Curriculum Vitae
Kimberly van Vulpen
ksvanvulpen@salisbury.edu

EDUCATION

PhD **University of Maryland, School of Social Work**
Doctor of Philosophy
Dissertation: *End-of-Life Care in U.S. Nursing Homes: Resident and Facility Factors that Predict Presence and Use of Services*
Dissertation Chairs: Donna Harrington, PhD & Banghwa Lee Casado, PhD
To be conferred May 2013

MSW **University of Maryland, School of Social Work**
Health Specialization
May 2013

BASW **Salisbury University, Social Work Department**
May 1993

EXPERIENCE IN HIGHER EDUCATION

2006 –current **Salisbury University, Social Work Department- Salisbury, MD**
Dual Degree Coordinator/Instructor (2012-current)
Satellite Field Coordinator (2009-2012)
Assistant Field Coordinator (2006-2009)

Masters level courses taught:
- Social Work Research I
- Social Work Research II Client-Centered Evaluation
- Social Work Practice Skills Lab
- Field Instruction and Seminar (Foundation & Concentration)

Bachelors level courses taught:
- Social Work Research I
- Social Work Research II Client-Centered Evaluation
- Social Work Interviewing Skills and Techniques
- Human Behavior in the Social Environment I
- Social Work with Older Persons
- Field Instruction and Seminar
- Independent Study

Invited lectures:
- Social Work in Health Care
- Psychology of Death & Dying

Student Academic Advising:

BASW (2007-current)
Dual Degree Advising (2012-current)
MSW (2009-Spring 2012)

PROFESSIONAL WORK EXPERIENCE

1994-2006 **Coastal Hospice- Salisbury, MD**
Duties: Served as Clinical Director, Counseling Coordinator and Clinical Social Worker providing counseling services for terminally ill patients and their families. Provided supervision for social work staff, pastoral care, music therapy, and bereavement staff.

1995-1998 **Counseling Associates-Salisbury, MD**
Duties: Provided private counseling services to individuals and families. Utilized therapeutic interventions in working with adults and children.

1993-1995 **Peninsula Regional Medical Center-Salisbury, MD**
Provided social work and discharge planning services for inpatient care including community resource referrals, support groups, and patient advocacy.

RESEARCH EXPERIENCE

Research Interests: End-of-life care, Gerontology, Social Work Education, On-Line/Hybrid Learning, Compassion Fatigue

2010 **Project Title:** *Assessing for the Needs and Preference for Culturally and Linguistically Appropriate Caregiver Intervention in the Korean American Community*
PI: Banghwa Lee Casado, PhD, MSW
Role: Research team member.

2009 **Susan G. Koman for the Cure, Maryland**
Koman Maryland Focus Group
Role: Worked with Debbie Gioia, PhD in conducting focus groups for breast cancer survivors, providers, and community members.

PUBLICATIONS-REFEREED

Casado, B. L., **van Vulpen, K. S**., & Davis, S. L. (2010). Unmet needs for home and community-based services among frail older Americans and their caregivers. *Journal of Health and Aging*, *23* (3), 529-553.

PUBLICATIONS-INVITED ARTICLES

Svoboda, D. V., Jones, A. L., **van Vulpen, K**., & Harrington, D. (2012). Programmed instruction. In: J. A. C. Hattie & E. M. Anderman (Eds.), *The international handbook of student achievement.* New York, NY: Routledge Publishers.

Sacco, P., & **van Vulpen, K.** (2011). End of Life Care and Addictions: A family systems approach. [Book Review] *Journal of Social Work Practice with the Addictions, 11* (1), 87-88.

van Vulpen, K.S. (2008) Helping your child when a loved one dies. *Delmarva Youth Magazine,* 26.

PRESENTATIONS-REFEREED

Venable, V. & **van Vulpen, K.,** (2012, January). Making bricks without straw: An example of a Web-based experiential learning experience for students. Proposal accepted for presentation at the 3rd Annual Salisbury University Teaching & Learning Conference, Salisbury, MD.

van Vulpen, K., & Casado, B. (2010, November). Unmet needs for home and community-based services among frail older Americans and their caregivers. Poster accepted for presentation at the 2010 Gerontological Society of America Conference, New Orleans, LA

Russo, M., & **van Vulpen, K.S**. (2009, April). Co-morbid addiction at end-of-life: A theoretical approach. The Johns Hopkins Bloomberg School of Public Health: Third Annual Conference for the Dissemination of Student Research on Addictions, Infectious Disease, and Public Health. Baltimore, MD.

van Vulpen, K.S., & Capen, A. (2006, November). Compassion fatigue. Workshop presented at the Hospice Network of Maryland's Annual Conference, Baltimore, MD

PRESENTATIONS-INVITED

van Vulpen, K.S. (2011, October). End-of-life care in U.S. nursing homes: Resident and facility factors that predict presence and use of services. Grantmakers in Aging Annual Conference, McLean, VA.

PRESENTATIONS-CONTINUING EDUCATION WORKSHOPS

van Vulpen, K.S. (2011, September). Psychosocial assessment of older adults. Eastern Shore AHEC: Colloquium on Older Adults, Easton, MD.

van Vulpen, K.S. (2011, September). Secondary Trauma. Workshop presented at the Wicomico County Board of Education Mentoring Program, Salisbury, MD.

van Vulpen, K.S. (2010, October). Psychosocial assessment of older adults: Skills session. Geriatrics and Gerontology Education and Research Program (GGEAR), Easton, MD.

van Vulpen, K.S. (2010, March). Field of aging: Current challenges and possibilities of the future. Keynote presented at the Aging in Worcester Conference, Ocean City, MD.

van Vulpen, K.S. (2007, November). Taking care of yourself while taking care of others. Workshop presented at the Eastern Shore Oncology Conference, Salisbury, MD.

van Vulpen, K.S. (2006, May). A panelist discussion of holistic care needs of the terminally ill. Workshop presented at the Lower Shore Mental Health Association's Annual Conference, Salisbury, MD.

van Vulpen, K.S. (2005, October). Emotional challenges of hospice patients and their families. Workshop presented at the Hospice Care: Emotional and Spiritual Needs conference, Salisbury, MD.

van Vulpen, K.S. (2004, November). Emotional pain in the terminally ill. Presentation at the Hospice Care and Spirituality conference sponsored by Salisbury University's Social Work Department and Coastal Hospice, Salisbury, MD.

INVITED LEGISLATIVE TESTIMONY

Maryland Senate- Education, Health, and Environmental Affairs Committee (March 11, 2008). Provided testimony supporting SB 848 regarding social work licensing continuing education requirements.

