Evaluating the Perceptions of Quality of Life in Informal Caregivers Caring for Hospice Patients

Rashandra Fisher Laws
University of Southern Mississippi

Follow this and additional works at: https://aquila.usm.edu/dnp_capstone

Part of the Geriatric Nursing Commons, Other Nursing Commons, and the Public Health and Community Nursing Commons

Recommended Citation
https://aquila.usm.edu/dnp_capstone/42

This is brought to you for free and open access by The Aquila Digital Community. It has been accepted for inclusion in Doctoral Projects by an authorized administrator of The Aquila Digital Community. For more information, please contact aquilastaff@usm.edu.
EVALUATING THE PERCEPTIONS OF QUALITY OF LIFE IN INFORMAL CAREGIVERS CARING FOR HOSPICE PATIENTS

by

Rashandra Fisher Laws

Abstract of a Capstone Project
Submitted to the Graduate School
of the University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Nursing Practice

December 2014
ABSTRACT

EVALUATING THE PERCEPTIONS OF QUALITY OF LIFE IN INFORMAL CAREGIVERS CARING FOR HOSPICE PATIENTS

by Rashandra Fisher Laws

December 2014

Maintaining or improving quality of life for informal caregivers is important as they endure the burden of providing care to terminally ill loved ones on a daily basis. Caregivers are at a greater risk for depression, deteriorating physical health, financial difficulties, and premature death than demographically similar non-caregivers (Demiris et al., 2010). The goal of this capstone project was to determine the effectiveness of the creativity, optimism, planning, and expert information (COPE) intervention, which address specific needs of the family and caregiver.

Twenty informal caregivers completed the Quality of Life (QoL) Index tool, which measured their perceptions of five different domains related to quality of life. The domains were (a) overall quality of life, (b) health, (c) social, (d) psychological, and (e) family. Ten informal caregivers were provided with the routine services given by the hospice agency. The remaining informal caregivers were given the routine services and care in addition to the services in the COPE intervention. At the end of 30 days, all 20 informal caregivers completed the QoL tool again to determine if there was any difference in their perceptions of the five quality of life domains. There was an increase in the scores in both groups; however, the scores increased more with the informal caregivers who received the COPE intervention. Although the scores increased in both groups, the increase was not statistically significant because of the small number of
informal providers used in this project. In addition, the verbal responses by the informal caregivers who received the intervention showed positive outcomes.
EVALUATING THE PERCEPTIONS OF QUALITY OF LIFE IN INFORMAL CAREGIVERS CARING FOR HOSPICE PATIENTS

by

Rashandra Fisher Laws

A Capstone Project
Submitted to the Graduate School
of the University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Nursing Practice

Approved:

Dr. Rowena Elliott
Committee Chair

Dr. Kathleen Masters

Dr. Karen Coats
Dean of the Graduate School

December 2014
DEDICATION

I would like to dedicate this capstone project to my daughter, Karson Thai Laws. Karson, you have been the inspiration that I needed to continue to push forward. I thank God for you, my little angel. I would like to thank my husband, Marwin, for all of his love and support. I would also like to thank my sister, Lenzy, for all of her help during this journey. A special thanks to my parents, Mr. Lenzy and Dr. Kimberly Fisher, for their spiritual guidance and loving support. To God be the glory.
ACKNOWLEDGMENTS

A special thanks to God for the faith, drive, and strength to keep going when hard times were upon me. You gave me the strength and the mind to keep the faith. I hold Ephesians 3:20 very close to my heart. I would like to thank my committee chair, Dr. Rowena Elliott, and committee member, Dr. Kathleen Masters, for all of their advice and support throughout this process. I would also like to thank Dr. Elliott for showing me that “it can be done.” Special thanks to Dr. Dale Magoun for the statistical analyses of data for this capstone project.
# TABLE OF CONTENTS

ABSTRACT .................................................................................................................. ii

DEDICATION ................................................................................................................ iv

ACKNOWLEDGMENTS ............................................................................................... v

LIST OF TABLES .......................................................................................................... viii

LIST OF ABBREVIATIONS ........................................................................................ ix

CHAPTER

I. INTRODUCTION ........................................................................................................ 1
   Background and Significance
   Statement of Purpose
   Definition of Terms

II. REVIEW OF LITERATURE ...................................................................................... 6
   Hospice
   Criteria for Hospice Caregivers
   Theoretical Framework
   Doctor of Nursing Practice (DNP) Essentials
   Assumptions
   Resource Requirements

III. METHODOLOGY .................................................................................................... 32
   Design of the Project
   Setting
   Sample
   Procedures
   Ethical Protection of Human Subjects

IV. RESULTS .................................................................................................................. 38
   Analysis of Data

V. DISCUSSION ............................................................................................................ 46
   Limitations
   Implications
   Implications for Nursing Practice
Implications for Research
Implications for Education
Benefits
Challenges for Project

APPENDIXES .................................................................................................................51

REFERENCES ..................................................................................................................62
LIST OF TABLES

Table

1. Demographic Data Summary ......................................................................................38
2. Individual Group Demographic Summary .................................................................39
3. Summary of Subscale Scores ......................................................................................43
4. Test Results for Comparing Groups ........................................................................45
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE</td>
<td>Angiotensin Converting Enzyme</td>
</tr>
<tr>
<td>ACT</td>
<td>Assessing Caregivers for Team Intervention</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>ADRD</td>
<td>Alzheimer’s Disease or Related Disorder</td>
</tr>
<tr>
<td>APRN</td>
<td>Advanced Practice Registered Nurse</td>
</tr>
<tr>
<td>CAT</td>
<td>Caring Assessment Tool</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>COPE</td>
<td>Creativity, Planning, Optimism, and Expert Intervention</td>
</tr>
<tr>
<td>CQLI-R</td>
<td>Caregiver Quality of Life-Revised</td>
</tr>
<tr>
<td>CQOLC</td>
<td>Caregiver Quality of Life Index-Cancer</td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebrovascular Accident</td>
</tr>
<tr>
<td>DNP</td>
<td>Doctor of Nursing Practice</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
<tr>
<td>QLI</td>
<td>Quality of Life Index</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>ROM</td>
<td>Role Overload Measure</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>ZBI</td>
<td>Zarit Burden Inventory</td>
</tr>
</tbody>
</table>
CHAPTER I
INTRODUCTION

Hospice care provides palliative and passionate care for individuals and their families in the last phases of a terminal disease, so they may live with dignity (Demiris, Oliver, & Whittenberg-Lyles, 2009). According to the National Hospice and Palliative Care Organization’s (NHPCO’s) Standard of Practice for Hospice Programs, “hospice provides support and care for persons in the last phases of an incurable disease so they may live as fully and as comfortable as possible” (National Hospice and Palliative Care Organization [NHPCO], 2000, p.1). The NHPCO (2000) further described “palliative care as the treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life” (NHPCO, 2000, p.1). According to Demiris et al. (2010, p. 1005), “informal caregivers, mainly spouses, family members, friends, or others, assume the unpaid caregiving role of the loved one, and are crucial elements in the delivery of hospice services.” The majority (80%) of terminally ill individuals receive care from informal caregivers who can be responsible for everything from management of the household and finances to medical and personal care of the patient (Empeno, Raming, Irwin, Nelesen, & Lloyd, 2011, p. 593). The importance of informal caregivers is very necessary, and because the goals of hospice care include attention to patients’ families, hospice providers should be more concerned about the quality of life for caregivers (Wilder, Oliver, Demiris, & Washington, 2008). According to Empeno et al. (2011), studies have shown that the emotional and physical experiences involved with providing care can burden the most capable caregiver. Some experiences that caregivers face may include depression, cancer, heart disease, diabetes, arthritis, and increased
disposition to mental decline (Empeno et al., 2011). Caregivers are at a greater risk for depression, deteriorating physical health, financial difficulties, and premature death than demographically similar non-caregivers (Demiris et al., 2010).

Background and Significance

According to Demiris et al. (2009), the number of individuals and their families receiving hospice services has grown by 162% during the past 10 years, making hospice care the most desired service for terminally ill individuals in the United States. Research reveals that the use of hospice care increased from 21.6% in 2000 to 42.2% in 2009 (Teno et al., 2013). According to Empeno et al. (2011), hospice care is designed to support families and caregivers, as well as patients, but there are few options available to assist caregivers with their daily responsibilities of patient care. Many families caring for terminally ill older adults report making major life changes and personal sacrifices to care for their relative such as feeling overwhelmed with requests from the hospice patient being cared for, not having enough time for self, and trying to care for hospice patients and life responsibilities (Garlo, O’Leary, Ness, & Fried, 2010).

According to Kutner et al. (2009) caregivers of hospice patients experience multiple stressors such as lack of emotional support, deficit in self-care, and anticipation of bereavement that can negatively impact physical, psychological, and emotional health. According to Demiris et al. (2009) in addition to the physical requirements with caregiving and the emotional support, family caregivers are often proxies for clinical decision-making, given the deteriorating condition of the patients. The financial cost of caregiving can also be overwhelming due to the cost of healthcare, lost time at work, changing jobs, or even needing to move to another location to provide care (Wilder et al.,
Maintaining the quality of life for informal caregivers is important, as “the estimated economic value of care provided by family caregivers was $450 billion a year, which exceeded Medicaid spending and approximately 90% of the entire expenditure of Medicare” (Lin, Fee, & Wu, 2012, p. 343).

Research studies have shown that caregivers experience negative psychological effects resulting in negative health outcomes. According to Bevans and Sternberg (2012), some effects can be severe emotional distress, fatigue, sleep impairment, difficulty maintaining focus, and energy depletion. Recent research has highlighted the significance related to understanding the risks of unmet needs of informal caregivers of patients at the end of life (Demiris et al., 2010). According to Whittenberg-Lyles, Demiris, Oliver, and Burt (2011), caregiver burden serves as a catalyst for psychological concern that arise from emotional burnout. Research has also shown that negative psychological strain effects have been documented in multiple nationalities and diverse cultures (Garlo et al., 2010).

