 18

			Extraction
Variable	Skew	Kurtosis	Communality
QOL-3	-1.34	1.38	0.24
Psy-2	0.58	-0.49	0.32
CS-1	1.35	0.48	0.39
CS-2	-0.75	1.32	0.54
CS-3	0.84	-0.46	0.11
Sp-1	-0.51	-0.13	0.62
Sp-5	-0.65	0.29	0.51

*Mis-specified Indicator Variables* 

*Note:* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual

At this point the decision was made to remove the problematic measured variables and rerun the analysis to test whether they were leveraging the data. The removal of all three clinical status indicator variables necessitated removing the latent variable – clinical status, leaving a three factor model with at least 2 measured variables per latent variable. The bivariate relationships now show a range of 0.50 to 0.93 between the indicators within a given construct (Table 19).

	QOL-1	QOL-2	Sp-2	Sp-3	Sp-4	Phy-1	Phy-2	Psy-1
QOL-1	1		-	-	-	-	-	-
QOL-2	0.497(**)	1						
Sp-2	0.053	0.141(**)	1					
Sp-3	0.029	0.119(*)	0.797(**)	1				
Sp-4	0.033	0.107(*)	0.695(**)	0.61(**)	1			
Phy-1	-0.53(**)	-0.472(**)	0.070	0.095	0.020	1		
Phy-2	-0.55(**)	-0.532(**)	0.048	0.053	-0.006	0.880(**)	1	
Psy-1	-0.55(**)	-0.531(**)	0.070	0.091	0.023	0.862(**)	0.929(**)	1
Means	42.47	23.84	9.85	6.59	6.27	9.75	20.62	19.85
Standard Deviations	9.28	8.29	4.69	3.69	2.91	4.10	10.98	12.65

Bivariate Correlations of Eight Retained Indicator Variables

*Note.* CS = Clinical Status; Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual;: ** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

This new model was entered into AMOS and a  $\chi^2$  of 18.324 (df 17, p=0.37), a

CFI of 0.00, and a RMSEA of 0.01 (90% C.I. 0.000 - 0.048) resulted, indicating that the

model matrix and sample matrix could not be proven to be significantly different at the

0.05 level. No significant standardized residuals were found (Table 20).

Table 20

	Sp-2	Sp-3	Sp-4	Phy-1	Phy-2	Psy-1	QOL-1	QOL-2
Sp-2	0.000							
Sp-3	-0.008	0.000						
Sp-4	0.006	0.035	0.000					
Phy-1	0.297	0.933	-0.443	0.000				
Phy-2	-0.232	0.017	-1.020	0.020	0.000			
Psy-1	0.236	0.800	-0.433	-0.029	-0.001	0.000		
QOL-1	-0.831	-1.072	-0.787	-0.398	-0.102	-0.218	0.000	
QOL-2	0.938	0.733	0.707	0.570	0.173	0.035	0.000	0.000
Made Dhas	Discolaria T. F	Dary Daryala	1 a si sali OC	O. 114	of I for Co	Carinita al		

Standardized Residual Matrix for the Three Factor Measurement Model

*Note*. Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual

The largest Mahalanobis' distance was reduced to 30.78 and the Mardia's coefficient was reduced to 2.39 (C.R. 1.89). Since the fit indices had met the level set a priori, analysis of standardized regression weights and R² values was conducted. See Figure 8 for this report. The covariances and variances for the actual and implied data are provided in the Appendix J and K.



*Note.* **Pathway fixed to 1 in unstandardized model. * Significant at the 0.05 level *Figure 8.* The Geriatric Cancer Experience in End of Life (three factor) Measurement

Model.

While the  $R^2$  of 0.50 for QOL-1, QOL-2, and 0.53 for Sp-4 show that approximately 50% of the variability in these variables is explained by the latent construct, the other  $R^2$ s range from 0.70 to 0.94. All of the regression pathways between the latent and measured variables are statistically significant at alpha 0.05. The variability between Symptom Experience and Quality of Life are seen to be significantly related. However, co-variation between Symptom Experience and Spiritual Experience and between Spiritual Experience and Quality of Life was not significant. As the symptom experience (greater number of symptoms, more severe symptoms, and more distress) increases, quality of life (physical/psychological and functional well-being) significantly decreases. The structural adaptation of this model was ready to be tested now that the measurement model fit.

#### Assessment of the Full Structural Model

## Assessment of Model Fit

The structural adaptation of the three factor model, with Quality of Life as an endogenous variable was entered into AMOS. For parsimony's sake no covariance was hypothesized between the Symptom Experience and the Spiritual Experience as there had been no significant covariance in the measurement model. Analysis of this model generated a  $\chi^2$  of 19.803 (df 18, *p* =0.344), a CFI of 0.99, and a RMSEA of 0.016 (90% C.I. 0.000 -0.048). No large residuals (>2.58) were found in the standardized residual covariance matrix (Table 21).

	*		3					
	Sp-2	Sp-3	Sp-4	Phy-1	Phy-2	Psy-1	QOL-1	QOL-2
Sp-2	0.000							
Sp-3	-0.006	0.000						
Sp-4	0.003	0.035	0.000					
Phy-1	1.403	1.899	0.398	0.000				
Phy-2	0.955	1.054	-0.117	0.018	0.000			
Psy-1	1.404	1.821	0.455	-0.025	-0.001	0.000		
QOL-1	-1.487	-1.644	-1.288	-0.269	0.035	-0.086	-0.123	
QOL-2	0.270	0.150	0.197	0.693	0.308	0.166	-0.155	-0.122
Note Dhy	- Dhysical	Dev - Deveh	alogical: O(	$\mathcal{M} = \mathcal{O}_{\mathrm{Hol}}$	r of Life: Sp	- Spiritual		

Standardized Residual Matrix for the Three Factor Structural Model

*Note*. Phy = Physical; Psy = Psychological; QOL = Quality of Life; Sp = Spiritual

And so, the analysis of the regression weights and R²'s were conducted. Figure 9

presents the findings.



*Note:* **Pathway fixed to 1 in unstandardized model. * Significant at the 0.05 level *Figure 9.* The Geriatric Cancer Experience in End of Life (three factor) Structural Model.

## Results of the Analysis of the Full Structural Model

This three factor structural model with Quality of Life as an outcome variable shows that 67% of the variability in quality of life is explained by the person's symptom experience: specifically the number of symptoms, the severity and distress that they cause, and the person's spiritual experience: the need for inspiration, spiritual activities, and religion. As the number of symptoms, their severity and distress increase, the person's quality of life decreases. However, as the person's spiritual experience increases, their quality of life also increases. The structural path coefficients can be interpreted as the standard unit of change in the endogenous variable given a change in the exogenous variable holding the other variable constant. Note the addition of the disturbance term (d) for the endogenous Quality of Life latent variable. The disturbance term designates the proportion of unexplained variance in endogenous variables in a model  $(1-R^2)$ . Thirty three percent of the variability in the person's quality of life score is not explained by this model. Written as an equation, the full structural equation model can be expressed as:

 $\eta = -0.80 \xi 1 + 0.20 \xi 2 + \zeta$ 

where  $\eta$  – endogenous variable (Quality of Life)  $\xi$  – exogenous variables (Symptom and Spiritual Experience)  $\zeta$  – unexplained variability

The R² between the measured and latent variables remain the same as in the measurement model and range from 0.50 to 0.95. All of the regression pathways between the latent and measured variables are statistically significant and the pathways from both the Symptom Experience and Spiritual Experience to Quality of Life are significant at alpha 0.05. The covariance and variance matrices for both the actual and implied data are found in Appendices J and K. While the residuals were greater in the structural model than the measurement model, they were not significantly greater. Using Byrne's (Byrne, 2001) recommendation to test the  $\chi^2$  change between the two models, the critical value with one degree of freedom is 3.84. The difference between the measurement (CMIN 18.324, df 19) and structural (CMIN 19.803, df 18) models was found to be  $\chi^2$  -1.479, df 1. This is not an unexpected finding as the structural model is an adaptation of the measurement model. The recommendation is made that if the  $\chi^2$  shows no significant difference, to accept the more parsimonious of the two models (Garson, n.d.).

## Hypothesis Testing

The overall purpose of this study was to test a conceptual model of the geriatric cancer experience in end of life as adapted from Emanuel and Emanuel's Framework for a Good Death (1998). The research question asked: Does the Geriatric Cancer Experience in End of life model accurately represent the self-reported experience of the geriatric cancer patients newly admitted to a hospice home care setting? To assess this, two specific aims and seven hypotheses were developed.

## Specific Aim 1

To establish the fit of the measurement model of the Geriatric Cancer Experience in End of Life.

*Hypothesis 1:* The Geriatric Cancer Experience in End of Life is a five-factor structure composed of clinical status, physical, psychological, spiritual and quality of life latent variables as proposed in the conceptual model.

This hypothesis was not supported. None of the set limits for the fit indices -  $\chi^2$ , CFI, and RMSEA were met. During an exploratory phase of model specification, the Geriatric Cancer Experience in End of Life was found to be a three-factor structure composed of the Symptom Experience, Spiritual Experience and Quality of Life. In rejecting this hypothesis, all of the following hypotheses are also rejected. Specific comments are made under each hypothesis.

*Hypothesis 2*. The variability in older adult's responses in the end of life cancer experience can be explained by these five factors.

This hypothesis is also not supported. However, Quality of Life was found to covary significantly with their Symptom Experience in the measurement model.

*Hypothesis 3.* Consistent with the literature, the five factors are correlated but the error terms of the measured variables are not.