PROFESSIONAL MEMBERSHIPS & LICENSURE

1997-current	**Licensed Certified Social Worker-Clinical** Maryland Board of Social Work- Approved Social Work Clinical Supervisor . License #09580
2012-current	**Counsel of Social Work Education**
2009-current	**Gerontological Society of America**
2010-current	**The Association for Gerontology Education in Social Work**
2006-2009	**Mid-Atlantic Field Instructors Consortium**

SALISBURY UNIVERSITY SERVICE

2006-current **Department Committees**
Assessment Committee (2012-current)
Practice Content Committee (2006-current)
Field Content Committee (2006-2012)
Research Content Committee (2010-current)
Faculty Search Committee (2009)
Continuing Education Committee (2006-2010)

2006-current Represented department at University Open Houses

2011-2012 **New Student Reader Facilitator**

2010-2012 **Phi-Alpha Honor Society**- Helping with 2 student satellite sites. Ended Spring 2012

2007-2010 **Lower Shore Early Intervention Program**
Served on several search committees, provided consultation and clinical supervision.

COMMUNITY SERVICE

2006-current **Coastal Hospice's Palliative Care Advisory Board**
2007-current **Health South Home Health Professional Advisory Board**
2007-2009 **Wicomico Mentoring Project Advisory Board**
2006-2010 **Wicomico County Mentor**
2002-2006 **Hospice Foundation of America's Annual Living with Grief Teleconference Site Coordinator**
1996-1998 **Shore-Up's Project Renaissance Program Advisory Board**
1994 **Wicomico County American Cancer Society Service Representative**

AWARDS

2011 **Grantmakers in Aging Fellowship**

2009-current **Graduate PLUS Award**
University of Maryland Baltimore, Graduate School

2009 **Academic Excellence for Higher Education Award**
University System of Maryland Hagerstown
Social Work Field Education

Abstract

Title of Dissertation: End-of-Life Care in U.S. Nursing Homes: Resident and Facility Factors that Predict Presence and Use of Services

Kimberly van Vulpen, Doctor of Philosophy, 2013

Dissertation Directed by: Donna Harrington, PhD, Professor and PhD Program Director

Banghwa Lee Casado, PhD, Associate Professor

University of Maryland School of Social Work

Research has demonstrated the benefits of nursing homes offering specialized end-of-life services for their residents. These benefits include improved symptom management and emotional support. Prior research has identified, however, that referrals and use of these specialized end-of-life services for nursing home residents is still quite minimal, leaving significant unmet needs for these individuals in their last days of life. The purpose of this study was to explore the resident and organizational factors that may serve as catalysts and barriers to providing quality end-of-life care in U.S. nursing homes.

This study is a cross-sectional design utilizing secondary data from the 2004 National Nursing Home Survey. A logistic regression analysis and multi-level regression analyses were performed to explore predictors for the presence and use of end-of-life services in these facilities.

There were several facility variables that predicted the presence of end-of-life services in the facilities. Facilities that were for-profit, larger in size, and participated in end-of-life planning initiatives were more likely to offer end-of-life services. Facility

geographic location was also a predictor with those nursing homes located in the West being less likely to offer end-of-life services. Factors specific to the nursing home resident that predicted utilization of end-of-life services included older age, decreased bed mobility, reports of pain, indicators of emotional distress (depression, sadness, or anxiety), and specific diagnoses (neoplasms and respiratory diseases). Having an advanced directive in place also increased the resident's odds of utilizing EOL services. Residents with primary payment sources of Medicare and Medicaid were found to be less likely to utilize services.

With one-fifth of the deaths in the United States occurring in nursing home facilities, it is essential to ensure that quality end-of-life programs are in place to address the needs of the residents. Understanding the potential barriers for both the nursing home in implementing programs and the resident in accessing the services is essential in developing strategies for policies and procedures for quality end-of-life care.

End-of-Life Care in U.S. Nursing Homes:
Resident and Facility Factors that Predict Presence and Use of Services

by
Kimberly Searcey van Vulpen

Dissertation submitted to the faculty of the Graduate School
of the University of Maryland, Baltimore in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2013

Acknowledgments

This study was generously supported by a dissertation funding grant through the University of Maryland, School of Social Work.

This project required the use of both the public and restricted data from the National Nursing Home Survey. I would like to thank the staff at the Research Data Center in Hyattsville, Maryland for their guidance and hospitality as I was working at their facility. The findings and conclusions in this paper are those of the author and do not necessarily represent the views of the Research Data Center, the National Center for Health Statistics, or the Centers for Disease Control and Prevention.

I would like to express my sincere appreciation to all the wonderful professors and staff of the PhD program at University of Maryland, School of Social Work. I am especially grateful to the members of my dissertation committee, Drs. Karen Hopkins, Paul Sacco, and Mercedes Bern-Klug from the University of Iowa. A very special thank you is going out to my dissertation co-chairs, Drs. Donna Harrington and Banghwa Lee Casado. I can't begin to express how much I have appreciated your guidance during my time in the PhD program. Your patience, support, and mentorship have meant so much.

I want to acknowledge my peers in the doctoral program. I feel blessed to now call you my friends. You understood when things got tough, and kept me laughing along the way. I would also like to thank my colleagues in the Social Work Department at Salisbury University. I could not work with better people, and appreciate all your support and guidance. To my lifelong friends who cheered me on, provided a listening ear, and always had kind words of support, I appreciate each of you more than you know.

I want to thank my entire family who pulled together in many ways to help me reach this goal. I am blessed with the most supportive parents, Nancy and Jim Searcey, who have always been willing to help in any way they can. Thanks, Mom and Dad, for your love and sacrifices that have helped me to be where I am today.

To my wonderful children, Alex and Amanda, I am so proud of each of you. Having you two as my children is by far my proudest accomplishment. Thanks for making me smile every day, and keeping my feet grounded to what is truly important. To my wonderful husband, Gaby - you earned this degree too through your never ending support, love, and tons of patience. I could not have done this without you. I love you more than you know.

Lastly, I would also like to recognize my grandparents, Jake and Kathleen Searcey, who both passed away while I was pursuing this degree. No words can express my gratitude to both of you for your never ending love and support. Thanks for all the life lessons you taught me. Most of all, thanks for showing me how to have faith.

Table of Contents

List of Tables

List of Figures

Chapter One: Introduction and Conceptual Framework

Studies on end-of-life care (EOL) have suggested that the needs of dying nursing home residents are not being met (Temkin-Greener, Zheng, Norton, Quill, Ladwig, & Veazie, 2009). These unmet needs often lead to physical (e.g., pain and dyspnea) and emotional (e.g., depression, anxiety, and loneliness) discomfort in the last days of life (Reynolds, Henderson, Schulman, & Hanson, 2002). The seriousness of this is even more profound when we consider that over 1000 people die in U. S. nursing homes each day (Munn et al., 2007). Over 20% of deaths in the U.S. occur in these facilities (Rice, Coleman, Fish, Levy, & Kutner, 2004; Zerzan, Stearns, & Hanson, 2000) and by 2040 this percentage is predicted to double to over 40% (Ersek, Grant, & Kraybill, 2005). The purpose of this study was to utilize a large national data set to explore the resident and organizational factors that may influence access and utilization of EOL services in U.S. nursing homes.