Statement of Purpose

The purpose of this capstone project was to evaluate the effectiveness of the Creativity, Planning, Optimism, and Expert Intervention (COPE) intervention in maintaining the quality of life in informal caregivers caring for hospice patients in a hospice agency located in central Mississippi. The PICOTS question guiding this capstone project was: Will an informal caregiver’s perception of Quality of Life (QoL) change after the implementation of the COPE intervention during 30 days of caring for a hospice patient in the home setting?
Definition of Terms

_Hospice_- “Hospice provides support and care for persons in the last phases of an incurable disease so they may live as fully and as comfortable as possible” (NHPCO, 2000, p. 1). Hospice is end-of-life care that involves a team-oriented approach to quality medical care, pain and symptom management, and spiritual support tailored to a loved one’s needs (NHPCO, 2005).

_Palliative Care_- “Palliative care is the treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life” (NHCPO, 2000, p. 1). Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (World Health Organization [WHO], 2014).

_Care_- Care is attention to any needs of the person, including hands-on care, overnight care, respite, shopping, collection of medications, taking to appointments, emotional support, and bathing (Davidson, Abernathy, Newton, Clark, & Currow, 2013, p. 2).

_Formal Caregivers_- Formal caregivers are individuals paid to provide assistance (Empeno et al., 2011). A caregiver is a provider that is associated with a formal service system, whether he or she is paid to provide services or volunteer (Family Caregiver Alliance, 2014, p. 1).

_Informal Caregivers_- “An informal caregiver is an unpaid caregiver that assumes the primary responsibility of caring for a hospice patient at home” (Empeno et al., 2011,
Informal caregivers may be spouses/partners or adult children but may also be siblings, parents, other relations, or friends” (Wilder et al., 2008, p. 312).

**Caregiver Burden**- Caregiver burden can be defined as “the physical, financial, and psychosocial hardships associated with caring for a loved one, usually a family member” (Garlo et al., 2010, p. 2316). Caregiver burden refers to a high level of stress experienced by someone caring for an individual with some type of illness (Tull, 2014).

**Terminal Illness**- Terminal illness is the “state of being in the final stages of a fatal disease” (Terminal, 2004, p. 738). A terminal illness is a disease that will result in the death of the individual regardless of any treatment intervention (Terminal illness, n.d).

**Primary Caregiver**- The primary caregiver is the individual who provides the hospice patient with the most assistance with his or her activities of daily living such as bathing, dressing, and grooming (Garlo et al., 2010, p. 2317).

**Quality of Life (QoL)**- “A person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans, 1990, p. 15) is quality of life.

**Respite**- Respite is “an arrangement to allow caregivers relief from their care commitments, which may be provided on a regular basis or in emergency” (Greenwood, Habbi, & Mackenzie, 2012, p. 2). “Respite is planned, temporary relief for the primary caregiver through the provision of substitute care” (Herbert & Schulz, 2006, p. 1181).
CHAPTER II
REVIEW OF LITERATURE

The review of literature focused on the impact of informal caregiver-centered interventions, decreasing caregiver burden, and the quality of life of caregivers when caring for terminally ill patients. The Elton Bryson Stevens Company host (EBSCOhost), PubMed/MedLine, and CINAHL databases were utilized to complete the review of literature search. Key words in the review of literature search were caregiver burden, hospice caregiver interventions, and caregiver role strain. The review of literature ranged from the years 2001–2014 (Appendix A).

Hospice

According to the National Hospice and Palliative Care Organization (NHPCO, 2012), “hospice is considered the model for quality compassionate care for people facing a life-limiting illness” (p. 1). Hospice provides services to these individuals such as expert medical care, pain management, and emotional and spiritual support to properly fit the patient’s needs. Hospice is provided in a number of settings such as the patient’s home, nursing home, hospice clinics, and long-term care facilities. Hospice services are provided to patients with any terminal illness such as Alzheimer’s disease, cancer, HIV/AIDS, and cardiovascular disease. Hospice services are also provided to individuals of any age, religion, or race.

A family member identified as the primary caregiver mainly provides hospice care. The primary caregiver provides care in its entirety such as medication administration, pain management, financial support, and assistance with activities of daily living (e.g., bathing, dressing, grooming, eating, and transferring from bed to chair).
and instrumental activities of daily living (e.g., transportation, grocery shopping, housework, managing finances, and preparing meals). A hospice staff medical team consisting of physicians (primary and hospice), nurses, social workers, aides, spiritual counselors, and volunteers assist in caring for hospice patients. The role of each discipline is to work collaboratively to provide independent services to the hospice patient. The role of the physician is to manage the patient’s pain and symptoms such as nausea, vomiting, and depression. The nurses provide home visits and educational support to family on how to care for the individual in the home setting. Social workers are needed to assist with making external resource connections such as meals on wheels, assistance with Medicare or Medicaid paperwork, or nursing home placement, if needed. The role of the hospice aide is to assist the caregivers with the bathing, dressing, feeding, or transferring of the hospice individual. Spiritual counselors (also known as chaplains) provide bereavement care and counseling to family members and friends. Volunteers assist the caregiver by providing direct support such as sitting with the individual and allowing caregivers to complete errands, keep medical appointments, or have time to socially interact with other friends and family members; providing clinical support such as assisting with clerical services that support patient care; and providing general support such as helping with fundraising efforts (NHPCO, 2012).

Criteria for Hospice

According to NHPCO (2014), “in order for an individual to be eligible for hospice services under Medicare, the individual must be covered under Medicare Part A certified as terminally ill, and given a prognosis of six (6) months or less” (p. 1). Medicare Part A
covers services such as hospital care, skilled nursing facility care, nursing home care, hospice, and home health services (Medicare.gov, 2014).

In order to gain admission to hospice services, certain criteria related to the admitting diagnosis are met. According to NHPCO (2013), the most common diagnoses admitted to hospice services for 2012 secondary to the cancer diagnosis (36.9%) were debility unspecified (14.2%), dementia (12.8%), heart disease (11.2%), and lung disease (8.2%) (p. 7).

Dementia

According to Herbert and Schulz (2006), “of the four (4) million Americans with Alzheimer’s disease or related disorder (ADRD), three (3) million reside in the home setting” (p. 1178). The admission process for an individual with this diagnosis must provide evidence that shows poor prognosis. The patient has to show signs of severe dementia such as (a) ability to speak is limited to approximately six intelligible words or fewer, (b) speech is limited to a single intelligible word in an average day or in the course of an interview, (c) individual is unable to walk without personal assistance, (d) individual cannot sit up without assistance, (e) individual has lost ability to smile, or (f) individual has lost ability to hold up his or her head independently.

The individual must also demonstrate all characteristics that show a severe decline such as (a) unable to dress without assistance, (b) unable to bathe properly, (c) incontinence of urine and stool, (d) inability to ambulate independently, and (e) unable to speak meaningfully.

To complete the eligibility process of an individual with dementia, the individual must have one or more other complications within the past year that are closely related to
the dementia diagnosis such as (a) aspiration pneumonia, (b) upper urinary tract infection, (c) multiple decubitus ulcers, (d) recurrent fever after antibiotics, (e) unwillingness to take foods or fluids sufficient for life, (f) unintentional weight loss greater than 10% over previous six months, and (g) serum albumin less than 2.5 gm/dl.

Heart Disease

According to Herbert and Schulz (2006), the “New York Heart Association class III (comfortable only at rest) or IV failure (symptoms at rest) have a 25% annual mortality, a prognosis worse than that of most cancers” (p. 1179). Admission to hospice services with a diagnosis of heart disease such as heart failure has certain criteria that have to be met. Heart failure is a “general term used to describe several types of cardiac dysfunction that results in inadequate perfusion of tissue with vital blood-borne nutrients” (Brashers, 2006, p. 1129).

In efforts to gain eligibility with a diagnosis of heart disease, an individual must demonstrate specific signs and symptoms (e.g., dyspnea at rest and on exertion, weakness, chest pain, sweating, profound weight loss, and crackles upon auscultation). The individual must also be placed on optimal diuretic therapy (e.g., Lasix [Furosemide], Bumex [Bemetadine], and Zaroxolyn [Metolazone]). Diuretics lower the blood pressure by decreasing blood volume and cardiac output (Abrams, 2001). The individual must also be prescribed nitrates (e.g., Nitroglycerin patch and isosorbide dinitrate [Isordil] or Apresoline). Nitrates are used to decrease the frequency and severity of angina (chest pain) (Abrams, 2001). Angiotensin Converting Enzyme (ACE) inhibitors (e.g., Benazepril [Lotensin], Captopril [Capoten], and Enalapril [Vasotec]) are also used in the
treatment and management of heart disease. ACE inhibitors prevent the vasoconstriction of the blood vessels (Abrams, 2001).

*Pulmonary Disease*

In order to gain admission into hospice services with the diagnosis of pulmonary disease, the individual must exemplify specific symptoms such as dyspnea at rest, housebound, chair bound, oxygen-dependent, and increased visits to the emergency room/hospital in the last six months. A Karnofsky score of less than 50 is also required. The individual having this score indicates the individual is unable to care for self, requires equivalent of institutional or hospital care, and has diseases that may be progressing rapidly. The individual also must have an Activities of Daily Living (ADL) score of less than 18. The areas scored during the evaluation are (a) bathing, (b) dressing, (c) toileting, (d) transfer, (e) continence, and (f) feeding. These scores range from four indicating independent, to one indicating completely dependent.

**Caregivers**

According to the Cancer Support Community (2014), “a caregiver is anyone who provides physical, emotional, spiritual, financial, or logistical support to a loved one with a chronic, disabling, or life-threatening illness” (p. 1). Caregivers may have responsibilities such as shopping for food and cooking, cleaning the house, paying bills, giving medication, and providing company and support for negative emotions such as anger and depression.

Research has shown that there are currently 44 million people, or 21% of the adult population, aged 18 and older providing care to an ill or disabled family member suffering with Alzheimer’s disease, cardiovascular disease, or cancer (Herbert & Schulz,
Research further shows that the typical caregiver is a 46-year-old woman, with some college experience, who is providing more than 20 hours of care per week consisting of bathing, grooming, dressing, and manually transporting the patient from bed or chair (Herbert & Schulz, 2006).

Caregivers providing care for loved ones often limit their personal activity, preventing them from maintaining school or work, or taking proper care of themselves. Caregivers often suffer adverse physical decline such as sleep disturbances, severe fatigue, and poorer physical health (Wilder et al., 2008). These effects are primarily due to caregivers ignoring their own physical health to provide care to the loved one.