This hypothesis was also not supported. Further, while the five factors were correlated, the error terms for two of the Spiritual measured variables (e11 and e15) were also correlated (R= 0.49).

Specific Aim 2

To confirm the full structural model of the Geriatric Cancer Experience in End of Life.

*Hypothesis 4.* The full structural model of the Geriatric Cancer Experience in End of Life is a five-factor structure composed clinical status, physical, psychological,

spiritual, and quality of life latent variables, and quality of life is dependent on the other factors, as proposed in the conceptual model.

The five factor full structural model was not tested due to the significant misfit in the measurement model. However, the three factor structural model was tested and met set criteria.

*Hypothesis 5*. The variability of the older adult end stage cancer patients in the experience can be explained by the relationships between the five factors.

In the three factor model, the Symptom and Spiritual Experience of the person explains 67% of the variability in their Quality of Life score.

*Hypothesis 6.* Consistent with the literature, the four factors (clinical status, physiological, psychological, and spiritual) are correlated but the error terms of the measured variables are uncorrelated.

Once again, the five factor model is rejected, however, in the three factor model Symptom Experience and Quality of Life and Spiritual Experience and Quality of Life are correlated and their error terms are not.

*Hypothesis 7.* There is a statistically significant pathway from the four factors (clinical status, physiological, psychological, and spiritual) to quality of life in the older adult end stage cancer population.

This was also not supported. But significant pathways were found between the Symptom and Spiritual Experience and Quality of Life in the three factor model.

#### Post hoc Power Analysis

MacCallum and colleagues (1996) calculations for post hoc power analysis were utilized. The specified conditions include an alpha of 0.05, an RMSEA for H:0 of 0.05, an RMSEA for H:1 of 0.08, and then the degrees of freedom for the model and sample size to conduct the calculations. For the structural model, the degrees of freedom were 18 and the sample size was 403. The power was determined to be 1.00. This is the power to detect a false null hypothesis. This power was determined to be adequate for the study.

## Chapter Summary

In the first part of this chapter the sample characteristics are reported. The preliminary analysis of the data and assessment of bivariate relationships were reported next. The measurement model, with assessment of fit and modifications, was fitted and reported next. The original five factor model was revised to a three factor model and then the testing of the full structural model was reported. In the next section the hypothesis testing was conducted. All of the hypotheses were rejected when the five factor model did not meet the fit indices. But the findings for the three factor model were reported. Sixty seven percent of the variability in quality of life for the geriatric cancer patient in end of life is predicted by their symptom and spiritual experiences. Post hoc power analysis was then reported. In the next chapter the implications of the study are discussed.

#### Chapter Five

## Discussion

In the first part of this chapter the sample, key findings (with aims discussed in order), limitations, implications for nursing, recommendations for future work, and lessons learned are discussed. Differences between the model and the literature are also discussed. The overall study is then summarized.

#### Sample

Four hundred and three newly admitted hospice patients participated in this study. The average subject was likely to be a Caucasian male, approximately 80 years of age, who identifies himself as a Christian. He is a high school graduate, cared for by his spouse, and living in the suburbs. This is comparable with a national data set of hospice patients which reported that 81% of hospice patients are Caucasian and 82% are 65 years of age and older (NHPCO, 2008). Conner and colleagues report that rates of hospice utilization are greater in suburban areas and the Southeastern United States (Connor, Elwert, Spence, & Christakis, 2007). Current research using hospice and oncology populations also show a preponderance of self reported Christians, unless purposive sampling techniques are utilized (Hermann, 2006; Taylor, 2003b; Taylor & Mamier, 2005). This sample reported an average of 10 symptoms, an average total symptom severity score of 21 (possible score 0-100), an average total symptom distress score of 20 (possible score 0-100). This is also reflective of samples in the literature. Mean numbers of symptoms in previous research in geriatric metastatic oncology populations have been

reported to range from 3 to 11 with severity and distress levels in the first and second quartile of the scale (Klinkenberg et al., 2004; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle et al., 1994). An overall quality of life index of 102.4 (possible score 0-140) reported by this sample was comparable with other studies as occurring in the 50th-75th percentile on the scale (Brown et al., 2006; Donnelly et al., 2001; McMillan & Weitzner, 2000). An average of one unmet spiritual need was reported with 71% of the sample reporting no or one unmet spiritual needs (range 0-10 from a possible 0-17). This finding is also reflective of previous studies (Hermann, 2001; Murray et al., 2004; Taylor, 2003b).

## Key Findings

## Specific Aim 1: Establishing the Fit of the Measurement Model

The first aim of the study was to establish the fit of the measurement model of the adaptation of Emanuel and Emanuel's (1998) framework with data from geriatric (65+) hospice patients with cancer using structural equation modeling. The developers of the framework had used exploratory factor analysis in a follow up study to assess construct validity and stability over time of the framework and found that the model was valid and stable. It was also reported that eight factors accounted for 46% of the variability in the person's responses. Three of the factors identified are comparable with the current study – psychological distress, spirituality/religiosity, sense of purpose, but odds ratios and correlations are the only statistics reported making comparison with this current study problematic (Emanuel et al., 2000). It should be noted here that, as originally conceptualized, a nebulous outcome variable "overall experience of the dying process" was the end point of the framework (Emanuel & Emanuel, 1998) (p.23). No other testing

of this framework was found using SEM with which to compare the present study. No studies were found that measured quality of life, as an outcome variable, utilizing SEM in the oncology or end of life literature. The search was then expanded and two studies were identified as using AMOS software to test health related quality of life. Nuamah and colleagues (1999) tested a Roy Adaptation Model based theory of health related quality of life (HRQOL) in newly diagnosed oncology patients. Only two latent variables (severity and HRQOL) were hypothesized with six measured exogenous variables. While hypothesis testing was conducted and fit indices of the models reported, symptom distress, functional status, and depression were conceptualized as the measured indicators of HRQOL- a HRQOL scale was not used. For the current study, symptom distress (Psy-1), functional status (CS-2), and depression (Psy-2) served as predictors and not outcome variables. Also, no squared multiple correlations were reported in the Nuamah study between the indicators and latent variables, nor between the predictors and outcome variables, making it impossible to compare and contrast the two studies. Hofer and colleagues (2005) tested a conceptual model of HRQOL based on Wilson and Cleary's theoretical model of Health Related Quality of Life in early stage heart disease patients using SEM. That study reported that 49% of the variability in HRQOL is predicted by a very non-parsimonious model. However, the fit indices accepted were not as rigorous as in the current project, For example, a  $\chi^2$  of 513.28, df 188, CFI of 0.92, and a RMSEA of 0.06 were accepted. The design of the model also made comparison with the current study problematic. For example, Wilson and Cleary's model theorizes that physical functioning mediates symptom status. The Geriatric Cancer Experience in End of Life

does not. Both Nuamah and Hofer note the paucity of research with which to compare samples, methods, and findings.

While it was originally conceptualized that quality of life covaried with four other latent variables (clinical status, physiological, psychological, and spiritual), this project found that the model which fit the data best was a three factor model where quality of life covaried significantly with a combination of physiological and psychological (now called the symptom experience) domains (R=-0.79).

## Specific Aim 2: Confirming the Structural Model

*Alternative Models.* While a five factor structure was conceptualized from the theoretical framework (Figure 3), structural equation modeling supported the modification to a three factor model (Figures 10 &11).



Figure 3. The Geriatric Cancer Experience in End of Life – Five Factor Model



*Figure 10.* The Geriatric Cancer Experience in End of Life – Three Factor Conceptual Measurement Model.



*Figure 11*. The Geriatric Cancer Experience in End of Life – Three Factor Conceptual Full Structural Model

As noted in Chapter One, alternative models cannot be ruled out in SEM (Raykov, 2006). The concept of equivalently fit models has been noted to exist and yet be universally ignored in covariance structure analysis (MacCallum, Wegener, Uchino, & Fabrigar, 1993). In studies, such as this one with highly correlated exogenous variables and cross-sectional data, the likelihood of alternative models increases. A review of 53 published covariance structural models found that 90% could yield a plausible alternative model and half of the studies yielded more than 16 equivalent models. The validity of the conclusions drawn by the investigators can be called into question when alternative models exist and are not given careful consideration. MacCallum and colleagues suggest several techniques for managing the issue of alternative models. Some of the recommendations can only be used in future studies. For example, manipulating key variables experimentally and collecting longitudinal data. Neither of these recommendations is plausible in this present study. MacCullum further notes that areas of substantive interest may indeed have alternative explanations of the same data and the investigator does better to confront and evaluate the alternative models than ignore them. The status of a priori specification is not believed to give greater validity to a model (1993).

When goodness of fit indices cannot distinguish between models, interpretability of parameter estimates and meaningfulness of the model become the criteria. When the  $\chi^2$  did not change significantly between the measurement model and structural model the question raised is: Is quality of life better measured as an independent or dependent variable? To use other constructs, is it better understood as a state or trait of the personality? One assumption made about health related quality of life has been that it reflects the totality of the individual's experiences and perceptions over their life trajectory and is time-dependent (Walters, Campbell, & Lall, 2001). While the discussion as to whether quality of life is dispositionally determined (trait) or situationally determined (state) is interesting, it is beyond the scope of this project. Future research is recommended to tease out the effect of disposition on self perceived quality of life. In this study, both the measurement model (Figure 8) and the full structural model (Figure 9) are found to be equally valid and meaningful explanations of the end of life experience for older adults with cancer while the structural model is more parsimonious.