Defining End-of-life care in Nursing Homes

In exploring EOL care in nursing homes, the terms palliative care and hospice care are often used interchangeably in the literature. There are, however, distinct differences in the two terms that may impact the approach to care. The Center to Advance Palliative Care (2011) defines palliation as the practice of reducing suffering in individuals with progressed illness, often in the later stages of their life. This form of practice takes an interdisciplinary team approach that focuses on the physical, emotional, and mental aspects of illness for individuals and their families (Bern-Klug, 2010; Phillips, Davidson, Jackson, Krisjanson, Daly, & Curran, 2006). Although hospice is a form of palliative care, the difference exists in the stage of disease progression. Hospice services are generally offered to individuals with a terminal diagnosis of six months or less (National Hospice and Palliative Care Organization [NHPCO], 2010a). As in palliative care, hospice is provided by an interdisciplinary team focusing on comfort care, not cure. For the purpose of this study, end-of-life care in nursing homes was explored based on the definition of palliative care. End-of-life care was not limited to only hospice services, but also included the facility palliative care practices.

Facilities can offer these end-of-life care practices to their residents in different ways. Some may offer end-of-life services in the form of outside contracts where hospice agencies in the community provide the additional end-of-life care to the residents in the facility. Other nursing homes may have their own specially trained staff or have separate specialty units focusing specifically on providing hospice, palliative, or end-of-life services. The approach to care may be different at the individual facilities, but generally the services offered have the same goals including pain and symptom management, and counseling support to reduce physical, emotional, mental, and spiritual suffering of their residents in their last stages of life (Ersek & Wilson, 2003).

History of Hospice and Palliative Care

In exploring the history of hospice and palliative care, their paths start from the same origin. The concept of hospice was first introduced in the early 1960’s by Dame Cicely Saunders when she started educating the medical community about the benefits of a holistic approach to caring for the terminally ill. Founding the first modern hospice in 1967, St. Christopher’s Hospice in London, this model of specialized care provided a framework for a movement in the United States to care for the dying (National Hospice and Palliative Care Organization [NHPCO], 2010b).

In 1963, Dame Cicely Saunders introduced the concept of hospice care to the United States while serving as a guest lecturer at Yale University. This lecture created significant interest among U.S. health care professionals. In addition, it sparked awareness about the possible unmet needs of those dying in the United States (Conner, 2007). Dame Saunders was integral in educating the hospice pioneers in the U.S., even returning and serving as a guest faculty member at Duke University in 1965 (NHPCO, 2010b).

Many national meetings were held in the United States that resulted in the formation of the National Hospice Organization in 1978 and the establishment of the first standards of care for hospice programs in 1979 (Conner, 2007). In addition, the U.S. Department of Health, Education and Welfare created a task force in 1978 that informed the government of the need to provide federal support to hospice care. In 1983, Congress initiated the Medicare Hospice Benefit that provided the insurance coverage for medical and psychosocial support for the terminally ill. In 1986, this benefit was made permanent and then extended to those individuals residing in nursing home facilities (NHPCO, 2010b). With the increased awareness about this holistic type of care and providing palliative comfort to individuals not only in end stage diseases, the National Hospice Organization changed its name to the National Hospice and Palliative Care Organization in 1999 (Conner, 2007). Since that time, there continues to be much attention on policy, research, and education on hospice and palliative care in the U.S. (NHPCO, 2010b).

There are many benefits of providing hospice and palliative care services for residents at the end-of-life. In a review of prior research and literature, Stevenson and Bramson (2009) reported that prior studies have shown that the benefits of hospice care include better symptom management, less use of artificial feeding, and reduced need for hospitalizations for nursing home residents at the end of life. However, the National Hospice and Palliative Care Organization (2005, as cited by Casarett, Karlawish, Morales, Crowley, Mirsh, & Asch, 2005) reported that only 1 in 4 dying nursing home residents actually get referred to hospice care. In addition, for those facilities that do not have formal hospice contracts, research is limited and little is still known about the benefits of their approaches to EOL care practices (Miller, Lima, Gozola, & Mor, 2010). Facility, policy, and financial characteristics have been identified as barriers that limit these formal EOL care services within the facilities. These barriers include lack of knowledge that palliative care services are even available, limited staffing to address the specialized treatment goals, and reduction in reimbursement rates when residents elect their hospice benefit (Meier, Limm, & Carlson, 2010).

With a significant amount of U.S. deaths occurring in nursing homes, and prior research identifying gaps in quality and presence of care, research is needed to further understand the practices and utilization of EOL services in nursing homes. This chapter presents information on the significance of EOL care especially related to access and use of services in these facilities. It also presents the research aims, and provides a description of the conceptual framework, Andersen and Newman's (1973) behavioral model for health services utilization, that guides this study. Finally, this chapter offers a discussion of the relevance of EOL care in nursing homes to the social work profession.

Problem Statement and Research Questions

Over 1.7 million older adults currently live in nursing homes in the U.S. (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006; Hanson, Reynolds, Henderson, &

Pickard, 2005). For the deaths occurring in the United States of individuals 85 years old and over, more than half will die in these facilities (Bern-Klug, 2009). Because many older adults are now dying in nursing homes, addressing EOL care practices at these facilities is of utmost importance (Wowchuk, McClement, & Bond, 2007).

Although, there are limited studies on the process of EOL care practices in nursing homes (Temkin-Greener et al., 2009), studies that have been conducted have found that receiving hospice care has significant benefits to the dying residents including improved care for pain management (Baer & Hansen, 2000; Miller, Mor, Wu, Gozalo, & Lapane, 2002) and emotional and spiritual support (Baer & Hansen, 2000). In addition, studies have shown that residents receiving hospice care required fewer acute care admissions than those residents not receiving the specialized services (Casarett et al., 2005; Gozalo & Miller, 2007) and family members of residents also report an increased satisfaction with care during the last week of life for those receiving the specialized services (Casarett et al., 2005).