According to Lim and Zebrack (2004), “caregivers often feel tired, isolated, and overwhelmed, because they lack support, training information, and a sympathetic ear” (p. 1).

Lund, Ross, Peterson, and Groenvold (2014) conducted a cross-sectional questionnaire study focusing on informal caregiver tasks and consequences and their relation to the experiences of caring for a patient with cancer. The study also concentrated on the status of how well the caregiver managed providing care to the patient. Tasks that were performed by the caregiver in the study consisted of providing emotional support; symptom management pertinent to the cancer diagnosis such as nausea, fatigue, and managing pain; cooking; and housekeeping. The study included 590 caregivers who were given the Cancer Caregiving Tasks, Consequences and Needs Questionnaire tool to complete. This tool consisted of 72 items measuring cancer caregiving tasks and consequences and the caregivers’ needs mainly concerning information, communication, and contact with healthcare professionals. The tool
contained nine subscales and 31 single-question items. The tool conveyed the scores on a scale ranging from 0 (no problems) to 100 (maximum problems). The reliability and validity of this tool was tested and yielded a Cronbach’s alpha score ranging from 0.65–0.95. The study showed a large proportion of the participants reporting a heavy workload related to needing practical help and psychological support to decrease stress.

According to Baider and Surbone (2014), caregiving provided by elderly individuals is expected to increase to 70% of all cancer patients in the Western part of the world. Cancer has grown to become a chronic disease of the elderly population with an estimated growth from 6 million in 2008, to 11 million in the upcoming decade (Baider & Surbone, 2014). Due to this anticipated growth, the number of older persons caring for their spouses is expected to increase (Baider & Surbone, 2014). The study conducted by Baider and Surbone focused on the integrative evaluation of caregiving in older adults. The study further concentrated on the impact of age, culture, and gender of the caregiver. Results showed that 60% women were functioning in the role as caregivers. Research further depicted 34% take care of two or more people (Baider & Surbone, 2014). The study showed that culture had an input in the management of caregiving. Research showed that “African American and Hispanic caregivers were more likely than white caregivers to reduce work hours to stay home and care for an ill family member” (Baider & Surbone, 2014, p. 3). Many of these caregivers were an average age of 63 years.

Duggleby, Schroeder, and Nekolaichuk (2013) conducted a qualitative study that focused on 13 caregivers of individuals with dementia living in a long-term care facility and their perception of hope. According to Duggleby et al., “hope is a psychosocial resource that is essential to the psychological, spiritual, and physical well-being of family
members caring for persons with dementia” (p. 1). In this study, 23 open-ended face-to-face interviews were conducted. This study used Thorne’s interpretive description methodological approach to provide a more distinct view of the concept of hope in the caregivers: “Interpretive description is a qualitative research approach that provides an integrative description of a phenomenon” (Duggleby et al., 2013, p. 2). Participants in this qualitative study completed interviews related to their perception of hope and documented their views of hope in a diary over a two-week period. The interview lasted 60–90 minutes and took place either in the home of the participant or in a meeting room located at the long-term care facility. All of the participants were Caucasian, and 46% were daughters of the patients. Most of the participants were retired, had education beyond high school, and lived in an urban setting. Participants expressed their perceptions of hope by using responses such as a “better tomorrow” and a “desire for things to be different from the reality of what is” (Duggleby et al., 2013, p. 4). The participants’ hope for themselves was “that they could continue to be present and experience a connection with their family member or friend residing in the long-term care facility” (Duggleby et al., 2013, p. 5).

Davidson et al. (2013) conducted a random annual population-based cross-sectional health survey, The South Australian Health Omnibus Survey: “An omnibus survey is a method of quantitative research using a stratified sample where data on a wide variety of subjects is collected during the same interview” (p. 2). The Omnibus Survey was done face to face and administered by a research organization supported by the government. The survey focused on the characteristics of caregivers of individuals with heart failure such as level of care provided, length of care provided, and whether they felt
that enough support was provided to assist the caregivers in the care regime. The information, in turn, was compared to other caregivers caring for patients with other diagnoses (Davidson et al., 2013). This study consisted of 373 respondents, with 84 of them providing day-to-day care. The mean age for caregivers with heart failure in this study was 55.7 years of age compared to other active caregivers with aging at 49.4 years of age. The study also reported a period of caregiving for individuals with heart failure ranging from 48.9 to 66.2 months.

**Caregiver Burden**

According to Garlo et al. (2010), “as physicians are preparing to care for an older population of patients with chronic diseases, assessing caregiver burden and understanding caregiver needs are increasingly important” (p. 2). Caregiver burden is common with caregivers providing care to individuals with cancer, heart failure, and chronic obstructive pulmonary disease (COPD) (Garlo et al., 2010). Caregiver burden refers to the emotional response of the caregiver when responding to the changes and demands consistent with the role of caregiving (Higginson & Gao, 2008).

Demiris et al. (2009) conducted a meta-analysis that focused on hospice caregivers and the interventions needed to address and decrease the experience of caregiver burden when caring for hospice patients. A framework labeled “Assessing Caregivers for Team Interventions” (ACT) was used to integrate family caregivers and patients into one unit of care, to function as one. The ACT framework is based on the ongoing assessment of the background context, primary, secondary, and intra-psychic stressors as well as outcomes of the caregiver experience and ultimately the design and delivery of appropriate interventions to be completed by the hospice team. Intra-psychic
stressors were identified as anxiety, depression, and decreased self-esteem. The interventions implemented by the hospice team included:

- problem definition and formulation, which involved gathering data and information, articulating the issue in clear terms, identifying the challenge, and setting realistic goals;
- generation of alternative coping strategies;
- decision-making skills; and
- solution implementation. Interventions were delivered by a hospice interdisciplinary team to assist in decreasing the amount of burden with caregivers.

The aim also focused on reducing actual caregiving tasks and providing support and enhancing caregivers’ coping skills and education. This study provided interventions that promoted evidence-based approaches that were valuable to the hospice community. These interventions consisted of identifying challenges and stressors such as medication administration or pain management that were verbalized by the caregiver and specified as causing a burden. Addressing caregiver issues and implementing interventions to address those issues are critical to the care of hospice patients receiving palliative care.

Empeno et al. (2011) conducted a study using a sample of 123 hospice caregivers. The caregivers were aged 55 or older. Eligibility criteria included the ability to communicate in English and a verbal request for services that was not covered by the individual’s insurance. The study aimed at providing an intervention of placing referrals to other resources that were not provided by the hospice agencies, to assist in decreasing caregiver burden with the caregiver population. Respite care was one of the services
measured in this study. The respite care service provided by the agency was compared for usage before and after service introduction. The results showed that there was a significant decrease in hospice respite care from an average of 10.7 to 6.5 days compared to the previous year. The Pearlin Role Overload Measure (ROM) was utilized in the study before introduction of the resource. The ROM tool is a four-item measure of caregiver stress. The items in the tool contain the following statements:

- “You are exhausted when you go to bed at night;”
- “You have more things to do than you can handle;”
- “You don’t have time just for yourself;” and
- “You work hard but never seem to make any progress” (Empeno et al., 2011, p.594).

The ROM tool provided responses on a four-point Likert scale measuring the following:

- 0- not at all
- 1- somewhat
- 2- quite a bit
- 3- completely

The tool was re-administered after the service period of 10 months (February–December) was completed. The study showed that in 123 caregiver phone interview follow-ups, the largest number of caregivers (90%) received direct assistance with patient care. Overnight assistance was requested by 17%, home delivered meals by 4%, and house cleaning services by 3%.

Garlo et al. (2010) conducted a qualitative research study to determine the extent of caregiver burden over time with caregivers of persons with advanced chronic disease.
The study design was an observational cohort with interviews held over 12 months. Participants consisted of caregivers of 179 persons over the age of 60 years with advanced cancer, heart failure, or COPD. Caregiver burden was assessed using a 10-item short-form of the Zarit Burden Inventory (ZBI) to measure psychosocial distress. The scoring of the tool was completed using a five point Likert scale with the following responses:

- “never,”
- “rarely,”
- “sometimes,”
- “often,” and
- “always” (Garlo et al., p. 3).

The tool rated each item with the score of 0–4. The sum of each item provided a total score of 0–40. The median caregiver burden score was five on a scale of 0–40, which indicated that the caregiver reported at least 2 of 10 distressing concerns (e.g., not having enough money, needing more help with tasks, and needing more emotional support) some of the time. A score of five showed (Garlo et al., 2010, p. 5):

- “reporting of one concern occurring ‘always’ and an additional concern occurring ‘rarely,’ or
- “reporting of one concern occurring ‘sometimes’ and an additional concern occurring ‘frequently.’

However, results showed 10% of the participants reported no burden.

Whittenberg-Lyles et al. (2011) conducted a qualitative research study that focused on the challenges of caregiving and their impact on the physical quality of life
and psychological distress. Data was obtained using audiotapes of intervention
discussions between hospice caregivers and research social workers. The results showed
that the majority of the concern with the hospice caregivers was psychological (49%),
physical (28%), social (22%), and spiritual (2%). This study showed a reinforced need for
assessing caregivers in hospice care, with emphasis on the importance of providing
caregiver education.

Pierce, Thompson, Govoni, and Steiner (2012) conducted a quantitative research
study related to caregivers’ emotional strain when caring for patients who had
experienced a diagnosis of cerebrovascular accident (CVA) or stroke. The study involved
73 caregivers providing care to individuals with CVA. The study randomly assigned 36
of the caregivers to a group that had access to a web-based intervention and email
discussion. The study showed that caregivers were primarily (a) worried about patient’s
status, (b) running on empty, and (c) losing self. This study also informed nurses that
patients needed more supportive education interactions.

Cedano et al. (2013) conducted a cross-sectional study from July 2009 to June
2011 to assess quality of life and burden of caregivers for 80 persons with COPD who
used specialized outpatient centers. The study used the Medical Outcomes Study
Questionnaire (SF-36), Caregiver Burden Scale (CBS), and Katz Index. The SF-36 is a
36-item short-form health survey used to assess the caregivers’ quality of life. The 36
items were divided into eight domains: vitality, functioning, bodily pain, general health,role physical, role emotional, social functioning, and mental health. The CBS was used
for measuring the impact on caregivers’ lives by the care given to patients with chronic
illnesses. It contained 22 questions, and was divided into five domains: general strain,
isolation, environment, emotional involvement, and disappointment. The Katz Index tool was used to access the functionality in the ADL. This tool measured the individual’s ability to perform specified activities and his or her level of independence.