Symptom experience. While the five factor model was not supported, the three factor model both supports previous research and highlights new areas for nursing interventions. Since McDaniel and Rhodes' (1995) conceptualization of the symptom experience (symptom occurrence and distress levels caused by those symptoms) of patients, multiple nurse scholars have studied the phenomena (Doorenbos, Given, Given, & Verbitsky, 2006; Kris & Dodd, 2004; Miaskowski et al., 2006; Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000; Rhodes, McDaniel, & Matthews, 1998; Tranmer et al., 2003). Miaskowski and colleagues (2006) used cluster analysis to identify sub groups of cancer patients and then tested whether the sub groups differed on quality of life indices. An inverse relationship was found between symptom subscales and total scores and quality of life in this study. Those patient groups reporting low symptom scores scored significantly higher on the quality of life instrument than those reporting high fatigue/ low pain, low fatigue/ high pain, or all high symptom scores. A post hoc analysis

showed that while physical, psychological, and social well-being differed significantly across the sub groups, spiritual well-being did not.

In the Geriatric Cancer Experience in End of Life model the Symptom Experience latent variable encapsulates the number of symptoms that the person is experiencing, the severity level of those symptoms, and the distress levels that the person reports. This sample reported an average of 10 symptoms, which is comparable to other reported studies (Gift et al., 2003; Kris & Dodd, 2004; Tranmer et al., 2003). The most frequently reported symptoms (>50%) were lack of energy (86.2%), dry mouth (71.3%), pain (68%), lack of appetite (61.4%), shortness of breath (57.7%), and feeling drowsy (56.5%). The mean severity level per symptom reported was 2.07 (possible 0-4) and mean distress level per symptom was 1.96 (possible 0-4). This is also reflective of previous research with the MSAS in comparable populations (Kris & Dodd, 2004; Tranmer et al., 2003). The contribution that this study makes to our understanding of the geriatric end of life experience is the very strong negative effect of the symptom experience on quality of life ( $\beta$  -0.80). Quality of life is becoming an outcome variable of importance and this study supports the contention that uncontrolled symptoms, and the distress that they cause, degrade quality of life in end of life.

*Spiritual experience*. As noted in Chapter Two, spirituality is gaining increasing attention as a health research variable in end of life but gaps exist in what we know about the role of spiritual issues in end of life (George, 2002; Goldstein & Morrison, 2005). Psychometric issues related to taxonomy and social desirability have been noted (Stefanek et al., 2005; Sulmasy, 2002; Taylor, 2003a). Personal faith has been shown to be associated with and promote coping in cancer (Weaver & Flannelly, 2004). A meta-
analysis of 49 studies examining the relationship between religious coping and psychological adjustment to stress found a moderate positive relationship between positive religious coping strategies and adjustment. It was also found that individuals experienced less depression, anxiety, and distress while using positive religious coping (Ano & Vasconcelles, 2005). The construct of hope has also shown a relationship with spirituality/religiosity in this population (Chochinov & Cann, 2005; Weaver & Flannelly, 2004). Further work is needed to assess whether hope mediates the relationship between spirituality and quality of life. Sulmasy (2002) states that the measurement of religious/spiritual needs may be more meaningful than measures of religiosity or religious coping in end of life. This is supported by the study conducted among advanced cancer patients which showed that unmet needs in this population was an independent predictor of quality of life - as unmet needs increased quality of life decreased (Hwang, Chang et al., 2004). The instrument used in this study – the Spiritual Needs Inventory, was developed to measure the spiritual needs of patients near end of life. The items arose from a qualitative study conducted among hospice patients. The individuals defined their understanding of the word spiritual and then provided examples of needs related to their definition. For the instrument development, spiritual needs are defined as "something required or wanted by an individual to find meaning and purpose in life" (Hermann, 2006) p.737). This definition was developed to attempt to measure both the existential and religious dimensions of the construct and to provide a valid and reliable measure for persons who may or may not define themselves as overtly religious. Psychometric work on the instrument by the developer reported that the 17 items loaded onto five factors – an outlook, inspiration, spiritual activities, religion, or community

factor (2006). These five subscales were used as the measured variables for the latent Spiritual variable. There were significant measurement issues related to univariate nonnormality, communality, and error term covariance with these subscales in this study. When a separate principle factor analysis was conducted on this instrument with the data from this sample, only three factors were extracted. However, when the measured variables were reconfigured into a three indictor schema and tested on the five factor measurement model with SEM, it did not converge and a nonpositive definite matrix error message was generated. Byrnes (2001) notes that this is most commonly caused by multicollinearity. Inspection of the standardized residual covariance matrix showed serious model mis-specification. Thus, the five indicator structure of the Spiritual Needs Inventory was retained until the decision was made to exclude all indicators with large non-normality, low communality, and error covariance. Those spiritual need indicators retained factored onto the inspiration (to talk about spiritual matters, sing/listen to inspirational music, be with people who share my beliefs, and read a religious text), spiritual activities (use inspirational materials, use phrases from a religious text, and read inspirational materials), and religion (pray and go to religious services) factors. The contribution that this study makes to our understanding of the geriatric end of life experience is the moderate, positive effect ( $\beta$  0.20) of spiritual practices on quality of life. People who express a greater need for spiritual behaviors experience an increase in quality of life.

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#### Limitations of the Study

#### Secondary Data Analysis

Problems with secondary data analysis have been described (Polit, 1983). They can be categorized as 1) restrictive: sample designs limitations, relevant variables not included, lack of linkages between data, or 2) error prone: patterns of missing data, inaccurate responses, and missing documentation. This study suffered from the restrictive limitations. While the measured variables in this study were selected as part of the larger study utilizing the theoretical framework, there were problems. The clinical status indicators were psychometrically and conceptually problematic. The person's functional and cognitive status was used as screens for admission to the study, and so there were psychometric problems related to restriction of range. There were also conceptual problems with using just functional and cognitive status as indicators of the person's overall clinical status. The addition of number of comorbidities, number of recent hospitalizations, nutritional status, number of falls would also strengthen the analysis (Balducci, 2003; Hurria et al., 2006; Rao & Cohen, 2004). McMillan's adaptation of Emanuel and Emanuel's framework also divided the physiologic and psychologic domains, whereas this data showed that they were reflective of a higher level latent variable, called here, "symptom experience".

#### A priori Fit Indices

A second limitation was the setting of rigorous fit indices a priori. While the fit indices are recommended by the texts chosen, examination of current publications show that less rigorous standards are often used (Hofer, 2005; Nuamah et al., 1999). If a significant  $\chi^2$  had been accepted and CFI of 0.90 and RMSEA of 0.08 had been

accepted, the five factor measurement model would have met the criteria and the testing of the five factor structural model conducted. The  $\chi^2$  for this model was 210.21, the CFI was 0.96 and the RMSEA was 0.60. The five factor model showed significant standardized regression weights between the exogenous and endogenous variables and a R² of 0.82 between Quality of Life and the other four factors. However, some of the standardized residuals showed large mis-specification. But in keeping with prior decisions, this model was rejected. However, it is believed that if the indicator variables had not shown marked amounts of non-normality and multicollinearity, the five factor model may have produced better indices and predicted a greater amount of the variability in quality of life.

#### Implications for Nursing

The significance of this study is twofold. First, in the research setting, testing of this three factor model provides evidence for its validity as a conceptual model to guide end of life research for geriatric patients. The model will strengthen future studies by providing a useful guide for understanding the relationships between symptoms (their frequency, severity, and distress), spirituality (the need for inspiration and religion), and quality of life in the experience in end of life of geriatric cancer patients. It will also be useful to guide the selection of variables and hypotheses, once again strengthening the science.

Second, the model will provide a validated framework for the development of nursing processes for geriatric end of life care. Assessment and interventions based on conceptual frameworks have been recommended as essential to the professional identity of nursing (Cooley, 2000; George, 2002; *NIH State-of-the-Science Conference Statement*  *on improving end-of-life care*, 2004; Peterson, 2004). This study provides evidence for the importance of symptom assessment and spiritual assessment, the development of plans of care inclusive of symptom control and spiritual care, and then the implementation and evaluation of those plans utilizing quality of life as an indicator for the utility of the care provided by nurses. It should also be noted that while both the symptom experience and spiritual experience independently contributed to quality of life in this study, the magnitude of the effect of the symptom experience was greater than that of the spiritual experience, supporting the argument for adequate symptom management in the allocation of limited resources and testing of new interventions before spiritual care practices.

As hospice care is delivered in an interdisciplinary setting where there is significant role blending, this model provides a conceptualization of the human experience which can be utilized by multiple disciplines. Patients, caregivers, physicians, social workers, volunteers and chaplains can also benefit from understanding the interplay of the symptom experience, the spiritual experience, and quality of life. This model supports the need for caring for both the physical and metaphysical dimensions of the person's life. It also highlights a need for holistic care inclusive of the physical, emotional, and spiritual domains.

#### **Recommendations for Future Work**

As has been discussed in the body of this work, recommendations for future work involve building on what has been found here. First, due to the exploratory work done during the model fitting phase of this study, these findings need to be confirmed in an independent sample of geriatric hospice patients. This will provide further evidence of the strength of the model. Second, the effect of mediating processes on quality of life in this model needs to be explored. Use of randomized controlled trials with a treatment and control arm would strengthen our understanding of the mediation of interventions or inherent qualities in the person on their perception of quality of life.