The use of hospice care in U.S. nursing homes has seen an increase in recent years. Miller et al. (2010) conducted a longitudinal study from 1999 to 2006 and found that the rate of outside hospices actually providing care in nursing homes increased by 50%, and that the use of hospice services for those dying residents increased from 14% to 33%. Other studies have shown that the use of hospice/EOL services actually ranged below 10% to 29% (Bercovitz, Decker, Jones, & Remsberg, 2008; Johnson, Teno, Bourbonniere, & Mor, 2005). Although prior research has supported the benefits of providing hospice services to nursing home residents at the end-of-life, these studies identify that there is still a significant group of dying residents who are not receiving care. Further research is needed to better understand what factors may serve as catalysts and barriers to not only utilization of hospice services, but also other EOL practices dedicated to pain and symptom control for individuals with end-stage or terminal conditions. This study addressed this need and aimed to understand factors affecting utilization of EOL services for residents in nursing homes at the end of life. Specifically, this study explored the following two questions:

Research Question 1: What facility and administrative factors predict the presence of EOL services in nursing homes in the U.S.?

Research Question 2: What factors related to the nursing home organization and resident characteristics predict the utilization of EOL care services in nursing homes in the United States?

Understanding these factors may help nursing homes and individual practitioners identify ways to implement services and interventions that work toward improving access, utilization, and quality of EOL care in these facilities. Awareness of possible barriers and catalysts is essential in working to change policy, educate consumers, and implement new services to meet needs.

Theoretical Framework

Andersen and Newman's (1973) behavioral model for health services utilization served as the guiding model for this study. This framework was a revision of the Andersen's model for health service utilization, which was first developed in 1968 to help understand how and why individuals utilize formal health care services (Andersen, 1995). The goal of Andersen's initial model was to understand individual and societal determinants for utilization of health services and assist in the development of policies that would ensure equal access to those services. In addition, it was designed to not only provide an explanation of why individuals access services, but also predict utilization (Andersen, 1995).

The initial behavioral model developed in 1968 proposed that an individual's utilization of health services may be directly related to factors that could encourage or hinder use (Andersen, 1995). These factors were categorized into three domains: predisposing, enabling, and need. Predisposing factors (e.g., age, gender, marital status, race, health beliefs) were identified as those demographic and personal characteristics that influenced or biased the use of health care services. Enabling factors were considered as the resource components (e.g., insurance, environment, family resources) that could impact the ability to access health services. Finally, need factors were those conditions related to the diagnosis or health care issues (perceived or evaluated) that were ultimately the reasons why health services would be utilized (Kwak, Haley, & Chiriboga, 2008).

Andersen and Newman (1973) proposed that in addition to the individual determinants of the original model, there may be societal factors that also influence health services use. Factors such as medical technology, social norms for health care treatment, and health care system characteristics were added to the model. Andersen and Newman (1973) clarified that societal norms are reflected not only in formal legislation, but also in the values and beliefs of society. These beliefs include issues related to an individual's right to medical care, and the social concern for access and quality of care for all. Andersen and Newman (1973) also identified that advances in medical technology also influence health service use due to not only improving access, but also service effectiveness resulting in a reduction of mortality rates, improved public health, and better curative treatments.

The other component added to the model in the revisions by Andersen and Newman (1973) included the health care system. They identified that the organization and resource components of the health care system together "shape the provision of health care services to the individual" (p. 100). Factors that are identified under the resource component include the volume of care (e.g. staff to resident ratios) and distribution of services (e.g. presence of services throughout the country). The factors identified under the organizational component include access (how individuals enter the system and barriers to receipt of care) and structure (characteristics of the system).

The Andersen and Newman model (1973) has been utilized in research with the elderly including exploring health services utilization (Chappel & Blandford, 1987), social support and usage of specialized transportation (Nasvadi & Wister, 2006), use of flu vaccinations for community elderly (Chiatti et al., 2011), and health literacy (Wister, Malloy-Weir, Rootman, & Desjardins, 2010). Andersen's behavioral model of health service utilization has also been utilized to explore the individual factors (predisposing, enabling, and need) for the utilization of hospice (Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Kwak et al., 2008) and nursing home care (Chatterjee, Mehta, Sherer, & Aparasu, 2010; Wallace, Levy-Storms, Kington, & Andersen, 1998).

Prior research that has utilized the behavioral model for health service utilization, however, did not include the health services system component proposed by the 1973 revision. Andersen (1995) acknowledged the role that organizational factors have on possibly predicting and explaining health care use. He reflected that the original model did not always accommodate a thorough exploration of these characteristics. However, he indicated that there would be benefits to understanding the differences between the organizations and how they provide their services. Based on Andersen's (1995) suggestion that adding these factors would not "damage" the model, detailed characteristics of the facility, medical directors, nursing home administrators, and EOL services were examined as the health services system domain of the current study.

Figure 1 illustrates a modified Andersen and Newman behavioral model that is used for the conceptual framework of this study. Prior research and literature on EOL care in nursing homes guided the selection of the specific resident and facility factors in the model for this study. For the health services system, Rice et al. (2004) identified that factors specific to the nursing home (e.g., size of nursing home, for-profit status, and administrative factors) may have an impact on the presence of EOL services in the facility. For this study, characteristics about the facility, medical director, and nursing home administrator were explored to determine their impact on use and presence of EOL services in the facilities. The predisposing factors that were explored under the individual determinants included resident demographics (Buchanan, Choi, Wang, & Ju, 2004). Because prior studies have identified that they have a possible relationship on use of EOL services, advanced directives (Bercovitz et al., 2008) and resident's source of payment (Lu & Johantgen, 2010) were explored as possible enabling factors. The need characteristics included resident's diagnosis, and additional health care needs (levels of pain, behavior, mobility, and resident indicators of distressed mood). Prior research has shown that certain diagnoses and health care needs may impact whether EOL services were accessed (Lu & Johantgen, 2010).