**Quality of Life**

Quality of Life is defined by the World Health Organization (WHO) as an individual’s views of life in the context of the environment and the relationship attachment to personal goals and concerns (Bobes, Garcia-Portilla, Bascaran, Saiz, & Bousono, 2007, p. 1). According to Opara, Jaracz, and Brola (2010), the quality of life is a multi-dimensional construct that contains at least three domains such as physical, mental, and social components.

Bobes et al. (2007) conducted a literature review that focused on assessing the difficulties of quality of life in individuals with schizophrenia and the effects of antipsychotic medications related to the management of the mental illness and quality of life. According to Bobes et al. (2007), individuals utilized medications such as aripiprazole (Abilify), olanzapine (Zyprexa), and ziprasidone (Geodon). Antipsychotic medications used in the management of schizophrenia that have fewer side effects are believed to improve the quality of life in schizophrenic individuals (Bobes et al., 2007).

Nyanzi, Wamala, and Atuhaire (2014) conducted a cross-sectional design study focused on individuals with diabetes mellitus, their perceptions of quality of life, and the disease process. The study consisted of 219 participants attending a diabetes clinic in Uganda. The participants were predominately female (72.6%) and above 49 years of age (56.1%); the highest percentage of the participants had primary education (47.5%), and 36.5% had post-primary education. According to Nyanzi et al. (2014), individuals with
the diagnosis of diabetes mellitus experience stressors such as management of the disease and multiple medications, which can have negative effects on the quality of life. The study utilized the QoL standardized instrument. The tool used a five-point Likert scale and yielded a Cronbach’s alpha of > 0.7, which expressed the reliability of the tool. The study focused on five quality domains, which included role limitations due to physical health, mental health, treatment satisfaction, physical endurance, and diet satisfaction. In regard to the domains of the study using the five-point Likert scale, a mean score of 4.04 related to role limitations with physical health, mean scores of 3.82 and 3.96 indicated satisfaction with mental health and treatment, and the scores of 3.83 and 3.86 were the domains of physical endurance and diet satisfaction. Results of the study showed that the quality of life among diabetic individuals is highly associated with age, education level, and status of diabetic foot ulcers.

**Caregiver Quality of Life**

According to Lim and Zebrack (2004), the “quality of life is a construct that encompasses health and functioning, socioeconomic status, psychological, emotional, and spiritual aspects, and family” (p. 2). In addition, “the quality of life of caregivers may partly be influenced by other existing environmental stressors, stress appraisals, coping methods, and social support” (Lim & Zebrack, 2004, p. 2). Literature produced by McMillan et al. (2005) showed that providing care for terminally ill patients can take its toll on the caregiver’s quality of life and can erode the caregiver’s sense of mastery.

Lim and Zebrack (2004) conducted a systematic review of 19 literary articles focusing on the quality of life outcomes of family members caring for patients with chronic physical illnesses. The systematic review explored the concepts and instruments
used to measure caregiver’s quality of life. The Caregiver Quality of Life Index tool contains four domains related to physical, emotional, social, and financial wellbeing. The review showed that stress-related variables that influence caregivers’ quality of life include (a) patient and caregiver characteristics, (b) stressors, (c) stress appraisal, (d) stress coping methods, and (e) social support.

Luxardo, Brage, and Alvarado (2012) conducted a study using a hospice agency in Argentina and caregivers caring for patients in the home setting. The study’s aim was to describe an intervention provided by hospice staff in order to identify the holistic needs of home-caregivers for patients in their last stage of cancer. The intervention was focused on values such as love, charity, and compassion as well as expertise and end-of-life competence. The goal was to address the spiritual and emotional needs of the caregiver. The participants consisted of 40 hospice families who were interviewed according to their needs when providing care to the hospice patient. The study showed that the hospice staff should employ more interventions to assist in decreasing the amount of burden experienced by the caregivers.

Wilder et al. (2008) conducted a quantitative research study in two small hospice agencies in the Midwestern United States. The study consisted of 76 informal caregivers and 72 patients. Upon admission to hospice services, each of the participants who met inclusion criteria was informed that the hospice agencies were involved in a research study. The inclusion criteria included:

- “over the age of 18 years,”
- “access to standard telephone line,”
• “without functional hearing loss or with a hearing aid that allowed the participant to conduct phone conversations,” and

• “intact mental status as demonstrated by having a score greater than or equal to 7 on the questionnaire as assessed by the hospice registered nurse” (Wilder et al., 2008, p. 8).

The tool utilized for measurement in the study was the Caregiver Quality of Life Index-Revised (CQLI-R). This tool consisted of a self-reported quality of life for the following four items: emotional, social, financial, and physical. Each item was scored on a scale of 0–10, describing someone who had the lowest (0) or the highest (10) characteristics of the four domains. The caregiver completed the CQLI-R during an initial interview. The tool was later administered by phone at one month following enrollment into the program. The study provided results indicating that the social domain yielded the highest score of 7.91, and emotional quality of life was the next highest with a score of 7.71. The scoring of the financial domain was 7.00, and physical quality of life had the lowest score of 6.80.

Quality of Life Index

According to Ferrans (2014), the Quality of Life Index (QLI) tool was developed to measure quality of life in terms of satisfaction and importance related to various aspects of life. This tool has five domains, which include overall quality of life, health and functioning, psychological/spiritual, social and economic, and family. The QLI has also been used in a number of studies involving individuals with chronic diseases such as diabetes mellitus, hypertension, chronic kidney disease (CKD), and lung disease.
Yakar and Pinar (2013) conducted a descriptive study using the Caregiver Quality of Life Index-Cancer (CQOLC), which measured the quality of life of 120 family members caring for cancer patients living in Turkey. This tool covered the assessment of physical, emotional, family, and social functioning. The CQOLC tool consisted of 35 items and used a five-point Likert scale (from 0, not at all, to 4, very much). The majority of the caregivers were female caregivers (72.5%) and married (75.8%) with a mean age of 44.7 years.

Penckofer et al. (2012) conducted an exploratory design. The study focused on poor diabetes mellitus management, depression of women with Type 2 diabetes mellitus, and quality of life. The study included 23 women who were diagnosed with diabetes mellitus, Type 2 within the past six months and were performing glucose finger sticks at least four times daily (morning, lunch, dinner, and before bedtime). The researchers conducted two visits to the participants. The first visit lasted approximately two hours for collection of data (height, weight, blood pressure, HbA1c, glucose, and tool completion). The second visit lasted approximately 20 minutes and included the assessment of skin for erythema or edema. The study utilized the QLI tool, diabetes mellitus version. The questionnaire consisted of 34 items that measured satisfaction and importance of (a) health and functioning, (b) social and economic, (c) psychological/spiritual, and (d) family impact on the quality of life for persons with diabetes mellitus. Cronbach’s alpha for reliability and validity was .94–.97. The study results showed no significant difference between the participants’ age, years with diabetes mellitus, body mass index, and HbA1C. The mean age was 51 years.
Rannestad and Skjeldestad (2010) conducted a case-control pilot study to determine the usefulness of the QoL tool in the assessment of the urinary incontinence and the impact on women’s lives. The study consisted of 160 cancer survivors with urinary incontinence. The quality of life of the participants was measured using the Ferrans and Powers’ QLI tool, which measured quality of life regarding satisfaction and importance related to domains of life such as health and functioning, socioeconomic, psychological/spiritual, and family. These items were scored using a six-point Likert scale with a total score ranging from 0–30, with the higher scores indicating a higher quality of life. The study resulted showing that urinary incontinence was common among women and had a negative influence on all domains of quality of life.

Theoretical Framework

The theoretical framework for this project focused on caring. Caring is a belief or value, an intention, a process, and a way of being human that enhances personhood and leads to feeling cared for, which is a precursor to optimal health outcomes (Duffy, 2011). According to Swanson (2006), caring could be defined as a “nurturing way of relating to a valued ‘other’ toward whom one feels a personal sense of commitment and responsibility” (p. 355).

The Nursing as Caring Theory

According to Duffy (2011), “the nursing as caring theory is considered to be a grand theory. This theory was intended to be a practice theory that honors the special nature of all persons as caring” (p. 508). The major concepts of this theory are parenthood, the nursing situation, calls for nursing, and nursing as caring (Duffy, 2011). According to Schoenhofer and Boykins (1993), “nurturing relationships with caring for
others” (p. 83). This theory embraces nursing as caring and defines caring as “the body of
knowledge from which professional nursing uniquely responds to its social duty” (Duffy,
2011, p. 509). The major assumptions of this theory are summarized as follows
(Shoenhofer & Boykins, 1993):

- persons are caring by virtue of their humanities;
- persons are caring from moment to moment;
- persons are whole or complete in the moment;
- personhood is a process of living grounded in caring;
- personhood is enhanced through participating in nurturing relationships with
caring others; and
- nursing is both a discipline and a profession.

*Watson’s Theory of Human Caring*

According to Tourville and Ingalls (2003), Watson’s Theory of Human Caring is
a widely accepted and practiced nursing theory. Watson’s theory focuses on the
importance of human caring; was based on a form of humanism; and has its origins in
metaphysics, the philosophy of being and knowing (McCance, McKenna, & Boore,
1999). According to McCance et al. (1999), Watson described caring as “a value and an
attitude that has a will, intention, or a commitment, that manifests itself in concrete acts”
(p. 1390). Watson’s theory is composed of 10 clinical caritas that influence the profession
of nursing in relevance to patient care. The 10 clinical caritas include (Watson, 2007):

- practice of loving kindness and equanimity within context of caring
  consciousness;
• being authentically present and enabling and sustaining the deep belief system and subjective life world of self and the one being cared for;

• cultivation of one’s own spiritual practices and transpersonal self, going beyond ego self, opening to others with compassion and sensitivity;

• development and sustaining a helping–trusting, authentic, caring relationship;

• being present to and supportive of the expression of positive and negative feelings with a connection of a deeper spirit of self and the one being cared for;

• creative use of self and all ways of knowing as part of the caring process, to engage in artistry of caring–healing practices;

• engaging in genuine teaching–learning experience that attends to unity of being and meaning attempting to stay within other’s frame of reference;

• creating healing environment at all levels, physical as well as non-physical, subtle environment of energy and consciousness, whereby; wholeness, beauty, comfort, dignity, and peace are potentiated;

• assisting with basic needs with an intentional caring consciousness, administering “human care essentials,” which potentiate alignment of mind/body/spirit, wholeness, and unity in all aspects of care, tending to both embodied spirit and evolving spiritual emergence; and

• opening and attending to spiritual–mysterious and existential dimensions of one’s own life–death and soul caring for self and the one being cared for.