#### Lessons Learned

As a researcher in training, many lessons have been learned during this project. Taken sequentially, the first lesson learned is the need for data that meet the assumptions of the method chosen. In the future, steps will be taken to learn how to analyze nonnormal data. For this study the decision was made to delete problematic data, but future work should involve transforming and retaining data. Further training is necessary to accomplish this. The second lesson learned is to approach the data and study iteratively. Later analysis and thinking would often cause the rethinking of previous methods and assumptions, necessitating returning to earlier analysis and rerunning data analysis. Rarely was the decision made to change anything, but the process and its outcome were better understood for this reanalysis. The third lesson learned was that sticking to predetermined methodology and decisions controls for a degree of subjectivity. In this study, the fit indices came close to the predetermined levels for the originally conceptualized models. While reviewing other, like research, less rigorous standards were found, and the desire to change the acceptable indices was great. However, one would assume that those researchers had the experience to know that those indices would be acceptable in their areas of expertise. For a beginning researcher, that was not the case in this study, so the recommended indices were retained. The next lesson learned was the need for transparency in reporting methods and findings. Boomsma (2000) has noted the

difficulty in assessing the merits of covariance structure analyses due to lack of information in publications. While research publications cannot take the place of textbooks on statistical methods, additional information on the variables, their covariance matrices, and the decision making process of the statistician would allow for the comparing and contrasting of studies. The last lesson learned is that when dealing with a broad outcome measure, such as quality of life, and multiple potential predictor variables (whether latent or measured) one might expect multicollinearity between the constructs. However, using this approach, a simpler and more parsimonious solution was arrived at and this type of approach should be considered in all analyses in which multiple measurements are made and are not known to be discrete.

#### *Chapter Summary*

In summary, evidence for the validity of the three factor Geriatric Cancer Experience in End of Life has been presented. The overall purpose of the study - to test a conceptual model, adapted from Emanuel and Emanuel's Framework for a Good Death, using structural equation modeling was conducted and reported. It is concluded that the Geriatric Cancer Experience in End of Life model is a valid conceptual model on which to base nursing practice and research specific to the complex needs of the older cancer patient in end of life.

#### References

- Abraham, A., Kutner, J. S., & Beaty, B. (2006). Suffering at the end of life in the setting of low physical symptom distress. *Journal of Palliative Medicine*, 9(3), 658-665.
- Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative performance scale (PPS): a new tool. *Journal of Palliative Care*, 12(1), 5-11.
- Ano, G. G., & Vasconcelles, E. B. (2005). Religious coping and psychological adjustment to stress: A meta-analysis. *Journal of Clinical Psychology*, 61(4), 461-480.
- Balducci, L. (2003). New paradigms for treating elderly patients with cancer: the comprehensive geriatric assessment and guidelines for supportive care. *Journal of Supportive Oncology*, 1(4 Suppl 2), 30-37.
- Balducci, L., & Beghe, C. (2000). The application of the principles of geriatrics to the management of the older person with cancer. *Critical Reviews in Oncology/Hematology*, 35(3), 147-154.
- Balducci, L., & Extermann, M. (2000). Management of cancer in the older person: a practical approach. *The Oncologist*, 5(3), 224-237.
- Barsevick, A. M., Dudley, W., Beck, S., Sweeney, C., Whitmer, K., & Nail, L. (2004). A randomized clinical trial of energy conservation for patients with cancer-related fatigue. *Cancer*, 100(6), 1302-1310.
- Barsevick, A. M., Dudley, W. N., & Beck, S. L. (2006). Cancer-related fatigue, depressive symptoms, and functional status: a mediation model. *Nursing Research*, 55(5), 366-372.
- Barsevick, A. M., Whitmer, K., Nail, L. M., Beck, S. L., & Dudley, W. N. (2006). Symptom cluster research: conceptual, design, measurement, and analysis issues. *Journal of Pain and Symptom Management*, 31(1), 85-95.
- Bentler, P. M., & Chou, C.P. (1987). Practical issues in structural modeling. *Sociological Methods & Research, 16*(1), 78-117.
- Binstock, R. H., & George, L.K. (2006). *Handbook of aging and social sciences* (6th ed.). Amsterdam: Elsevier.
- Boomsma, A. (2000). Reporting analysis of covariance structures. *Structural Equation Modeling*, 7(3), 461-483.

- Bradley, N., Davis, L., & Chow, E. (2005). Symptom distress in patients attending an outpatient palliative radiotherapy clinic. *Journal of Pain and Symptom Management*, 30(2), 123-131.
- Brown, P., Clark, M. M., Atherton, P., Huschka, M., Sloan, J. A., Gamble, G., et al. (2006). Will improvement in quality of life (QOL) impact fatigue in patients receiving radiation therapy for advanced cancer? *American Journal of Clinical Oncology*, 29(1), 52-58.
- Bruley, D. K. (1999). Beyond reliability and validity: analysis of selected quality-of-life instruments for use in palliative care. *Journal of Palliative Medicine*, 2(3), 299-309.
- Buchanan, D. R., O'Mara, A. M., Kelaghan, J. W., & Minasian, L. M. (2005). Quality-oflife assessment in the symptom management trials of the National Cancer Institute-supported Community Clinical Oncology Program. *Journal of Clinical Oncology*, 23(3), 591-598.
- Buck, H. G. (2007a). The Geriatric Cancer Experience in End of Life: model adaptation. University of South Florida.
- Buck, H. G. (2007b). Geriatric cancer patient's quality of life and symptom experience. University of South Florida.
- Byrne, B. M. (2001). *Structural equation modeling with AMOS: basic concepts, applications, and programming*. Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Cancer Facts and Figures 2006. (2007). Retrieved 06/21/06, from http://www.cancer.org/downloads/STT/CAFF2006PWSecured.pdf
- Cartwright, J. C., Hickman, S., Perrin, N., & Tilden, V. (2006). Symptom experiences of residents dying in assisted living. *Journal of the American Medical Directors Association*, 7(4), 219-223.
- Cella, D. (2005). Quality of life outcomes: measurement and intervention. *Journal of Supportive Oncology*, *3*(2), 133-134.
- Centers for Medicare and Medicaid Services. (2004). Medicare Benefit Policy Manual. Chapter 9 - Coverage of Hospice Services Under Hospital Insurance. Retrieved August 3, 2007, from <u>http://www.cms.hhs.gov/manuals/Downloads/bp102c09.pdf</u>

- Chang, C. H., Cella, D., Clarke, S., Heinemann, A. W., Von Roenn, J. H., & Harvey, R. (2003). Should symptoms be scaled for intensity, frequency, or both? *Palliative* and Supportive Care, 1(1), 51-60.
- Chang, V. T., Hwang, S. S., Feuerman, M., Kasimis, B. S., & Thaler, H. T. (2000). The memorial symptom assessment scale short form (MSAS-SF). *Cancer*, 89(5), 1162-1171.
- Chang, V. T., Hwang, S. S., & Kasimis, B. (2002). Longitudinal documentation of cancer pain management outcomes: a pilot study at a VA medical center. *Journal of Pain* and Symptom Management, 24(5), 494-505.
- Chochinov, H. M., & Cann, B. J. (2005). Interventions to enhance the spiritual aspects of dying. *Journal of Palliative Medicine*, 8 *Suppl 1*, S103-115.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet*, *360*(9350), 2026-2030.
- Connor, S. R., Elwert, F., Spence, C., & Christakis, N. A. (2007). Geographic variation in hospice use in the United States in 2002. *Journal of Pain and Symptom Management*, 34(3), 277-285.
- Cooley, M. E. (2000). Symptoms in adults with lung cancer. A systematic research review. *Journal of Pain and Symptom Management*, 19(2), 137-153.
- Cooley, M. E., Short, T. H., & Moriarty, H. J. (2003). Symptom prevalence, distress, and change over time in adults receiving treatment for lung cancer. *Psycho-Oncology*, *12*(7), 694-708.
- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research, 49*(Pt 10), 699-706.
- Curran, P. J., West, S.G., Finch, J.F. (1996). The robustness of test statistics to nonnormality and specification error in confirmatory factor analysis. *Psychological Methods*, *1*(1), 16-29.
- Deaths:final data for 2004. Retrieved August 27, 2007. from <u>http://www.cdc.gov/nchs/products/pubs/pubd/hestats/finaldeaths04/finaldeaths04.</u> <u>htm</u>
- Dodd, M., Cho, M. H., Cooper, B., Miaskowski, C., Lee, K. A., & Bank, K. (2005). Advancing our knowledge of symptom clusters. *Journal of Supportive Oncology*, *3*(6 Suppl 4), 30-31.

- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668-676.
- Donnelly, S., Rybicki, L., & Walsh, D. (2001). Quality of life measurement in the palliative management of advanced cancer. *Supportive Care in Cancer*, *9*(5), 361-365.
- Doorenbos, A., Given, B., Given, C., Verbitsky, N., Cimprich, B., & McCorkle, R. (2005). Reducing symptom limitations: a cognitive behavioral intervention randomized trial. *Psycho-Oncology*, 14(7), 574-584.
- Doorenbos, A., Given, C. W., Given, B., & Verbitsky, N. (2006). Symptom experience in the last year of life among individuals with cancer. *Journal of Pain and Symptom Management*, 32(5), 403-412.
- Ekland-Olson, S. (2007). AMOS frequently asked questions and answers. *The University* of *Texas at Austin* Retrieved November 27, 2007, from <u>http://ssc.utexas.edu/consulting/answers/faqs.html#AMOS</u>
- Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *Lancet, 351 Suppl* 2, SII21-29.
- Emanuel, L. L., Alpert, H. R., Baldwin, D. C., & Emanuel, E. J. (2000). What Terminally Ill Patients Care About: Toward a Validated Construct of Patients' Perspectives. *Journal of Palliative Medicine*, 3(4), 419.
- Extermann, M., Overcash, J., Lyman, G. H., Parr, J., & Balducci, L. (1998). Comorbidity and functional status are independent in older cancer patients. *Journal of Clinical Oncology*, 16(4), 1582-1587
- Fawcett, J. (2000). Analysis and evaluation of contemporary nursing knowledge : nursing models and theories. Philadelphia: F.A. Davis
- Ferron, J. (2007). Application of structural equation modeling in education (Class notes ed.). Tampa.
- Fu, M. R., LeMone, P., & McDaniel, R. W. (2004). An integrated approach to an analysis of symptom management in patients with cancer. *Oncology Nursing Forum*, 31(1), 65-70.
- Garson, G. D. (n.d.). Structural Equation Modeling. *Statnotes: topics in multivariate analysis*. Retrieved November 15, 2007, from <a href="http://www2.chass.ncsu.edu/garson/pa765/statnote.htm">http://www2.chass.ncsu.edu/garson/pa765/statnote.htm</a>

- George, L. K. (2002). Research design in end-of-life research: state of science. *Gerontologist, 42 Spec No 3*, 86-98.
- Gift, A. G., Stommel, M., Jablonski, A., & Given, W. (2003). A cluster of symptoms over time in patients with lung cancer. *Nursing Research*, *52*(6), 393-400.
- Given, C., Given, B., Rahbar, M., Jeon, S., McCorkle, R., Cimprich, B., et al. (2004). Does a symptom management intervention affect depression among cancer patients: results from a clinical trial. *Psycho-Oncology*, *13*(11), 818-830.
- Goldstein, N. E., & Morrison, R. S. (2005). The intersection between geriatrics and palliative care: a call for a new research agenda. *Journal of the American Geriatrics Society*, *53*(9), 1593-1598.
- Goodell, T. T., & Nail, L. M. (2005). Operationalizing symptom distress in adults with cancer: a literature synthesis. *Oncology Nursing Forum*, *32*(2), E42-47.
- Hampton, D. M., Hollis, D. E., Lloyd, D. A., Taylor, J., & McMillan, S. C. (2007). Spiritual needs of persons with advanced cancer. *American Journal of Hospice* and Palliative Care, 24(1), 42-48.
- Han, B., Remsburg, R. E., McAuley, W. J., Keay, T. J., & Travis, S. S. (2006). National trends in adult hospice use: 1991-1992 to 1999-2000. *Health Affairs*, 25(3), 792-799.
- Hansen-Kyle, L. (2005). A concept analysis of healthy aging. *Nursing Forum*, 40(2), 45-57.
- Hendry, F., & McVittie, C. (2004). Is quality of life a healthy concept? Measuring and understanding life experiences of older people. *Qualitative Health Research*, *14*(7), 961-975.
- Hermann, C. (2000). A guide to the spiritual needs of elderly cancer patients. *Geriatric Nursing*, *21*(6), 324-325.
- Hermann, C. (2001). Spiritual needs of dying patients: a qualitative study. *Oncology Nursing Forum*, 28(1), 67-72.
- Hermann, C. (2006). Development and testing of the spiritual needs inventory for patients near the end of life. *Oncology Nursing Forum*, *33*(4), 737-744.
- Hoekstra, J., Vernooij-Dassen, M. J., de Vos, R., & Bindels, P. J. (2006). The added value of assessing the 'most troublesome' symptom among patients with cancer in the palliative phase. *Patient Education and Counseling*.

- Hofer, S., Benzer, W., Alber, H., Ruttmann, E., Kopp, M., Schussler, G., & Doering, S. (2005). Determinants of health-related quality of life in coronary artery disease patients: a prospective study generating a structural equation model. *Psychosomatics*, 46(3), 212-223.
- Hu, L., Bentler, P. (1998). Fit indices in covariance structure modeling: sensitivity to underparameterized model mispecification. *Psychological Methods*, *3*(4), 424-453.
- Hurria, A., Lachs, M. S., Cohen, H. J., Muss, H. B., & Kornblith, A. B. (2006). Geriatric assessment for oncologists: rationale and future directions. *Critical Reviews in Oncology/Hematology*, 59(3), 211-217.
- Hwang, S. S., Chang, V. T., Cogswell, J., Alejandro, Y., Osenenko, P., Morales, E., et al. (2004). Study of unmet needs in symptomatic veterans with advanced cancer: incidence, independent predictors and unmet needs outcome model. *Journal of Pain and Symptom Management*, 28(5), 421-432.
- Hwang, S. S., Scott, C. B., Chang, V. T., Cogswell, J., Srinivas, S., & Kasimis, B. (2004). Prediction of survival for advanced cancer patients by recursive partitioning analysis: role of Karnofsky performance status, quality of life, and symptom distress. *Cancer Investigation*, 22(5), 678-687.
- Irwin, M., Artin, K. H., & Oxman, M. N. (1999). Screening for depression in the older adult: criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D). Archives of Internal Medicine, 159(15), 1701-1704.
- Jocham, H. R., Dassen, T., Widdershoven, G., & Halfens, R. (2006). Quality of life in palliative care cancer patients: a literature review. *Journal of Clinical Nursing*, *15*(9), 1188-1195.
- Johnson, D. C., Kassner, C. T., Houser, J., & Kutner, J. S. (2005). Barriers to effective symptom management in hospice. *Journal of Pain and Symptom Management*, 29(1), 69-79.
- Katz, S., Downs, T. D., Cash, H. R., & Grotz, R. C. (1970). Progress in development of the index of ADL. *Gerontologist*, 10(1), 20-30.
- Kim, H. J., McGuire, D. B., Tulman, L., & Barsevick, A. M. (2005). Symptom clusters: concept analysis and clinical implications for cancer nursing. *Cancer Nursing*, 28(4), 270-282; quiz 283-274.
- Klinkenberg, M., Willems, D. L., van der Wal, G., & Deeg, D. J. (2004). Symptom burden in the last week of life. *Journal of Pain and Symptom Management*, 27(1), 5-13.

- Kring, D. L. (2006). An exploration of the good death. ANS. Advances in Nursing Science, 29(3), E12-24.
- Kris, A. E., & Dodd, M. J. (2004). Symptom experience of adult hospitalized medicalsurgical patients. *Journal of Pain and Symptom Management*, 28(5), 451-459.
- Krisman-Scott, M. A. (2003). Origins of hospice in the United States: the care of the dying, 1945-1975. [review]. *Journal of Hospice and Palliative Nursing*, 5(4), 205-210.
- Kroenke, K. (2001). Studying symptoms: sampling and measurement issues. *Annals of Internal Medicine*, *134*(9 Pt 2), 844-853.
- Kutner, J. S., Kassner, C. T., & Nowels, D. E. (2001). Symptom burden at the end of life: hospice providers' perceptions. *Journal of Pain and Symptom Management*, 21(6), 473-480.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*, 9(3), 179-186.
- Lee, S. Y., Song, X.Y, Skevington, S., & Hao, Y.T. (2005). Application of structural equation models to quality of life. *Structural Equation Modeling*, *12*(3), 435-453.
- Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: an update. ANS. Advances in Nursing Science, 19(3), 14-27.
- Lichtenberg, P. A. (1999). Handbook of assessment in clinical gerontology: Wiley.
- Long, J. S. (1983). Covariance structure models: An introduction to LISREL (Vol. 07-034). Newbury Park: Sage.
- MacCallum, R. C., Browne, M. W., & Sugawara, H. M. (1996). Power analysis and determination of sample size for covariance structure modeling. *Psychological Methods*, *1*(2), 130-149.
- MacCallum, R. C., Roznowski, M. & Necowitz, L.B. (1992). Model modifications in covariance structure analysis: The problem of capitalization on chance. *Psychological Bulletin*, 111(3), 490-504.
- MacCallum, R. C., Wegener, D. T., Uchino, B. N., & Fabrigar, L.R. (1993). The problem of equivalent models in applications of covariance structure analysis. *Psychological Bulletin*, *114*(1), 185-199.

- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological Methods*, 4(1), 84-99.
- McDaniel, R. W., & Rhodes, V. A. (1995). Symptom experience. Seminars in Oncology Nursing, 11(4), 232-234.
- McMillan, S. C. (1996a). Quality-of-Life Assessment in Palliative Care. *Cancer Control*, *3*(3), 223-229.
- McMillan, S. C. (1996b). The quality of life of patients with cancer receiving hospice care. *Oncology Nursing Forum*, 23(8), 1221-1228.
- McMillan, S. C., & Mahon, M. (1994a). Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index. *Quality of Life Research*, *3*(6), 437-447.
- McMillan, S. C., & Mahon, M. (1994b). A study of quality of life of hospice patients on admission and at week 3. *Cancer Nursing*, 17(1), 52-60.
- McMillan, S. C., & Small, B. J. (2002). Symptom distress and quality of life in patients with cancer newly admitted to hospice home care. *Oncology Nursing Forum*, 29(10), 1421-1428.
- McMillan, S. C., & Weitzner, M. (1998). Quality of life in cancer patients: use of a revised Hospice Index. *Cancer Practice*, 6(5), 282-288.
- McMillan, S. C., & Weitzner, M. (2000). How problematic are various aspects of quality of life in patients with cancer at the end of life? *Oncology Nursing Forum*, 27(5), 817-823.
- Meuser, T., Pietruck, C., Radbruch, L., Stute, P., Lehmann, K. A., & Grond, S. (2001). Symptoms during cancer pain treatment following WHO-guidelines: a longitudinal follow-up study of symptom prevalence, severity and etiology. *Pain*, 93(3), 247-257.
- Miaskowski, C., Cooper, B. A., Paul, S. M., Dodd, M., Lee, K., Aouizerat, B. E., et al. (2006). Subgroups of patients with cancer with different symptom experiences and quality-of-life outcomes: a cluster analysis. *Oncology Nursing Forum*, 33(5), E79-89.
- Miller, G. A. (2006). WordNet: a lexical database for the English language. from <u>http://wordnet.princeton.edu/</u>

- Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Validity of the palliative performance scale from a survival perspective. *Journal of Pain and Symptom Management*, 18(1), 2-3.
- Moryl, N., Kogan, M., Comfort, C., & Obbens, E. (2005). Methadone in the treatment of pain and terminal delirum in advanced cancer patients. *Palliative and Supportive Care*, *3*(4), 311-317.
- Murray, S. A., Kendall, M., Boyd, K., Worth, A., & Benton, T. F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18(1), 39-45.
- NHPCO. (2008). NHPCO's facts and figures-hospice care in America. from <u>http://www.nhpco.org/files/public/Statistics_Research/NHPCO_facts-and-figures_Nov2007.pdf</u>
- *NIH State-of-the-Science Conference Statement on improving end-of-life care.* (2004). Paper presented at the NIH Consensus Development Program. from <u>http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dop</u> <u>t=Citation&list_uids=17308546</u>
- Nuamah, I. F., Cooley, M. E., Fawcett, J., & McCorkle, R. (1999). Testing a theory for health-related quality of life in cancer patients: a structural equation approach. *Research in Nursing and Health*, 22(3), 231-242.
- Nussbaum, J. F., Baringer, O., & Kundrat, A. (2003). Health, communication, and aging: cancer and older adults. *Health Communication*, 15(2), 185-192.
- Pargament, K. I., Magyar-Russell, G. M., & Murray-Swank, N. A. (2005). The sacred and the search for significance: Religion as a unique process. *Journal Of Social Issues*, 61(4), 665-687.
- Parker, K. P., Kimble, L. P., Dunbar, S. B., & Clark, P. C. (2005). Symptom interactions as mechanisms underlying symptom pairs and clusters. *Journal of Nursing Scholarship*, 37(3), 209-215.
- Peterson, S. J. B. T. S. (2004). *Middle range theories : application to nursing research*. Philadelphia: Lippincott Williams & Wilkins.
- Polit, D. F., & Hungler Bernadette P.,. (1983). Nursing research : principles and methods (2nd ed.). Philadelphia: Lippincott.

- Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., et al. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research*, 3(3), 183-189.
- Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Kiyasu, E., et al. (1994). The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30A(9), 1326-1336.
- Radloff, L. S. (1977). The CES-D scale: a self report depression scale for research in the general population. *Applied Psychological Measurements*, *1*, 385-401.
- Rao, A., & Cohen, H. J. (2004). Symptom management in the elderly cancer patient: fatigue, pain, and depression. *Journal of the National Cancer Institute*. *Monographs*.(32), 150-157.
- Raykov, T., & Marcoulides, George A. (2006). *A first course in structural equation modeling* (2nd ed.) Mahwah, N.J.: Lawrence Erlbaum Associates, Publishers.
- Register, M. E., & Herman, J. (2006). A middle range theory for generative quality of life for the elderly. *ANS. Advances in Nursing Science*, *29*(4), 340-350.
- Rhodes, V. A., McDaniel, R. W., Homan, S. S., Johnson, M., & Madsen, R. (2000). An instrument to measure symptom experience. Symptom occurrence and symptom distress. *Cancer Nursing*, 23(1), 49-54.
- Rhodes, V. A., McDaniel, R. W., & Matthews, C. A. (1998). Hospice patients' and nurses' perceptions of self-care deficits based on symptom experience. *Cancer Nursing*, 21(5), 312-319.
- Sahlberg-Blom, E., Ternestedt, B. M., & Johansson, J. E. (2001). Is good 'quality of life' possible at the end of life? An explorative study of the experiences of a group of cancer patients in two different care cultures. *Journal of Clinical Nursing*, 10(4), 550-562.
- Silveira, M. J., Kabeto, M. U., & Langa, K. M. (2005). Net worth predicts symptom burden at the end of life. *Journal of Palliative Medicine*, 8(4), 827-837.
- Singer, P. A., Martin, D. K., & Bowman, K. (2000). Quality end-of-life care: where do we go from here? *Journal of Palliative Medicine*, *3*(4), 403-405.
- SPSS. (2006). SPSS Graduate Pack 15.0 for Windows with AMOS 7.0.
- Stefanek, M., McDonald, P. G., & Hess, S. A. (2005). Religion, spirituality and cancer: current status and methodological challenges. *Psycho-Oncology*, *14*(6), 450-463.

- Stevens, J. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Mahwah, N.J.: Lawrence Erlbaum Associates.
- Sulmasy, D. P. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist, 42 Spec No 3*, 24-33.
- Taylor, E. J. (2003a). Nurses caring for the spirit: patients with cancer and family caregiver expectations. *Oncology Nursing Forum*, *30*(4), 585-590.
- Taylor, E. J. (2003b). Spiritual needs of patients with cancer and family caregivers. *Cancer Nursing*, *26*(4), 260-266.
- Taylor, E. J., & Mamier, I. (2005). Spiritual care nursing: what cancer patients and family caregivers want. *Journal of Advanced Nursing*, 49(3), 260-267.
- Tennstedt, S. L. (2002). Commentary on "Research design in end-of-life research: state of science". *Gerontologist*, 42, 99-103.
- Tishelman, C., Degner, L. F., Rudman, A., Bertilsson, K., Bond, R., Broberger, E., et al. (2005). Symptoms in patients with lung carcinoma: distinguishing distress from intensity. *Cancer*, 104(9), 2013-2021.
- Tranmer, J. E., Heyland, D., Dudgeon, D., Groll, D., Squires-Graham, M., & Coulson, K. (2003). Measuring the symptom experience of seriously ill cancer and noncancer hospitalized patients near the end of life with the memorial symptom assessment scale. *Journal of Pain and Symptom Management*, 25(5), 420-429.
- Vallerand, A. H., Hasenau, S., Templin, T., & Collins-Bohler, D. (2005). Disparities between black and white patients with cancer pain: the effect of perception of control over pain. *Pain Medicine*, 6(3), 242-250.
- Vig, E. K., & Pearlman, R. A. (2003). Quality of life while dying: a qualitative study of terminally ill older men. *Journal of the American Geriatrics Society*, 51(11), 1595-1601.
- Vig, E. K., & Pearlman, R. A. (2004). Good and bad dying from the perspective of terminally ill men. *Archives of Internal Medicine*, *164*(9), 977-981.
- Walke, L. M., Gallo, W. T., Tinetti, M. E., & Fried, T. R. (2004). The burden of symptoms among community-dwelling older persons with advanced chronic disease. Archives of Internal Medicine, 164(21), 2321-2324.
- Walker, L. O., & Avant, Kay Coalson. (2005). *Strategies for theory construction in nursing* (4th ed.). Upper Saddle River, N.J.: Pearson/Prentice Hall.

- Walsh, D., & Rybicki, L. (2006). Symptom clustering in advanced cancer. *Supportive Care in Cancer*, 14(8), 831-836.
- Walters, S. J., Campbell, M. J., & Lall, R. (2001). Design and analysis of trials with quality of life as an outcome: a practical guide. *Journal of Biopharmaceutical Statistics*, 11(3), 155-176.
- Weaver, A. J., & Flannelly, K. J. (2004). The role of religion/spirituality for cancer patients and their caregivers. *Southern Medical Journal*, 97(12), 1210-1214.
- Yancik, R. (2005). Population aging and cancer: a cross-national concern. *The Cancer Journal*, *11*(6), 437-441.

Appendices

### Appendix A: Katz Activities of Daily Living (ADL) Index

#### 

BATHING: Sponge bath, tub bath, or shower.							
□ Receives no assistance (gets into and out of tub by self if tub is the usual means of bathing	□ Receives assistance in bathing only one part of the body (such as the back of a leg).	O Receives assistance in bathing more than one part of the body (or not bathed).					
DRESSING: Get clothes from closets and drawers, including underclothes and outer garments, and uses fasteners, including suspenders if worn.							
Gets clothes and gets completely dressed without assistance.	Gets clothes and gets dressed without assistance except for tying shoes.	O Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed.					
<b>TOILETING:</b> Goes to the room termed "toilet" for bowel movement/urination, cleans self afterward, and arrange clothes.							
☐ Goes to toilet room. Clean self, and arranges clothes without assistance. (May use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying it in morning.)	O Receives assistance in going to toilet room or in cleaning self or arranging clothes after elimination or in use of night bedpan or commode.	O Doesn't go to toilet room for the elimination process.					
TRANSFER							
☐ Moves into and out of bed as well as into and out of chair without assistance. (May use object such as cane or walker for support.)	O Moves into or out of bed or chair with assistance.	O Doesn't get out of bed.					
CONTINENCE							
Controls urination and bowel movement completely by self.	O Has occasional accidents.	O Supervision helps keep control of urination or bowel movement, or catheter is used, or is incontinent.					