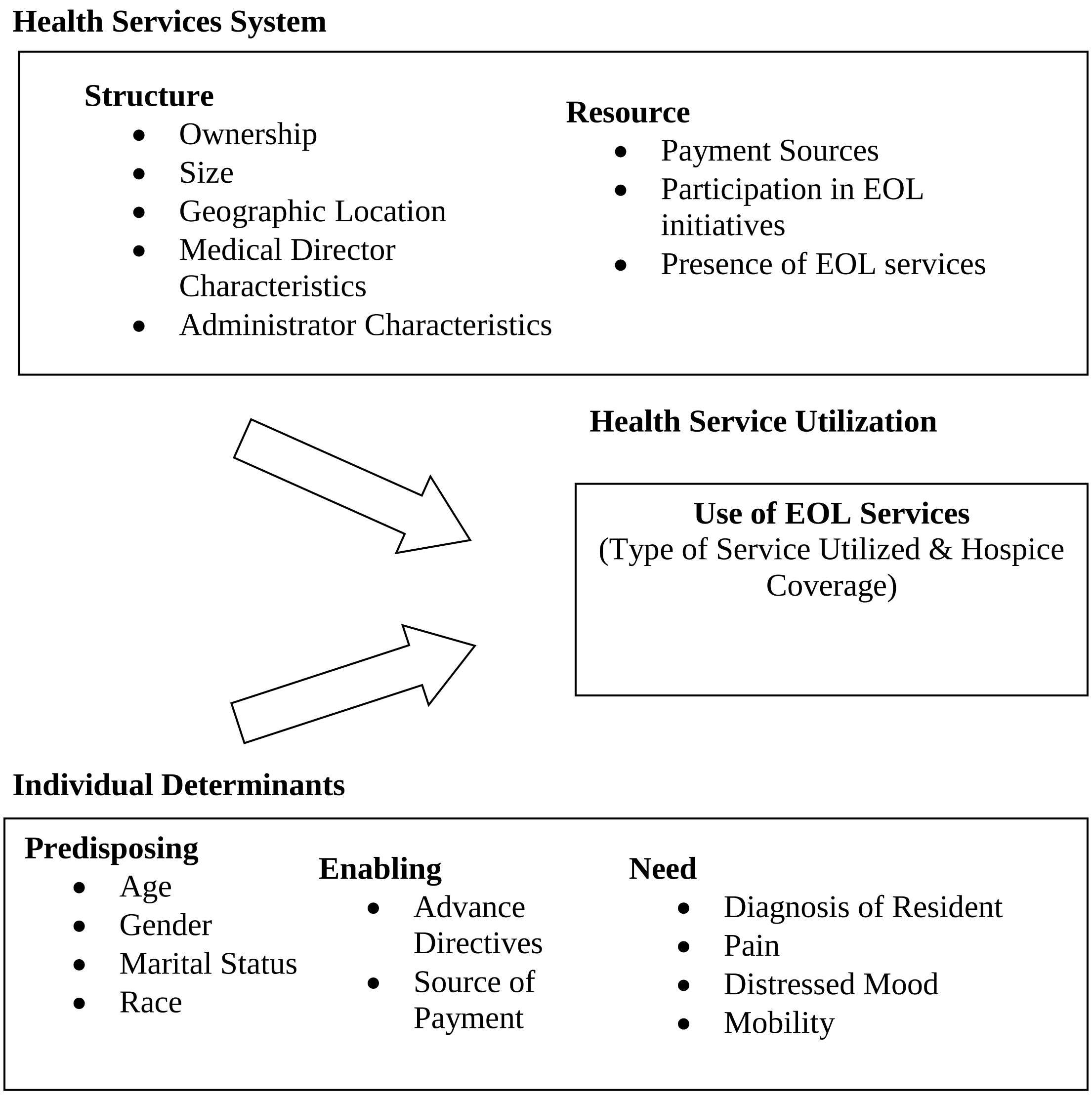

Figure 1: Conceptual Framework of the Study

It should be noted that the societal influences, such as technology and values identified in the Andersen and Newman theoretical framework (1973) are not included in the conceptual framework of this study because the secondary data used in the study do not provide variables that could measure such societal influences. Nevertheless, the current study represents the basic principles established by Andersen and Newman regarding the impact of these influences on health services utilization. This study acknowledges that further research is needed to identify the barriers and antecedents to quality EOL care for the growing population of those dying in U.S. nursing homes. It explores the health services system's independent impact on the presence of EOL services in nursing home facilities. In addition, it not only explored the individual determinants' role in use of services, but also the impact that the health services system has on utilization of services (see figure 1).

Relevance to Social Work

It is estimated that there are 50,000 social workers practicing in long-term care (U.S. Department of Health and Human Services [USDHHS], 2006). This number is expected to drastically increase as our aging population grows. By the year 2050, the number of social workers needed to work in long-term care is expected to be 110,000 (USDHHS, 2006). By the nature of their training and education, social workers can be a valuable resource in addressing the needs of the residents in nursing homes, especially in the area of EOL care. Based on their skills and training, social workers can fill many roles in the palliative care process in these facilities (Bern-Klug, 2010). Social workers have the skills to assess not only the physical needs, but also the psychosocial needs of the residents. This assessment also acknowledges the environmental factors that may help or hinder comfort care. Social workers can be an active part of a care team to help anticipate problems, and develop effective interventions in addressing needs. They have the training to educate staff and family members on the emotional, spiritual, and social needs of the individual. Social workers are also advocates for the residents' rights, and many times this is not only within the care team, but also at the facility and/or policy levels (Bern-Klug, 2010).

The National Association of Social Workers' Code of Ethics (NASW, 2008) charges social workers to advocate for vulnerable populations and provide service to address their needs. For those dying in nursing homes, the social work role as advocate is critical in making sure that these individuals' medical and psychosocial needs are being met. Social workers do so by drawing on their skills and knowledge to access services and promote change in facilities. Not only are social workers mandated to respect the uniqueness of each individual, they are also guided by practice principles that value the rights of those individuals to make their own choices (NASW, 2008).

The challenges that social workers have faced in EOL care in nursing homes are often due to the limited understanding of their professional role in these facilities (Munn & Adorno, 2008). Generally social workers will work with residents upon admission to conduct the intake assessment and complete the needed admission documentation. However, the barriers for further work with these residents include high caseloads and limited referrals from the medical staff for social work services with the residents (Munn & Adorno, 2008). Adding to this problem of role clarity is that little research has been conducted on the impact that social work services have on the nursing home interdisciplinary team. There is still a great deal that can be learned about how social workers' knowledge and beliefs impact end-of-life care practices in skilled nursing facilities. The importance of conducting further research on social work EOL care services in nursing homes is supported by a report through the Institute for the Advancement of Social Work Research (2005) to the Profession and Blue Print for Action. The report concluded that more multidisciplinary research needs to be conducted in these facilities to address the needs of the residents, to explore practices for EOL improvements, and to begin to understand the barriers and challenges present in providing quality of life care.

Chapter Two: Review of Literature

Nursing homes face many barriers in providing quality end-of-life care. These barriers often lead to unmet needs of their residents including pain and poor symptom management in their last days of life (Hanson et al., 2005). Barriers that have been identified exist on many different levels including at the resident, staff, administrative/structural, and policy levels. In order to understand current EOL care practices in nursing homes and those factors that may influence utilization of care, a review of literature was conducted using Web of Science, Academic Search Premier, PsychINFO, and SOCIndex. Key words for the search included nursing home, palliative care, end-of-life, and hospice. Current texts on palliative care and social work with the aging were also utilized along with web-based information from the national organizations representing hospice and palliative care services. Andersen and Newman's (1973) theoretical framework is used to guide and organize the literature review for this study. First, current EOL care practices in nursing homes including benefits and barriers are examined. To address the enabling, predisposing, need, and health system domains that may impact EOL care utilization, literature specific to the resident and organization are also explored.