According to Watson (2007), these caritas are an emerging model of transpersonal caring and moves from carative to caritas.
Watson (2009) describes nursing as a human science, with the major focus being the process of human care for individuals, families, and groups. Watson’s theory embraces the act of caring and promotes its use in providing effective healthcare to all individuals. The hospice environment and experience play a major role in how many caregivers view their role and participation in hospice care. According to Watson (2009), “this work (nursing) places human to human caring as central nursing responsibilities, the role and moral foundation for the profession” (p. 471). Watson’s theory brings to light the role of the nurse, and the way nursing is conducted. Watson’s theory services this capstone project because it correlates well with the importance of the capstone project. The clinical caritas that compile Watson’s theory form a strong bond that is essential. The clinical caritas were applied in the implementation of the project. Caregivers of hospice patients also desire to have their physical, spiritual, and emotional needs met. This theory allows the focus of those needs to be addressed and nurtured. According to Watson (2005), incorporating and including extant nursing theory to ground nursing knowledge is necessary for nursing science and allowing the discipline of nursing to inform and guide professional practice and knowledge development.

Watson’s theory is the theoretical framework for this capstone project because of the complexity it exemplifies with regard to caring. The clinical caritas of Watson’s theory demonstrate components of caring that are consistent with the attributes of this capstone project. The clinical caritas of (a) practicing of loving kindness within the context of caring and (b) being present and enabling the deep belief system and subjective life of self and the one being cared for correspond with the role of the informal caregiver and the giving of himself or herself to care for the patient. The caritas (c)
cultivation of one’s own spiritual practices and going beyond self, opening with compassion and sensitivity and (d) developing and sustaining a helping–trusting, caring relationship closely relate to the practice of what informal caregivers strive to promote, which is anticipatory of what this capstone project is founded upon. The caritas (e) being present and supportive of the expression of positive and negative feelings with a deeper spirit of self and (f) creative use of self and all ways of knowing as part of the caring process to engage in artistry of caring–healing practices support the focus of this capstone’s finding of intervention that stimulates the caregiver to develop other paths to assist in maintaining the sense of being. The caritas (g) engaging in genuine teaching–learning experience of the individual and (h) creating healing environment at all levels, physical as well as nonphysical, environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated assist the intervention component of the capstone project by supporting the need to develop and identify ways that informal caregivers can begin to care for themselves as well as the hospice patient being cared for. The final caritas of (i) assisting with basic needs with an intentional caring consciousness, administering “human care essentials,” which potentiate the alignment of mind/body/spirit wholeness, and unity in all aspects of care, embodied spirit and evolving spiritual emergence, and (j) opening and attending to spiritual and existential dimensions of one’s own life–death and soul caring for self and the one being cared for are the foundation for this capstone project because they allow the informal caregiver to be recognized as an individual with needs and essential necessities that are crucial to the well-being and longevity for one’s self. Watson’s theory forms a bridge that connects this capstone project with the belief of caring for others and also the ability to
recognize that caregivers must care for themselves in order to maintain a positive quality of life while acting in the role of a caregiver.

The Doctor in Nursing Practice (DNP) Essentials

The DNP essentials are very important to the professional maturity of the Advanced Practice Registered Nurse (APRN). The progression of the essentials is critical to the development, implementation, and evaluation of new practice guidelines (Appendix B).

The capstone project presents the opportunity to provide supporting evidence of an intervention that may help informal caregivers to better manage their role when caring for hospice patients. The intervention implemented in this capstone project may provide strategies for the hospice caregiver community that will empower members of that community to create and develop ways to better manage the informal caregiver role and better provide care to hospice patients.

APRNs in the hospice sector provide service to not only the hospice patient but also the patient’s family and immediate caregivers. Developing and implementing new ways to support the individuals who provide care exemplifies the readiness that a DNP-prepared APRN strives to incorporate in evidence-based practice.

**Essential I: Scientific underpinnings for practice.** This essential was important to this capstone project because it provided the influence needed to implement the project. The COPE intervention was used in evidence-based practice to determine its effectiveness in making a change in healthcare. This essential provided a bridge to implement and evaluate an approach to evaluate the quality of life in the informal caregiver population. The opportunity to identify an intervention that motivates informal
caregivers to manage and develop pathways to care for themselves was fortunate, not only to the patient but also to the informal caregiver.

**Essential VII:** Clinical prevention and population health for improving the nation’s health. This essential provides the basis for which the capstone project was completed. The health of informal caregivers is critical to the care of the hospice patient. Improving the health of informal caregivers and preventing other comorbidities cannot only increase the quality of life in these individuals but also assist with decreasing the amount of respite care required to in-patient facilities.

Assumptions

This capstone project is based on the following three assumptions:

- “Caregivers are likely to experience a higher level of distress when the care recipient exhibits more problem behaviors or shows greater dependency” (Lin et al., 2012, p. 345).
- “The more demanding the caregiver’s responsibilities, the greater the amount of emotional stress and suffering the caregiver experiences” (Whittenberg-Lyles et al., 2011, p. 384).
- “Interventions aimed at helping the caregiver cope with his/her role may help reduce burden and improve caregiver outcomes” (Garlo et al., 2010, p. 2322).
- “Difficulty of caregiving impacts the quality of life of caregivers and causes depression, psychological distress, guilt, loneliness, and restrictions on social activities” (Whittenberg-Lyles et al., 2011, p. 383).
Resource Requirements

The capstone project required no additional resources secondary to time to meet with the participants. The three visits to the participants were arranged during day-time hours. In order to effectively implement this project, the organization would need the following resources: (a) a full-time COPE administrator, (b) a copier, (c) a computer, (d) copy paper, and (e) transportation.
CHAPTER III

METHODOLOGY

The purpose of this capstone project is to evaluate the effectiveness of the COPE intervention in maintaining the quality of life in informal caregivers caring for hospice patients in a hospice agency located in central Mississippi.

Design of the Project

The design used for this capstone project was a quantitative, descriptive design. The target population for this project was informal caregivers of hospice patients of an urban hospice agency located in central Mississippi. A convenience sample consisted of 20 caregivers. The sample was selected from individuals who consented to participate in this capstone project. The inclusion criteria were:

- primary caregiver for a hospice patient;
- 18 years of age or older;
- caring for a hospice patient within the previous six-month period;
- English speaking; and
- ability to read and write at a fourth-grade level.

Setting

The setting utilized for this capstone project was a hospice agency located in central Mississippi. The hospice agency provided palliative care to patients with chronic or terminally ill diagnoses in their home. The hospice agency consisted of a team of an administrator, director of nursing, office manager, three nurse practitioners, five registered nurses, two licensed practical nurses, four nursing assistants, one social
worker, one chaplain, and one marketer. The hospice agency served about 32 patients and their informal caregivers. The hospice patients ranged from 60–104 years of age.

The purpose of this capstone project was to evaluate the perceptions of quality of life in informal caregivers caring for hospice patients in an urban hospice agency located in central Mississippi.

Sample

Permission to conduct the capstone project with informal caregivers of hospice patients enrolled with the services of a hospice agency located in central Mississippi was obtained from the administrator of the agency. A convenience sample of 20 informal caregivers caring for hospice patients enrolled under the central Mississippi hospice agency’s service was selected. The informal caregiver prospective participants were informed of the purpose of the capstone project and its inclusion criteria. The screening for the informal caregivers included reviewing inclusion criteria with each informal caregiver.

Procedures

Informal caregivers potentially qualifying for participation in this project met the inclusion criteria. The inclusion criteria for this project required the informal caregiver to be (a) primary caregiver for a hospice patient, (b) 18 years of age or older, (c) caring for a patient within the previous six-month period, (d) English speaking, and (e) have the ability to read and write at a fourth-grade level. After the number of qualified informal caregivers was determined, a brief oral presentation covering the purpose of the project, the importance of the project, and the plans for implementing the project was given to each informal caregiver participant. After consent was obtained from participating
informal caregivers, the informal caregivers were randomly assigned to one of two groups using a randomization procedure. The randomization procedure had the participants’ last names listed in alphabetical order. The first 10 names were assigned to group one, and the last 10 names were assigned to group two. Each group was composed of 10 informal caregivers. After the two groups were determined, the QLI tool (Appendix C) was administered by the project director in the caregiver’s home to the informal caregivers. The tool consisted of two separate parts with 33 questions covering the satisfaction and importance perception of the informal caregiver’s QoL. Part one of the QLI focused on the caregiver best describing how satisfied he or she was with the area of life proposed in the question. Part two of the QLI focused on the caregiver best describing how important the area proposed in the question is to him or her. Each question was rated on a six-point Likert-type scale rated as follows:

- 1-very dissatisfied,
- 2-moderately satisfied,
- 3-slightly dissatisfied,
- 4-slightly satisfied,
- 5-moderately satisfied, and
- 6-very satisfied.

The tool took approximately 10 minutes to complete. After implementation of the tool by the project director to the informal caregiver, each of the two groups received visits at 72 hours of admission to hospice, day 16 post-hospice admission, and day 30 of hospice admission. Each informal caregiver, depending on what group was assigned to him or her, received care as specified.
Group one received three routine visits from the capstone project director for the purpose of providing routine individual caregiver-based support to the informal caregivers. These visits consisted of allowing the informal caregiver to discuss his or her feelings, fears, and relationships related to the informal caregiver role. The first visit took place 72 hours after admission and lasted approximately one hour. The second visit took place on day 16 of caring for the hospice patient and lasted approximately 30 minutes. The last visit took place on day 30 of caring for the hospice patient and lasted 30 minutes.