FEEDINC							
FEEDING							
☐ Feeds self without assistance.	□ Feeds self except for assistance in cutting meat or buttering bread.	O Receives assistance in feeding or is fed partly or completely through tubes or by IV fluids.					
	INDEX						
A: Independent in all six functions.	E: Independent in all but bathing, dress	ing,					
1	toileting, and one additional function						
<b>B:</b> Independent in all but one of these	<b>F:</b> Independent in all but bathing, dress	ing,					
functions.	toileting, transferring, and one addition	al					
	function.						
C: Independent in all but bathing and	G: Dependent in all six functions						
one additional function.							
		-					
<b>D:</b> Independent in all but bathing,	Other: Dependent in at least two function	ions but O Indicates Dependence					
dressing, and one additional function.	not classifiable as C, D, E or F.	-					

(Katz et al., 1963)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity; No evidence of disease	Full	Normal	Full
90	Full	Normal Activity; Some evidence of disease	Full	Normal	Full
80	Full	Normal Activity with Effort; Some evidence of disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job/ Work; Some evidence of disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby/House Work; Significant disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to do any work; Extensive disease	Considerable assistance required	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As above	Mainly assistance	Normal or	Full or Drowsy
30	Totally Bed Bound	As above	Total Care	Reduced	Full or Drowsy or Confusion
20	As above	As above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As above	As above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death				

### Appendix B: PALLIATIVE PERFORMANCE SCALE

(Anderson et al., 1996)

### Appendix C: SHORT, PORTABLE MENTAL STATUS QUESTIONNAIRE Eric Pfeiffer, M.D.

**Instructions:** Ask questions 1-10 in this list and record all answers. Ask question 4A only if subject does not have a telephone. Record total number of errors based on ten questions.

1. What is the date today?

2. What day of the week is it?

3. What is the name of this place?

- 5. How old are you?
- 7. Who is the president of the U.S. now?

8. Who was president just before him?

9. What was your mother's maiden name?

10. Subtract 3 from 20 and keep subtracting 3 from each new number you get, all the way down.

TOTAL _____

(Lichtenberg, 1999)

### Appendix D: Memorial Symptom Assessment Scale (MSAS)

**Directions:** There are 25 symptoms listed below. Read each one carefully. If you have this symptom, check the "do have" box. Then circle the number that indicates **how severe it is** and **how much this symptom distresses or bothers you.** 

	How severe is this symptom? How									loes it d	istress or b	other y	ou?
	Symptom	Do have	Not at all	A little	Somewhat Severe	Severe	Very Severe		Not at all	A little bit	Somewhat	Quite a bit	Very much
				bit									
1	Difficulty Concentrating		0	1	2	3	4		0	1	2	3	4
2	Pain		0	1	2	3	4		0	1	2	3	4
3	Lack of energy		0	1	2	3	4		0	1	2	3	4
4	Cough		0	1	2	3	4		0	1	2	3	4
5	Feeling nervous		0	1	2	3	4		0	1	2	3	4
6	Dry mouth		0	1	2	3	4		0	1	2	3	4
7	Nausea		0	1	2	3	4		0	1	2	3	4
8	Vomiting		0	1	2	3	4		0	1	2	3	4
9	Feeling drowsy		0	1	2	3	4		0	1	2	3	4
10	Numbness/tingling in hands or feet		0	1	2	3	4		0	1	2	3	4
11	Difficulty sleeping		0	1	2	3	4		0	1	2	3	4
12	Feeling bloated		0	1	2	3	4		0	1	2	3	4

	How severe is this symptom?							How r	nuch doe	s it distress	or bothe	er you?
	Symptom	Do have	Not at all	A little bit	Somewhat Severe	Severe	Very Severe	Not at all	A little bit	Somewhat	Quite a bit	Very much
13	Problems with urination		0	1	2	3	4	0	1	2	3	4
14	Shortness of breath		0	1	2	3	4	0	1	2	3	4
15	Diarrhea		0	1	2	3	4	0	1	2	3	4
16	Feeling sad		0	1	2	3	4	0	1	2	3	4
17	Sweats		0	1	2	3	4	0	1	2	3	4
18	Worrying		0	1	2	3	4	0	1	2	3	4
19	Problem with sexual interest or activity		0	1	2	3	4	0	1	2	3	4
20	Itching		0	1	2	3	4	0	1	2	3	4
21	Lack of appetite		0	1	2	3	4	0	1	2	3	4
22	Dizziness		0	1	2	3	4	0	1	2	3	4
23	Difficulty swallowing		0	1	2	3	4	0	1	2	3	4
24	Feeling irritable		0	1	2	3	4	0	1	2	3	4
25	Constipation		0	1	2	3	4	0	1	2	3	4

# Appendix D (Continued)

TOTAL _____

(Portenoy, Thaler, Lornblith, Friedlander-Klar, Kiyasu, et al., 1994)

Appendix E: EVALUATION OF MOOD

# **CES-D**

Did you experience the following much of the time <u>during the</u> past week?"

YES	NO	
		I enjoyed life.
		I felt that everything I did was an effort.
		My sleep was restless.
		I was happy.
		I felt lonely.
		I felt depressed.
		People were unfriendly.
		I felt sad.
		I felt that people disliked me.
		I could not get going.

TOTAL: _____

(Radloff, 1977)

### Appendix F: SPIRITUAL NEEDS INVENTORY - PATIENT

**Directions:** This questionnaire contains 17 phrases that describe needs (activities, thoughts, or experiences) that some people have said they have during their illnesses. For some people these needs relate to the spiritual part of them. They define spiritual as that part of them that tries to find meaning and purpose in life. They believe a spiritual need is something they need or want in order to live their lives fully. Please mark the items that you consider to be your spiritual needs, and which of these are currently not met.

Column A	Column D					Column C	
	Please rate column th	e the items in at you answe	em in the s or no in	Is this need being met in your life right now?			
In order to live my life fully, I need to:		Rarely	Sometimes	Frequently	Always		
	Never						
1. Sing/listen to inspirational music	1	2	3	4	5	Yes	No
2. Laugh	1	2	3	4	5	Yes	No
3. Read a religious text (for example, Bible, Koran, Old Testament)	1	2	3	4	5	Yes	No
4. Be with family	1	2	3	4	5	Yes	No
5. Be with friends	1	2	3	4	5	Yes	No
6. Talk with someone about spiritual issues	1	2	3	4	5	Yes	No
7. Have information about family and friends	1	2	3	4	5	Yes	No
8. Read inspirational materials	1	2	3	4	5	Yes	No
9. Use inspirational materials (for example, repeating or living by phrases or poems)	1	2	3	4	5	Yes	No
10. Be around children (own or others' children)	1	2	3	4	5	Yes	No
11. Be with people who share my spiritual beliefs	1	2	3	4	5	Yes	No

#### Read the need in column A and then the questions in columns B and C before going on to the next need.

		(				1						
Column A												
	Column B					Column C						
	Please rate	e the items in	the column bel	ow For every it	em in the	Is this ne	Is this need being					
	column th	e the items in at you answ	er 2 or higher n	lease answer ves	or no in	mot in your life						
	corunni th	Column that you answer 2 of higher, prease answer yes of no m										
				IIght	10							
In order to live my life fully, I need to:		Rarely	Sometimes	Frequently	Always							
	Never											
12. Pray	1	2	3	4	5	Yes	No					
13. Go to religious services	1	2	3	4	5	Yes	No					
14. Think happy thoughts	1	2	3	4	5	Yes	No					
	-				_							
15. Talk about day to day things	1	2	3	4	5	Yes	No					
	1	2	2	4	-	V	NT					
16. See smiles of others	1	2	3	4	5	Yes	INO					
17 Use phrases from religious texts (for example, using phrases to	1	2	2	4	5	Vac	No					
17. Use philases from rengious texts (for example, using philases to	1	2	5	4	5	168	INO					
guide you each day such as Greater is He that is in me, than He that												
is in the world )												

Appendix F (Continued)

Other spiritual needs identified by the patient:

TOTAL: _____

(Hermann, 2001)

### Appendix G: HOSPICE QUALITY OF LIFE INDEX-14

The questions listed below ask about how you are feeling at the moment and how your illness has affected you. Please **circle the number on the line** under each of the questions, that best shows what is happening to you at the present time.



### Appendix G (Continued)

5) How sad do you feel?

very sad 0___1_2_3_4_5_6_7_8_9_10 not at all 6) How worried do you feel about your family and friends? very worried 0 1 2 3 4 5 6 7 8 9 10 not at all 7) How satisfied do you feel with your ability to concentrate on things? very dissatisfied 0____1___2___3__4__5___6__7___8__9___10 very satisfied 8) How much enjoyable activity do you have? none 0___1_2_3_4_5_6_7_8_9_10 a great deal 9) How satisfied are you with your level of independence? very dissatisfied 0 1 2 3 4 5 6 7 8 9 10 very satisfied 10) How satisfied are you with the physical care that you are receiving? very dissatisfied 0 1 2 3 4 5 6 7 8 9 10 very satisfied

### Appendix G (Continued)

11) How satisfied are you with the emotional support you get from your health care team?