Current EOL Care in Nursing Homes

Nursing homes can choose to address the end-of-life needs of their residents in different ways. Ersek and Wilson (2003) identified three primary approaches of end-of-life care in nursing home facilities. These approaches can include the use of formal hospice contracts, the utilization of specialized palliative care clinicians for consultations, or specific specialized palliative care units within the facilities. Miller and Han (2008) conducted a study focusing on EOL services in nursing homes. Using data from the 2004 National Nursing Home Survey, they reported that 78% of nursing homes in the United States have formal contracts with outside hospice programs. Nineteen percent of nursing homes reported having special programs and trained staff for hospice, 17% for palliative/end-of-life, and 27% for either hospice or palliative/end-of-life care. Only 9% of nursing homes, however, reported having special programs and trained staff for both hospice and palliative/end-of-life.

Benefits of EOL Care in Nursing Homes. Nursing homes are complex systems offering diverse services with the goal to meet the various needs of their residents. Specifically for those residents who require end-of-life care, it is important to acknowledge that palliative care in nursing homes is very different than the type of palliative care that is often provided in hospitals and in-home hospice settings. Hanson, Henderson, and Menon (2002) discussed these differences as "unique characteristics" of nursing home care. The fact that many of the individuals who are dying are long-term residents at the facility makes it such that the staff has the ability to develop a closer relationship with the resident, providing a more personalized approach to care. The nursing home facility is not only the place where the individual is receiving the needed medical care, but also where they reside. However, nursing homes are often challenged with high staff turnover and limited staff training that may impact early detection and referral for end-of-life services.

The benefits of comfort care for residents receiving EOL services in nursing homes have been supported in prior research. Miller et al. (2002) conducted a retrospective cohort study comparing pain management for hospice and non-hospice nursing home residents at EOL. The findings of their study suggested that residents enrolled in hospice care received more comprehensive pain management than those residents not enrolled in hospice. Those residents receiving hospice were more likely to receive treatment that closely followed the guidelines for chronic pain management in long-term care established by the American Medical Directors Association. These guidelines included more frequent pain assessment and appropriate analgesic treatment.

Using the 2004 National Nursing Home Survey, Miller and Han (2008) found that nursing homes that offered special programs with trained staff for hospice or palliative/EOL care were also more likely to offer special programs and trained staff for other care needs such as pain, behavior, and mental health. Miller and Han (2008) identified that these other programs may in fact precede EOL care programs due to the diagnoses related to cognitive impairment and the facility's goal to meet unmet needs. In an intervention study conducted by Hanson, Reynolds, Henderson, and Pickard (2005), training leadership teams in nursing homes on palliative care resulted in improved quality EOL practices including increased referrals to hospice care, increased assessment of pain, and more EOL discussions with residents. Research has also shown that hospice care has benefits of fewer EOL hospitalizations (Gozalo & Miller, 2007) and improved practices for ensuring the residents' comfort including less use of intravenous injections for medications, physical restraints, and tube feedings (Miller, Gozalo, & Mor, 2000).

Barriers of EOL Services in Nursing Homes. Studies on providing care in nursing homes have identified several barriers that prevent quality EOL care in the facilities. Nursing homes are often challenged with high staff turnover rates limiting continuity of care (Hanson, Henderson, & Menon, 2002). Another barrier in access to services is when nursing home staff identifies having limited knowledge and abilities to address the needs of their residents specifically in EOL care (Hill, Ginsburg, Citko, & Cadogan, 2005). In addition, nurses and health care assistants report the need for established formal support from the facility and their supervisors to address the emotional challenges of providing care to individuals who are dying (McGuigan, McElhinney, McTeggart, & McClure, 2009) .

In a study conducted by Brazil et al. (2006), three main types of barriers for palliative care practices were identified. One type of barrier was related to facility/staff capabilities, including barriers related to staffing, skills, lack of knowledge, lack of appropriate medications, and lack of communication. The second category included education and support, such as issues of limited EOL care protocols in the facilities, lack of palliative care consultation, lack of EOL practice guidelines, and lack of general information on palliative care. The last category was related to external resources including inadequate fee structures for reimbursement, lack of equipment to provide EOL care, and challenges related to the intense time commitment of addressing the specialized needs of the dying. Other studies had similar findings including barriers related to staff education needs and presence of needed resources (Brazil & Vohra, 2005; Greiner, Buhr, Phelps, & Ward, 2003).

Predisposing Factors

Andersen and Newman (1973) identified that predisposing factors of the individual may influence EOL care service utilization. The framework acknowledges that some individuals may have a higher likelihood of utilizing services due to factors related to their personal demographics. These demographics are often connected with how an individual maintains their health, their health risks, and whether they utilize services (Andersen and Newman, 1973).

Demographics. Studies conducted on the differences between residents receiving hospice/palliative care in nursing homes and those not receiving the specialized services have found that there may be demographic characteristics that predict use of EOL services. Using the 2000 Minimum Data Set for Nursing Home Resident Assessment and Care Screening, Buchanan et al. (2004) analyzed 18,211 nursing home admissions in the United States. They found that those residents receiving hospice care were more likely to be older, female, and widowed. In a longitudinal study utilizing the Minimum Data Set from 1999 to 2006, Miller et al. (2010) found that the demographic characteristics of nursing home residents receiving hospice care had not changed significantly through the years. Similar to previous studies, most of their hospice residents were female (67%), white (90%), and over 85 years of age (over 50%). These demographic findings were also supported in a study conducted by Cassarett, Hirshman, and Henry (2001). In comparing individuals who were receiving hospice care in the nursing home versus those residing in the community, findings suggested that those residents who were receiving hospice services in nursing homes were more likely to be female and not married compared to those living in the community.

Research on the use of hospice services has identified possible racial disparities. Using data sources including Medicare files and the Minimum Data Set, Lepore, Miller, and Gozalo (2011) explored the use of hospice care in 2006 among urban Black and White nursing home decedents. They found that Blacks were less likely to utilize hospice services than Whites. In a prior study, Buchanan et al. (2004) utilized the Minimum Data

Set for 2000 and also found that White residents were more likely to access hospice compared to Black, Hispanic, Asian, and American Indian residents. Kwak et al. (2008) explored racial differences among nursing home residents in Florida. Using the Florida Medicaid Long-Term Care Analysis file for 2000, 2001, and 2002, significant racial differences were also identified with White residents being 20% more likely to utilize hospice services compared to Black residents.

Enabling Factors

Although some individuals may be predisposed to utilizing health services, they also must have the means to be able to access those services. These factors can include resources or conditions that "permit a family to act on a value or satisfy a need regarding health service use" (Andersen & Newman, 1973, p. 109).