Group two received three routine visits from the project director. These visits consisted of allowing the informal caregiver to discuss his or her feelings, fears, and relationships related to the informal caregiver role. The first visit took place 72 hours after admission and lasted approximately one hour. The second visit took place on day 16 of caring for the hospice patient and lasted approximately 30 minutes. The final visit took place on day 30 of caring for the hospice patient and lasted approximately 30 minutes. This group was also taught a problem-solving intervention method. The intervention known as COPE was used to assist caregivers in maintaining or increasing their quality of life. COPE has four components—(a) creativity, (b) optimism, (c) planning, and (d) expert information—that assist in addressing specific needs of the family and caregiver. The creativity component focused on viewing problems from different perspectives in order to develop new strategies for solving caregiver problems. The optimism component focused on having a positive but realistic attitude toward the problem-solving process. The planning component focused on setting reasonable caregiving goals and thinking out the steps to reach those goals. The final component, expert information, focused on the caregiver recognizing when to seek assistance from professionals. This problem-solving
intervention was taught 72 hours after hospice admission, day 16 post admission, and day 30 post admission.

At the conclusion of the four weeks, group one and group two were re-administered the QLI tool. The reassessment was to determine if the implementation of the COPE intervention affected the perceptions of quality of life experienced by the caregivers.

Ethical Protection of Human Subjects

Application for permission to conduct the capstone project was obtained from the Institutional Review Board (IRB) of The University of Southern Mississippi (Appendix D) and the administrator of the central Mississippi hospice agency (Appendix E). The prospective informal caregiver participants were informed that their decision to participate in this research study would not affect the care provided to the hospice patient or benefits. Assurance of anonymity was given by the project director and showed an omitting space on the interview form for the prospective informal caregiver’s name or any identifying information. All informal caregiver participants in the capstone study were informed that there would be no compensation for their participation in the capstone project. The informal caregiver participants were informed that they had the right to withdraw from this capstone project study at any time without negative consequences. After all information regarding the capstone project was given, the informal caregiver participants were given the opportunity to ask questions regarding the capstone project and their participation. The informal caregivers were then asked to sign an informed consent.
Permission to use the research tool was obtained from the developer of the instrument (Appendix F). The project director began by selecting an urban hospice agency in central Mississippi. The project director met with the administrator at a scheduled meeting. The project director informed the administrator of the capstone project, the purpose, criteria of potential capstone participants, and the time expectancy for the interview completion. The project director met with each potential participant and explained the purpose of the capstone project, the criteria required, and the time expectancy for the interview completion.
CHAPTER IV
RESULTS

The capstone project had a convenience sample of 20 participants. The 20 participants consisted of 15 (75%) females and 5 (25%) males. The age groups of the caregivers ranged from 18 to 77 years of age. The convenience sample had 20 (100%) African-American participants. The sample showed a relationship to the hospice patient as a child, spouse, friend, or other. The participants had experience ranging from six months to 15 years in the role of a caregiver. Demographic data for gender, age, race/ethnicity, relationship to hospice patient, and the time in the role of an informal caregiver were analyzed using descriptive statistics (Appendix G), as shown in Table 1.

Table 1
Demographic Data Summary

<table>
<thead>
<tr>
<th>Variables</th>
<th>Percentage/n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>75% (n = 15)</td>
</tr>
<tr>
<td>Male</td>
<td>25% (n = 5)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>18–27</td>
<td>15% (n = 3)</td>
</tr>
<tr>
<td>28–37</td>
<td>5% (n = 1)</td>
</tr>
<tr>
<td>38–47</td>
<td>20% (n = 4)</td>
</tr>
<tr>
<td>48–57</td>
<td>30% (n = 6)</td>
</tr>
<tr>
<td>58 years of age or older</td>
<td>30% (n = 6)</td>
</tr>
<tr>
<td>Race/Ethnic Origin</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>100% (n = 20)</td>
</tr>
<tr>
<td>Relationship to Hospice Patient</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>50% (n = 10)</td>
</tr>
<tr>
<td>Spouse</td>
<td>15% (n = 4)</td>
</tr>
<tr>
<td>Friend</td>
<td>5% (n = 1)</td>
</tr>
<tr>
<td>Other</td>
<td>25% (n = 5)</td>
</tr>
</tbody>
</table>
The participants were randomly assigned to one of two groups. Ten participants were assigned to group one. Group one had nine (90%) females and one (10%) male. The group consisted of participants with ages ranging from 22 to 77 years. The group participants were all African American. The relationship to the hospice patient was identified as a child, spouse, friend, or other. The time in the role of a caregiver ranged from six months to 10 years. Ten participants were assigned to group two. Group two had six (60%) females and four (40%) males. The ages of the participants ranged from 24 to 60. The group participants were all African American. The relationship between the caregiver and the hospice patient was identified as a child, spouse, friend, or other. The time experience in the role of caregiver ranged from six months to 10 years. Table 2 provides a summary of individual group demographics.

Table 2

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Summary of Individual Group Demographics
Table 2 (continued).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–27</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28–37</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>38–47</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>48–57</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>58 or above</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Relationship to Patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Spouse</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Experience as a Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>1-5 years</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>5-10 years</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>10-15 years</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

The QLI tool was used to evaluate the perception of quality of life in informal caregivers. The tool evaluated five domains such as overall quality of life, health, social, psychological, and family. The tool consisted of two separate sections. Each section contained 33 questions. The first section of the QLI tool focused on the caregiver best describing how satisfied he or she was with the area of life proposed in the question. The second section of the QLI tool focused on the caregiver best describing how important the area proposed in the question was to him or her. Each question was rated on a six-point Likert-type scale rated as follows:

- 1-very dissatisfied
- 2-moderately satisfied
- 3-slightly dissatisfied
• 4-slightly satisfied
• 5-moderately satisfied
• 6-very satisfied

Informal caregivers in group one received three visits from the capstone project director for the purpose of providing routine individual caregiver-based support. These visits consisted of allowing the informal caregiver to discuss his or her feelings, fears, and relationships related to the informal caregiver role. The first visit occurred 72 hours after admission and lasted approximately one hour. The QLI tool was administered. This visit allowed the informal caregiver to discuss what the role of caregiver meant to him or her and what fears he or she had as a new caregiver. The second occurred on day 16 after admission and lasted approximately 30 minutes. During this visit, the informal caregiver discussed how he or she was adjusting to the role of a caregiver and new changes that had taken place since starting the new role. The last visit occurred on day 30 after admission and lasted approximately 30 minutes. During this visit, the caregiver discussed the difficulties that were being experienced since becoming a new caregiver.

Informal caregivers in group two received three visits from the project director for the purpose of providing routine caregiver-based support. These visits consisted of allowing the informal caregivers to discuss their feelings, fears, and relationships related to the informal caregiver role. This group was also taught a problem-solving intervention known as COPE, which was used to assist caregivers in maintaining or increasing their quality of life. COPE has four components—(a) creativity, (b) optimism, (c) planning, and (d) expert information—that assist in addressing specific needs of the family and caregiver. The creativity component focused on viewing problems from different
perspectives in order to develop new strategies for solving caregiver problems. The optimism component focused on having a positive but realistic attitude toward the problem-solving process. The planning component focused on setting reasonable caregiving goals and thinking out the steps to reach those goals. The final component, expert information, focused on the caregiver recognizing when to seek assistance from professionals.

The first visit took place 72 hours after admission and lasted approximately one hour. The QLI tool was administered. During this visit, the project director encouraged the informal caregiver to have a new approach to problem solving and finding time for social interaction with others (e.g., meetings, hobbies, shopping). This visit also encouraged the caregivers to have a positive attitude about the new role of an informal caregiver and building a relationship between their personal life and caring for someone else. The second visit took place on day 16 after admission and lasted approximately 30 minutes. This visit encouraged the informal caregiver to develop goals that were realistic and be creative in finding interventions that could enable them to reach the goals that were developed. The participants were also asked to keep a diary of their goals and interventions. The final visit took place on day 30 after admission and lasted approximately 30 minutes. During this visit, the capstone project director and the participants were able to review the diary developed by the participant. The capstone project director encouraged the caregiver to reach out for professional assistance when unable to safely manage or maintain the care of the hospice patient. The caregiver was encouraged to inform hospice staff of any difficulties experienced and was assured that a connection with an external resource would be arranged.
At the conclusion of the four weeks, groups one and two were re-administered the QLI tool. The tool evaluated the perception of overall quality of life, health, social, psychological, and family domains reported by the participants. The average values for these subscales for each group and category are displayed in Table 3.

Table 3

Summary of Subscale Scores

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre/Post</th>
<th>Overall</th>
<th>Health</th>
<th>Social</th>
<th>Psych</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>Pre</td>
<td>20.80</td>
<td>20.91</td>
<td>20.79</td>
<td>20.90</td>
<td>20.93</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>23.49</td>
<td>23.81</td>
<td>21.77</td>
<td>24.86</td>
<td>23.32</td>
</tr>
<tr>
<td></td>
<td>Difference</td>
<td>2.69</td>
<td>2.90</td>
<td>0.98</td>
<td>3.96</td>
<td>2.39</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>0.0275</td>
<td>0.0264</td>
<td>0.2632</td>
<td>0.0056</td>
<td>0.0576</td>
</tr>
<tr>
<td>Group 2</td>
<td>Pre</td>
<td>20.82</td>
<td>20.90</td>
<td>20.71</td>
<td>20.99</td>
<td>20.94</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>24.66</td>
<td>25.64</td>
<td>22.76</td>
<td>25.56</td>
<td>23.66</td>
</tr>
<tr>
<td></td>
<td>Difference</td>
<td>3.84</td>
<td>4.74</td>
<td>2.05</td>
<td>4.57</td>
<td>2.72</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>0.0002</td>
<td>&lt;0.0001</td>
<td>0.0610</td>
<td>0.0007</td>
<td>0.0077</td>
</tr>
</tbody>
</table>

The QLI tool measures quality of life regarding satisfaction and importance related to domains of life such as health and functioning, socioeconomic, psychological/spiritual, and family. The tool consisted of two separate sections, and each section contained 33 questions. These questions are scored using a six-point Likert scale with a total score ranging from 0–30, with the higher scores indicating a higher quality of life. Table 3 displays the pre and post averages related to the administration of the QLI tool. The table also displays the difference in averages along with the p-values. Group one pre-average scores ranged from 20.80–20.93 related to all five domains. Post-average scores ranged from 21.77–24.86. Group two pre-average scores ranged from 20.71–20.99. Post-average scores ranged from 22.76–25.64. As observed in Table 3, the post
averages were larger than the pre averages in each of the five categories in both groups one and two. In each case, the differences between pre and post averages of group two were numerically larger than those observed in group one. Statistically, group two displayed significant differences in each domain’s pre- and post-average scores, except for the social domain category displaying a p-value of 0.0610 (see the respective p-values in Table 3). This value is greater than the value of 0.05 showing little significance. The overall quality of life, health, and psychological domains were significant in the difference noted between pre and post averages. The p-values of these domains were less than the value of 0.05 showing less chance of statistical error. The social and family domains showed no significance between the pre and post averages. The averages of 0.98 related to the social domain and 2.39 related to the family domain showed very little change between the initial administration of the tool and post administration in group one. Group two also showed very little change with an average of 2.05 in the social domain and 2.72 in the family domain. The responses on the re-administering of the QLI tool improved numerically for most of the categories; however, the question pertaining to the effect of the intervention treatment in group two as compared to the group one remains.