Very dissatisfied 0____1_2_3_4_5_6_7_8_9_10 very satisfied

12) How satisfied are you with your relationship with God (however you define that relationship)? Very dissatisfied 0 1 2 3 4 5 6 7 8 9 10 very satisfied

13) Do your surroundings help improve your sense of well-being? not at all 0____1_2_3___4_5___6_7___8_9___10 very much

14) If you experience pain, how completely is it relieved?

no relief 0____1__2__3__4__5__6__7__8__9__10 complete relief

### TOTAL HQLI SCORE: _____

How bad is your pain when it is at its worst?

no pain 0____1__2__3__4__5__6__7__8__9__10 worst possible

(McMillan & Weitzner, 2000)

#### Appendix H: DEMOGRAPHIC DATA FORM

### Patient

1. Today's Date: ______ 2. Age: _____ 3. Gender: male female 4. Relationship to Caregiver: (circle number) - "I am my caregiver's 1. wife 6. son 2. husband 7. brother 3. mother 8. sister 4. father 9. significant other 5. daughter 10. other _____ 5. *Marital Status*: (circle one number) 1. never married 4. divorced 5. widowed 2. currently married 3. separated 6. *Ethnic background*: (circle one number) 6. Mixed (please specify): _____ 1. Caucasian 2. African American 3. Hispanic 4. Asian/Pacific Islander 7. Other (please specify): _____ 5. Eskimo/Native American Indian 7. Number of years of school completed: _____ 8. Cancer diagnosis: _____9. Months since diagnosis: 10. Current living arrangement: (circle one number) 1. live alone 2. live with spouse/partner 3. live with spouse/partner and children 4. live with children (no spouse/partner) 5. live with roommate who is not spouse/partner 6. live with parents 7. Other: specify _____

#### Appendix H (Continued)

#### 13. Which category best describes your current or most recent job? (circle one number)

- 1. Professional (e.g. teacher/professor, nurse, lawyer, physician, engineer)
- 2. Manager/administrator (e.g., sales managers)
- 3. Clerical (e.g. secretary, clerk, mail carrier)
- 4. Sales (e.g. sales person, agent, broker)
- 5. Service (e.g. police, cook, waitress, hairdresser)
- 6. Skilled crafts, repairer (e.g. carpenter, electrician)
- 7. Equipment or vehicle operator (e.g. truck drivers)
- 8. Laborer (e.g. maintenance, factory workers)
- 9. Farmer (e.g. owners, managers, operators, tenants)
- 10. Member of military
- 11. Homemaker (with no job outside of the home)
- 12. Other (please describe)

### 14. Religious affiliation (if

any):_____

15. Home is in: Urban area_____

Suburban area_____ Rural area_____ Appendix I: Informed Consent-Patient Social and Behavioral Sciences

University of South Florida

### Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study. Please read this carefully. If you do not understand anything, ask the person in charge of the study. **Title of Study:** Systematic Assessment to Improve Hospice Outcomes **Principal Investigator:** Susan C. McMillan, PhD, RN **Research Assistants:** 

Jill Boyd, MSW Leah Buck, RN, BSN Gail Chambers, RN, BSN, MSH, CHPN Kim Ramos Gryglewicz, MSW Betty Quinones, RN Jane Sidwell, MSW, RN, CHPN Margaret Zimmer, RN Kathleen D'Amico, RN

#### **Study Location(s):** Hernando-Pasco Hospice Tidewell Hospice and Palliative Care (formerly Hospice of Southwest Florida)

You are being asked to participate because you are a hospice patient with a cancer diagnosis.

### General Information about the Research Study

The purpose of this research study is to determine if giving complete information about you and your caregiver to the hospice team will result in improved symptom management and quality of life for you. In addition, we will assess your caregiver's well-being. We expect 306 patients and caregivers to participate in this study.

## Plan of Study

If you agree to participate, you will be visited two more times and asked about your symptoms and quality of life. While the nurse is talking with you about how you feel, the social worker will be talking with your caregiver about his or her feelings.

### **Payment for Participation**

You will not be paid for participating in this research, nor will the research cost you anything.

Appendix I (Continued)

# Benefits of Being a Part of this Research Study

By taking part in this study, you may increase our knowledge about the best ways to assess the needs and problems of hospice patients and their caregivers. If you are in the experimental group, it is possible that your care may be better as a result of these additional assessments.

# Risks of Being a Part of this Research Study

There are very minimal risks to participating in this study. Your privacy will be protected by the research team. If you are in the experimental group, the results of your assessments will be summarized and shared with the hospice team. Otherwise your data will be completely confidential. The completed data will be kept in a locked cabinet in a locked office. It is possible that you or your caregiver may become upset as a result of answering some of the questions. If the questionnaires become too upsetting, you may withdraw from the study at any time.

# **Confidentiality of Your Records**

Your privacy and research records will be kept confidential to the extent of the law. Only hospice staff will know your name; your consent form will be separated from the forms that you complete so that no data can be linked directly to you. The forms that you fill out will be coded, but no name will appear on any of these forms. Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board may inspect the records from this research project. When computerized, the data about you will be coded so your name will not appear in the computer.

The results of this study may be published. However, the data obtained from you will be combined with data from others in the publication. The published results will not include your name or any other information that would personally identify you or your caregiver in any way.

# Volunteering to Be Part of this Research Study

Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive, if you stop taking part in the study.

# **Questions and Contacts**

- If you have any questions about this research study, contact Dr. Susan McMillan at 813-974-9188 at any time of the night or day.
- If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at (813) 974-5638.

### Appendix I (Continued)

### Consent to Take Part in This Research Study

By signing this form I agree that:

- I have fully read or have had read and explained to me this informed consent form describing this research project.
- I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.
- I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.
- I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant

Printed Name of Participant

Date

### Investigator Statement

I have carefully explained to the subject the nature of the above research study. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks, and benefits involved in participating in this study.

Signature of Investigator Or authorized research investigator designated by the Principal Investigator Susan C. McMillan, PhD, RN Printed Name of Investigator Date
Variables	Sp-2	Sp-3	Sp-4	Phy-1	Phy-2	Psy-1	QOL-1	QOL-2		
Sp-2	21.918									
Sp-3	13.767	13.607								
Sp-4	9.470	6.536	8.460							
Phy-1	1.342	1.432	0.237	16.793						
Phy-2	2.445	2.127	-0.186	39.543	120.220					
Psy-1	4.139	4.232	0.834	44.631	128.597	159.500				
QOL-1	2.296	0.989	0.880	-20.05	-55.792	-63.983	85.917			
QOL-2	5.477	3.635	2.580	-16.02	-48.277	-55.493	38.173	68.582		
Note. $Sp =$	<i>Note</i> . Sp = Spiritual; Phy = Physical; Psy = Psychological; QOL= Quality of Life									

Appendix J: Covariances and Variances for Actual Data (N=403)

Variables	Spiritual	Symptom Experience	Quality of_Life	Sp-2	Sp-3t	Sp-4	Phy-1	Phy-2	Psy-1	QOL- 1	QOL- 2
Spiritual	20.017										
Symptom	0.000	13.730									
Experience	0.000										
Quality	5 5 5 5	-19.470	43.609								
of_Life	5.555										
Sp-2	20.017	0.000	5.555	21.92							
Sp-3	13.774	0.000	3.822	13.77	13.61						
Sp-4	9.467	.000	2.627	9.467	6.515	8.46					
Phy-1	0.000	13.730	-19.47	0.000	0.000	0.00	16.79				
Phy-2	0.000	39.488	-56.0	0.000	0.000	0.00	39.49	120.22			
Psy-1	0.000	44.718	-63.41	0.000	0.000	0.00	44.72	128.61	159.50		
QOL-1	5.555	-19.470	43.609	5.555	3.822	2.63	- 19.47	-56.0	-63.41	86.67	
QOL-2	4.948	-17.342	38.843	4.948	3.405	2.34	- 17.34	-49.88	-56.48	38.84	69.18

Appendix K: Covariances and Variances for Implied Data (N=403):

*Note*. Sp = Spiritual; Phy = Physical; Psy = Psychological; QOL = Quality of Life

## Appendix L: Syntax Used for Post-Hoc Power Analysis in SPSS

```
title 'power estimation for sem'.
compute alpha = 0.05.
compute rmsea0 = 0.05.
compute rmseaa = 0.08.
compute df = 18.
compute n = 403.
compute ncp0 = (n-1)*df*rmsea0**2.
compute ncpa = (n-1)*df*rmseaa**2.
do if (rmsea0<rmseaa).
compute cval = idf.chisq(1-alpha, df).
compute power = 1 - ncdf.chisq(cval, df,ncpa).
end if.
do if (rmsea0 > rmseaa).
compute cval= idf.chisq(alpha,df).
compute power = ncdf.chisq(cval,df,ncpa).
end if.
execute.
list alpha df n power.
exe.
```

:

I would like to thank Sarah Cobb, RN, PhD. who converted MacCallum and colleague's (MacCallum, Browne,& Sugawara, 1996) SAS syntax into SPSS and then so generously shared it with me.

## About the Author

Harleah G. Buck received a Bachelor's degree in Nursing from Columbia University in 1979 and has been in the BSN-PhD program in nursing from 2004-2008. Prior to coming to the University she was a Registered Nurse in palliative/hospice care and critical care nursing.. Ms. Buck's research interests are in the areas of gerontology, palliative care, and end of life.

Ms. Buck currently serves as project manager for multi-site NIH F01 NR008252-01A2 Systematic Assessment to Improve Hospice Outcomes, Susan C. McMillan, PhD., RN, FAAN, Principal Investigator. She is responsible for recruitment, training, and supervision of two teams of research assistants and maintaining the integrity of the intervention. She has also served as a research assistant on a previous RO1 on cancer pain and a pilot study with cancer survivors. She has published and presented on the national level in the areas of end of life and geriatric patients and their caregivers.