Advanced Directives. Communication about EOL wishes and advanced care planning have been identified as integral in improving quality of EOL care in long-term care (Tilly & Folk, 2008). The discussion of advanced directives often opens the door regarding conversations toward EOL care wishes. However, these discussions do not always happen in a timely manner and often leave the EOL wishes of nursing home residents unmet (Chan & Pang, 2010). Research has found that barriers to addressing these wishes in nursing homes included the reluctance to discuss difficult topics, not understanding the importance of communicating wishes, wanting to avoid the topic due to fear, and personal beliefs that do not support planning (Black et al., 2009).

Studies that have been conducted on EOL care services in nursing homes have identified a direct relationship between residents who have advanced directives and their use of services. A study utilizing the 2004 National Nursing Home Survey found that residents who were utilizing EOL care in the facility were more likely to have at least one form of advanced directive (Bercovitz et al., 2008). These findings were also supported by previous studies including one that utilized the National Minimum Data Set (Buchanan et al., 2004) and one that used the Minimum Data Set specifically for the State of Missouri (Parker-Oliver, Porock, Zweig, Ranitz, & Petroski, 2003). Both found that those individuals who were utilizing hospice services were more likely to have completed advanced directives including durable power attorney, do-not-resuscitate (DNR) orders, and/or living wills compared to other terminal residents. In a study conducted by Lu and Johantgen (2010) that explored factors associated with treatment restriction orders and hospice use for residents in nursing homes, findings showed that DNR and do-not-hospitalize orders were associated with increased likelihood of those residents utilizing hospice care in the facilities. They found that the existence of a do-not-hospitalize order was most impactful in increasing the odds for prompting EOL service utilization. Their findings also identified that Whites were more likely to initiate DNR and do-not-hospitalize orders compared to other races suggesting the need for increased cultural competency in addressing EOL wishes.

Source of Payment. In 2009, 83% of hospice care in the U.S. was funded through the Medicare Hospice Benefit (NHPCO, 2010c). Under this benefit, Medicare Part A recipients have the ability to select palliative care services over continued curative treatment. This selection activates the Medicare Hospice Benefit, which transitions the resident from pursuing curative treatment for their illness to identifying a hospice organization to manage their symptoms and comfort. Other payment sources for hospice care include private insurance or managed care (9%), Medicaid Hospice Benefit (5%), charity care (2%), self-pay (1%), and other payment sources (1%) (NHPCO, 2010c). The election of Medicare Hospice Benefit for nursing home residents has seen an increase in recent years. For those individuals who activated their Medicare Hospice Benefit in 2005, 28% were residing in nursing home facilities (Department of Health and Human Services, 2007).

Lu and Johantgen (2010) found that payment sources impacted hospice use. In their study on nursing homes in Maryland, they found that those residents who had Medicaid and other types of insurances or were self-paid were more likely to utilize hospice services compared to those who were Medicare only. Past research and literature have suggested that the Medicare reimbursement that currently exists in policy may actually serve as a barrier to utilization of hospice services in the nursing homes (Miller, Teno, & Mor, 2010) because by electing the Medicare Hospice benefit, residents waive their right to the standard Medicare Part A benefits for care related to their terminal illness. In addition, the Medicare Hospice Benefit does not pay for the room and board costs at the facility often creating financial challenges for the resident (Huskamp, Buntin, Wang, & Newhouse, 2001; Lu & Johantgen, 2010). These challenges often result in the resident either choosing not to activate their Medicare Hospice Benefit or require them to pay for their room and board costs through private-pay or Medicaid (Miller, Teno, & Mor, 2004).

Zerzan, Stearns, and Hanson (2000) found that the emphasis of palliative care versus curative care can often create organizational and administrative barriers in the facility. These barriers include reimbursement incentives that seem to be more directed to curative interventions and practices. This often creates an incentive for the facilities to maintain their residents at the curative level of practice due to the higher reimbursement rates. Thus, the need for higher reimbursement may ultimately serve as a disincentive for nursing homes to refer their dying residents for hospice services.

Need Factors

The presence of illness or the perception of health need is generally the most significant factor that identifies whether an individual will access health services. This often includes the perception of need, a clinical diagnosis, and evaluated severity of the problem (Andersen & Newman, 1973).

Studies have found that health care status related to primary diagnosis was a significant predictor for use of hospice services in nursing homes. Kwak et al. (2008) found that residents with cancer and dementia were significantly more likely to utilize hospice services compared to those residents with heart disease or other diagnoses. Buchanan et al. (2004) reported that hospice nursing home residents were more likely to have cancer, report more significant pain, and exhibit more cognitive impairments than other residents diagnosed with end-stage diseases. Parker-Oliver et al. (2003) identified similar characteristics related to cancer diagnosis and presence of pain for those residents accessing hospice care in the facilities. In addition to cancer diagnosis and pain, Lu and Johantgen (2010) found that additional health needs including shortness of breath, functional dependence, and cognitive limitations increased the likelihood of accessing hospice care in nursing homes.

In addition to specific diagnoses, the ability to adequately identify a resident's prognosis has been found to also impact referral and use of services. Levy, Morris, and Kramer (2008) conducted a study on the end-of-life outcomes for those residents who were identified at high risk of death. They found that utilizing a tool to help appropriately identify these individuals, EOL care outcomes improved including more referrals for palliative care services and reduction of hospital deaths. Welch, Miller, Martin, and Nanda (2008) also found that when nursing home staff had the ability to identify terminal decline in the facilities, residents were more likely to be referred for hospice services.

Health Care System

Studies that have explored the presence of EOL care in nursing homes have identified similar organizational and administrative characteristics among facilities.

Size, Location, and Profit Status. Studies that have explored palliative care in nursing homes have found that many of the facilities that offer specialized EOL care services share similar organizational characteristics. A study conducted on nursing homes in the State of Pennsylvania found that nursing homes that were larger in size or located in urban areas were more likely to offer palliative care services (Hodgson, Landsberg, Lehning, & Kleban, 2006). A study merging the 2004 National Nursing Home Survey with the 2004 Area Resource File and the Nursing Home Online Survey, Certification, and Reporting data found that facilities that were larger in size, located in the southern part of the United States, and were private, not-for-profit were more likely to offer special programs and trained staff for hospice or palliative/EOL care (Miller & Han, 2008). Miller and Han (2008) identified that these findings supported prior research showing hospice use being much higher in the South. In addition, they discussed how profit status may impact use due to reimbursement and profitability challenges. They stated that nursing homes that were not-for profit may be more open to “altruistic behavior to meet the needs of their residents" (Miller & Han, 2008, p. 875). Lu and Johangten (2010) found that residents who were in non-profit facilities were more likely to receive hospice services than those residents in facilities that were identified as for-profit.