Overall Scores

When comparing the group subscale scores of the difference between pre- and post-administration results, the analysis indicated that the sample size was not sufficiently large enough to imply that the intervention treatment implemented in group two significantly improved the overall results of the evaluation as compared to group one. A
comparison of the groups was performed using an independent \( t \)-test of the differences.

Table 4 provides the results of the comparison.

Table 4

*Test Results for Comparing Groups*

<table>
<thead>
<tr>
<th>Treatment-Control</th>
<th>Overall</th>
<th>Health</th>
<th>Social</th>
<th>Psych</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difference</td>
<td>1.1460</td>
<td>1.8400</td>
<td>1.0700</td>
<td>0.6110</td>
<td>0.3210</td>
</tr>
</tbody>
</table>

| \( p \)-value      | 0.2145  | 0.1097 | 0.2916 | 0.3534| 0.4228 |

As can be seen from Table 4, the \( p \)-values are larger than the significance level of 0.05. There can be the conclusion of the changes observed between pre- and post-subscales scores were independent of group one and group two. The \( p \)-values comparing the two groups’ average subscale scores ranged from 0.1097 to 0.4228, which indicates that differences in subscale score averages between group one and group two could not be established.
CHAPTER V
DISCUSSION

The capstone project evaluated the perceptions of informal caregivers after a 30-day period of caring for a hospice patient. The project also evaluated whether a difference in the perception of an informal caregiver can be observed through the implementation of an intervention during a 30-day period of time. The theoretical framework used for this capstone project was Watson’s Theory of Human Caring. This theory provided the groundwork for the project by injecting the caritas into the foundation of the project. The ability for the informal caregiver to recognize the importance of caring for one’s self is as important as caring for the hospice patient. In doing so, the informal caregiver is better able to recognize the necessities required to maintain a positive quality of life.

The capstone project included 20 participants acting in the role of informal caregivers for hospice patients. The 20 participants were randomly assigned to two groups. Group one in the capstone project served as the control group and was given 3 visits that allowed members of this group to express their feelings, fears, and relationships to the hospice patient, but was not introduced to an intervention. Group two was also given three visits to express feelings, fears, and relationships to the hospice patient, but was also introduced to the COPE intervention. The participants in group one and group two showed an increase in all subscales, but group two showed a significantly larger difference in pre and post scoring of the subscales. However, the sample size was not large enough to determine if the difference in scoring was primarily due to the introduction of the COPE intervention to group two.
The COPE intervention utilized in this capstone project introduced the participants with the opportunity to become more involved in the caregiver process and become empowered with caring for themselves as well as the hospice patient. The creativity component was implemented in this capstone project by encouraging the informal caregiver to have a new approach to problem solving when caring for the hospice patient and finding time for the caregivers themselves in regard to social interaction with others (e.g., meetings, hobbies, shopping). The optimism component geared caregivers to being positive about the role of an informal caregiver and building a relationship between their personal life and caring for someone else. The planning component encouraged the informal caregiver to develop goals that were realistic and find interventions that could enable him or her to reach the goals developed. Finally, the expert component encouraged the caregiver to reach out for professional assistance when unable to safely manage or maintain the care of the hospice patient. Expert consultation was also encouraged when the informal caregiver needed time away to care for personal concerns such as shopping, appointments, social meetings, and hobbies.

Limitations

This capstone project was limited to a small convenience sample of informal caregivers at one hospice agency in central Mississippi. Due to the number of patients enrolled in the hospice program during the implementation, the project denoted the small sample size utilized. The insufficiency of staff created difficulty with expanding the geographical area for evaluation to include rural informal caregiver participants in this project. The lack of diversity in the project participants limited the evaluation of quality of life in other races and nationalities.
Implications

Bahrami and Farzi (2014) found that care is provided by informal caregivers for a lengthy amount of time, but they do not receive adequate preparation, information, and/or support in relation to maintaining quality from life from health providers. Interventions such as supportive interventions include information and psychological support in the form of counseling in face-to-face encounters or telephone discussions (Bahrami & Farzi, 2014). Research further shows that “preservation of caregivers’ quality of life is a benefit to not only the caregiver, but also the patient by fulfillment of their needs” (Bahrami & Farzi, 2014, p. 2).

Implications for Nursing Practice

The results of the evaluation conducted by the APRN provided more knowledge of the importance in evaluating informal caregiver quality of life. The ability to assist individuals with developing and implementing new structure and organization is pertinent to the maintenance and preservation of healthcare. By increasing knowledge to the nursing community and improving clinical outcomes, the goal of preventing a physical, psychological, and emotional decline in informal caregivers is possible. Participants in this capstone project verbalized the need for support. Comments such as “Finally, someone is thinking about the caregiver” and “I need help with connecting with a caregiver-support group” encourage and support the need for this capstone project.

Implications for Research

Evidenced-based practice is the tool that guides the clinical practice of today. Implementing evidence-based practice into the clinical sector assists in creating an environment that has a supportive background for healthcare. Literary research provides a
foundation for healthcare providers to serve as a benchmark to determine what works in the clinical area. The need to continue to generate research will also provide help to other providers and disciplines in the future. In order to utilize this knowledge with future evidence-based research, the need for a larger sample size, diversity in sample size, and an expansion in geographical regions must be met. The cost analysis for the implementation of this capstone project into clinical practice was estimated at approximately $7,200.00 per year. The estimated costs consisted of the salary required for staff, resources for tool printing, and time needed to conduct visits and the intervention.

**Implications for Education**

Bahrami and Farzi (2014) found that despite changes in the quality of life after an intervention, supportive and educational programs based on interventions have shown a promotion of quality of life. This capstone project provides a means of education for the hospice community as well as other diagnoses that require the need for informal caregivers. The ability to identify components that are valuable to quality of life of this population is very crucial to the care and management of the patient. In the hospice community, caregivers provide the majority of the care. The opportunity to understand the trials and difficulties that the informal caregivers experience will allow healthcare providers to strategize, develop, and implement interventions that will assist in maintaining and increasing a positive quality of life, and a healthy outcome. The implementation of the COPE intervention with this population allows healthcare providers to know the benefits of the intervention and other possible pathways to assist the informal caregivers. The intervention can also serve a positive agent for nursing
education in the undergraduate level by teaching students the importance of caring for patients and their families. In doing this, holistic care is being preserved.

Benefits

An overview of the evaluation process of the capstone project showed that the results were beneficial to providing leverage in closing the gap between the lack of knowledge with quality of life in informal caregivers and also the development of interventions that can assist with the quality of life of informal caregivers. The APRN conducting the capstone project was better able to appreciate the time provided from caregivers. This capstone project is also beneficial because it allowed knowledge to be obtained from informal caregivers with different time spans in the role.

Challenges of the Project

The challenge posed with conducting this capstone project was the lack of interviewers to conduct the study. One interviewer was utilized to conduct the interviews and administer the QoL tool to the 20 participants at the time that the informal caregiver was available. The ability to administer and conduct the interviews was possible, but difficult. The interviewer was also charged with the task of encouraging the informal caregivers to develop ways that were realistic to their personal situation.
# APPENDIX A
EVALUATING THE PERCEPTIONS OF QUALITY OF LIFE IN INFORMAL CAREGIVERS CARING FOR HOSPICE PATIENTS

<table>
<thead>
<tr>
<th>Authors-Date</th>
<th>Study Type</th>
<th>Level of Study</th>
<th>Sample</th>
<th>Data Collection</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demiris et al. (2010)</td>
<td>Quantitative</td>
<td>1</td>
<td>29 caregivers of hospice patients</td>
<td>Interviews</td>
<td>Report higher quality of life and lower anxiety post-intervention</td>
</tr>
<tr>
<td>Demiris et al. (2009)</td>
<td>Qualitative</td>
<td>6</td>
<td>Hospice caregivers</td>
<td>Review of data</td>
<td>Interventions addressed to hospice caregivers</td>
</tr>
<tr>
<td>Empeno et al. (2011)</td>
<td>Quantitative</td>
<td>3</td>
<td>123 hospice caregivers</td>
<td>Surveys</td>
<td>Decreased amount of respite care utilized after referral intervention</td>
</tr>
<tr>
<td>Garlo et al. (2010)</td>
<td>Qualitative</td>
<td>4</td>
<td>Caregiver of 179 terminally ill patients</td>
<td>Interviews</td>
<td>Burden was a measure of adapting to caregiver role</td>
</tr>
<tr>
<td>Lim &amp; Zebrack (2004)</td>
<td>Qualitative</td>
<td>5</td>
<td>Caregivers of family with chronic illnesses</td>
<td>Literature Review 19 articles</td>
<td>Increased need for longitudinal and comprehensive study</td>
</tr>
<tr>
<td>Luxardo, Brage, &amp; Alvarado (2012)</td>
<td>Qualitative</td>
<td>3</td>
<td>Caregivers of hospice patients with cancer</td>
<td>Interviews</td>
<td>Pros and cons of intervention with caregivers in the home setting</td>
</tr>
<tr>
<td>Wilder, Oliver, Demiris, &amp; Washington (2008)</td>
<td>Quantitative</td>
<td>3</td>
<td>76 informal caregivers</td>
<td>Questionnaires</td>
<td>Increased need for caregiver intervention for quality of life</td>
</tr>
<tr>
<td>Whittenberg-Lyles et al.</td>
<td>Qualitative</td>
<td>1</td>
<td>Hospice</td>
<td>Audiotapes</td>
<td>Specific emphasis on need for</td>
</tr>
<tr>
<td>Authors-Date</td>
<td>Study Type</td>
<td>Level of Study</td>
<td>Sample</td>
<td>Data Collection</td>
<td>Key Findings</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
<td>----------------</td>
<td>--------</td>
<td>-----------------</td>
<td>--------------</td>
</tr>
<tr>
<td>(2011)</td>
<td></td>
<td></td>
<td>caregivers</td>
<td>Face-to-face encounters</td>
<td>caregiver education to increase quality of life</td>
</tr>
</tbody>
</table>
## APPENDIX B

### MEETING THE DOCTOR OF NURSING PRACTICE (DNP) ESSENTIALS

<table>
<thead>
<tr>
<th>DNP ESSENTIALS</th>
<th>DNP ESSENTIAL OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Essential I - Scientific Underpinning for practice</td>
<td>Utilized evidence-based literature to implement and evaluate a new approach for informal caregiver quality of life intervention</td>
</tr>
<tr>
<td>Essential II - Organizational and System Leadership for Quality Improvement and Systems Thinking</td>
<td>Implemented an intervention for informal caregivers of hospice patients to increase problems solving skills and positive outcomes of quality of life</td>
</tr>
<tr>
<td>Essential III - Clinical Scholarship and Analytical Methods for Evidence-Based Practice</td>
<td>Reviewed evidence-based guidelines to implement and evaluate evidence-based intervention</td>
</tr>
<tr>
<td>Essential IV - Information Systems/Technology and Patient Care Technology for the Improvement and Transformation Health Care</td>
<td>Reviewed evidence-based literature related to informal caregiver quality of life and educated staff on interventions to increase quality of life in informal caregivers of hospice patients</td>
</tr>
<tr>
<td>Essential V - Health Care Policy for Advocacy in Health Care</td>
<td>Initiated leadership role in educating hospice staff of interventions to promote positive quality of life perceptions in informal caregivers</td>
</tr>
<tr>
<td>Essential VI - Interprofessional Collaboration for Improving Patient and Population Health Outcomes</td>
<td>Collaborated with other interprofessional disciplines to promote and generate positive outcomes for informal caregivers and hospice patients</td>
</tr>
<tr>
<td>Essential VII - Clinical Prevention and Population Health for Improving the Nation’s Health</td>
<td>Implemented intervention that will assist in reducing informal caregiver burden and increasing quality of life by empowering informal caregivers to manage psychosocial, physical, and emotional components of health</td>
</tr>
<tr>
<td>Essential VIII - Advanced Nursing Practice</td>
<td>Provided support and guidance to hospice staff and informal caregivers to increase educational knowledge of interventions and methods to be utilized in maintain quality of life while in the role of an informal caregiver and provider</td>
</tr>
</tbody>
</table>

Note: American Association of College of Nursing, 2006
## APPENDIX C

### QUALITY OF LIFE INDEX

**Ferrans and Powers**  
**QUALITY OF LIFE INDEX®**  
**GENERIC VERSION - III**

**PART I.** For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>HOW SATISFIED ARE YOU WITH:</th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. Your health care?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. The amount of pain you have?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. The amount of energy you have for everyday activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. Your ability to take care of yourself without help?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. The amount of control you have over your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. Your chances of living as long as you would like?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8. Your family’s health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>9. Your children?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>10. Your family’s happiness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>11. Your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>12. Your spouse, lover, or partner?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>13. Your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>14. The emotional support you get from your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>15. The emotional support you get from people other than your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

(Please Go To Next Page)  
© Copyright 1984 & 1998 Carol Estwing Ferrans and Marjorie J. Powers
### HOW SATISFIED ARE YOU WITH:

<table>
<thead>
<tr>
<th></th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Your ability to take care of family responsibilities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>17. How useful you are to others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>18. The amount of worries in your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>19. Your neighborhood?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>20. Your home, apartment, or place where you live?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>21. Your job (if employed)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>22. Not having a job (if unemployed, retired, or disabled)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>23. Your education?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>24. How well you can take care of your financial needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>25. The things you do for fun?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26. Your chances for a happy future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>27. Your peace of mind?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>28. Your faith in God?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>29. Your achievement of personal goals?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>30. Your happiness in general?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>31. Your life in general?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>32. Your personal appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>33. Yourself in general?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

(Please Go To Next Page)

© Copyright 1984 & 1998 Carol Estwing Ferrans and Marjorie J. Powers
**PART 2.** For each of the following, please choose the answer that best describes how *important* that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

**HOW IMPORTANT TO YOU IS:**

<table>
<thead>
<tr>
<th></th>
<th>Very Unimportant</th>
<th>Moderately Unimportant</th>
<th>Slightly Unimportant</th>
<th>Slightly Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. Your health care?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. Having no pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. Having enough energy for everyday activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. Taking care of yourself without help?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. Having control over your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. Living as long as you would like?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8. Your family's health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>9. Your children?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>10. Your family's happiness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>11. Your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>12. Your spouse, lover, or partner?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>13. Your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>14. The emotional support you get from your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>15. The emotional support you get from people other than your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

(Please Go To Next Page)

© Copyright 1984 & 1998 Carol Estwing Ferrans and Marjorie J. Powers
### HOW IMPORTANT TO YOU IS:

<table>
<thead>
<tr>
<th>Question</th>
<th>Very Unimportant</th>
<th>Moderately Unimportant</th>
<th>Slightly Unimportant</th>
<th>Slightly Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Taking care of family responsibilities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>17. Being useful to others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>18. Having no worries?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>19. Your neighborhood?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>20. Your home, apartment, or place where you live?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>21. Your job (if employed)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>22. Having a job (if unemployed, retired, or disabled)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>23. Your education?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>24. Being able to take care of your financial needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>25. Doing things for fun?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26. Having a happy future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>27. Peace of mind?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>28. Your faith in God?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>29. Achieving your personal goals?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>30. Your happiness in general?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>31. Being satisfied with life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>32. Your personal appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>33. Are you to yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

© Copyright 1984 & 1998 Carol Estwing Ferrans and Marjorie J. Powers
APPENDIX D

INSTITUTIONAL REVIEW BOARD APPROVAL

INSTITUTIONAL REVIEW BOARD
118 College Drive #5147 | Hattiesburg, MS 39406-0001
Phone: 601.266.5997 | Fax: 601.266.4377 | www.usm.edu/research/institutional.review.board

NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months.

Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: 14061802
PROJECT TITLE: Evaluating the Perceptions of Quality of Life in informal caregivers Caring for Hospice Patients
PROJECT TYPE: New Project
RESEARCHER(S): Rashandra Fisher Laws
COLLEGE/DIVISION: College of Nursing
DEPARTMENT: Systems Leadership and Health Outcomes
FUNDING AGENCY/SPONSOR: N/A
IRB COMMITTEE ACTION: Expedited Review Approval
PERIOD OF APPROVAL: 08/18/2014 to 08/17/2015

Lawrence A. Hosman, Ph.D.
Institutional Review Board
APPENDIX E
HOSPICE AGENCY APPROVAL LETTER

July 14, 2014

Rashandra Fisher Laws
4225 Old Port Gibson Road
Vicksburg, MS 39175

Dear Mrs. Laws,

It is our pleasure to accept your request to utilize this facility to conduct your Capstone Project. I feel that your chosen subject matter is highly relevant to the nature of our business. The findings of your project will be very valuable to the hospice community.

Should you have any questions or concerns, you may contact me at our office at 601-661-9752. I wish you much success in your endeavors.

Respectfully,

Joyce Blue, RN, BSN, MHS
CEO

2705 Clay Street, Vicksburg, MS 39183
Phone 601-661-9752 * Toll-Free 866-661-9752 * Fax 601-661-6021
APPENDIX F

PERMISSION TO USE QUALITY OF LIFE INDEX

The University of Southern Mississippi Mail - Permission to use Quality of Life Index Instrument - Page 1 of 2

EAGLE APPS

Permission to use Quality of Life Index Instrument

Ferrans, Carol <cferrans@uic.edu>
To: Rashandra Fisher <rashandra.fisher@eagles.usm.edu>

Mon, Jun 9, 2014 at 12:46 PM

Dear Ms. Laws,

Thank you for your email. I am pleased to grant you permission to use the Quality of Life Index for your project described below. There is no charge for this permission. Copies of the instrument, scoring, and other information is posted on our website at www.uic.edu/orgs/qol. I've also attached answers to commonly asked questions, which others have found helpful.

I wish you every success with your project and doctoral program.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Professor and Associate Dean for Research
Co-Director, UIC Center of Excellence in Eliminating Health Disparities
University of Illinois at Chicago
College of Nursing (M/C 802)
845 S. Damen Avenue (Room 606)
Chicago, IL 60612
Phone 312.996.8445
Fax 312.996.4979

From: Rashandra Fisher [mailto:rashandra.fisher@eagles.usm.edu]
Sent: Sunday, June 08, 2014 10:32 PM
To: Ferrans, Carol
Subject: Permission to use Quality of Life Index Instrument

Commonly asked questions.doc
31K

https://mail.google.com/mail/u/0/?ui=2&ik=378389c3bf&view=pt&q=from:cferrans%40uic... 7/28/2014
APPENDIX G

DEMOGRAPHIC FORM

Please circle the appropriate letter.

1. Age:
   A. 18-27
   B. 28-37
   C. 38-47
   D. 48-57
   E. 58 or above

2. Gender:
   A. Male
   B. Female

3. Race:
   A. American Indian/Alaskan Native
   B. Asian/Pacific Islander
   C. African American/Non-Hispanic
   D. Caucasian/Non-Hispanic
   E. Hispanic
   F. Other/Specify _________________

4. Years of experience in caregiver role
   A. 6 months
   B. 1-5 years
   C. 5-10 years
   D. 10-15 years

5. Relationship to hospice patient:
   A. Spouse/Significant Other
   B. Child
   C. Sibling
   D. Friend
   E. Other
REFERENCES


Oncology Nursing Forum, 17(3), 15–19.