Administrator Characteristics. Administrative characteristics were also found to influence the existence and use of EOL care practices in facilities. Studies have shown that opinions of nursing home administrators toward the benefits of hospice care have an impact on whether EOL services are utilized in their facilities (Hanson, Sengupta, & Slubicki, 2005; Rice et al., 2004). Those administrators who reported their beliefs that residents can receive the same quality of care in the facility without the additional services of hospices were more likely to not consider utilizing additional EOL care practices at their organization. Similarly, use of hospice services in the facilities was found to be directly linked with administrators who held the attitude that hospice was necessary to improve care. In addition, Miller and Han (2008) found that those facilities that had administrators who had completed additional educational requirements and examinations to receive certification from the American College of Health Care Administrators had an odds of 1.6 of offering special programs and trained staff for hospice/EOL services. This finding indicates that ongoing education and certifications for administrators may impact use of services. Rice et al. (2004) found that administrators who had longer tenure were actually less likely to consider EOL care models at their facility.

Physician/Medical Director Characteristics. Although nursing home physicians do not spend as much direct time with the resident as the care staff in the facilities, their role in EOL care implementation including diagnosis, prognosis, and referral for services is very important (Hanson & Henderson, 2000). Often times, the physicians and/or medical directors set the tone for the care that the resident will receive (Keay, Alexander, McNally, Crusse, & Eger, 2003). Those facilities that had physicians on staff or had medical directors that worked more than 3 days a month at the facility were also found to be more likely to offer specialized programs and trained staff (Miller and Han, 2008). The benefits of additional training for nursing home physicians in terminal care was supported in an intervention study focusing on physicians and medical directors in facilities located in the State of Maryland (Keay et al., 2003). Results from this study showed that those facilities where physicians had completed the advanced education training had statistically higher outcomes for EOL comfort care including symptom management, improved hygiene practices, and bereavement support.

Summary

Although the presence of EOL care services has increased in U.S. nursing homes, current literature has suggested that the needs of dying residents in these facilities are still going unmet. As evidence points to various benefits of EOL care for dying persons, additional research is needed to explore the possible factors that influence service presence, access, and utilization of EOL services. Although nursing homes may choose different ways to address the EOL needs for their residents, there is still limited research on the effectiveness of the different approaches to care. However, the benefits that have been identified in the limited research include improvements in symptom management, reduced hospitalizations, interventions that focus on comfort care, and improved discussion about EOL wishes. Research has shown that there are many factors that may serve as catalysts and barriers for palliative care service implementation and utilization. These barriers exist at the policy, organizational, and individual levels. Prior literature and research have demonstrated that there are several resident factors that have been identified as predicting use of EOL services. These included demographic characteristics, physical need, payment sources, and the existence of advanced directives. Organizational factors that have been identified include size of facility, location, and for-profit status. In addition, specific characteristics related to the nursing home administrator and physician/medical director have also been identified including attitudes toward EOL care services, educational training, and length of service.

Although prior studies have identified that there are characteristics about the nursing home residents and facilities that separately impact access and use of EOL services, no research has explored how the combination of residents and facility characteristics may affect EOL care utilization. Addressing this gap in research, this study examines residents and facility-related variables together in a multilevel model using a large national nursing home data set. Previously used in education and economic research, the multilevel analysis allows for the ability to assess individual factors within social contexts (Bickel, 2007). Because this study explores individuals who are residents within different nursing home facilities, the multilevel model allows for a stronger consideration of how differences based on the facility may impact individual characteristics for utilizing EOL services. This approach further supports Andersen and Newman's (1973) theoretical framework, which acknowledges that the health services system may impact health care utilization. The following chapter will provide a more thorough discussion of the method for this study along with a description of the individual and facility variables that were explored.

Chapter Three: Method

Research Design

This study is a secondary data analysis of the 2004 National Nursing Home Survey (NNHS). Factors associated with EOL services (presence and utilization) related to the nursing home resident and organizations are explored.

Data Source

The NNHS was first conducted in 1973 to provide descriptive information on nursing homes in the United States. Six surveys have been conducted since 1973; the most recently conducted survey was done in 2004. These surveys not only focused on the services that were provided in the facilities, but also characteristics of the staff and residents (Caffrey, 2010). This current study utilized the data from the facility and resident modules of the 2004 survey.

Part of data from the NNHS is available for public use on the Centers for Disease Control and Prevention (CDC) website (www.cdc.gov/nchs/nnhs/nnhs). This study utilized a portion of the public data, but also required the assistance of the National Center for Health Statistics (NCHS) Research Data Center (RDC) to access additional variables that are not available for public access. A proposal was submitted to the RDC to request that the individual facility, staffing, and resident datasets be linked. The RDC requires researchers who are requesting the additional information, including the integration of the data, to submit an application and research proposal to reduce the potential risk of any disclosure of information. Data collection for the National Nursing Home Survey was approved by the NCHS Research Ethics Review Board (ERB). Analysis of the de-identified data from the survey is exempt from the federal regulations for the protection of human research participants, and analysis of the restricted data through the NCHS Research Data Center was approved by the NCHS ERB.

Sample. The NNHS utilized a cross-sectional two-stage probability design for sampling selection. The sampling frame was collected from those facilities that held state nursing home licenses or nursing home certifications by the Centers for Medicare and Medicaid Services. Stratified sampling methods were utilized at the first stage to select the nursing home facilities based on bed size and metropolitan status. Within those strata, the facilities were further divided into subgroups based on type of ownership, certification, and geographic factors. Systematic sampling with probability around facility bed size was utilized for final sample selection, which consisted of 1,500 nursing homes from a sampling frame of 16,628 facilities (Bercovitz et al., 2008; National Center for Health Statistics, 2011). Of those 1,500 facilities invited to participate, 283 nursing homes refused to participate and 43 were found not to meet requirements of the study due to some facilities not providing nursing services, going out of business, or being a duplicate facility already included in the sample. This left a final sample of 1,174 participating facilities for a response rate of 81% (Bercovitz et al., 2008).

The second stage of the sampling process involved the selection of the residents within the facility. A random sample of 12 residents from each facility was selected by the NNHS interviewer utilizing a random sampling program on a computer-assisted personal interviewing (CAPI) system on the day that data were collected at the facility. The resident sampling frame at each facility consisted of all the current residents as of midnight the day before the interview. The study also included those residents who were hospitalized or absent, but were maintaining a bed hold at the facility. If the facility had fewer than 12 residents, all the residents in the facility were selected (Bercovitz et al., 2008; National Center for Health Statistics, 2011). At this second stage of resident selection 14,017 residents were selected for the sample. Of those residents, 502 declined to participate and 8 did not meet the requirements which included being on the active resident list prior to midnight the night before the survey was conducted. Therefore, a total of 13,507 residents participated in the study for a response rate of 78% (Bercovitz et al., 2008; National Center for Health Statistics, 2011).

Data Collection. A self-administered questionnaire via CAPI was used to gather facility and resident data. Data were collected during August 2004 through December 2004. The interviewer collected the facility data first. This helped to clarify whether the facility met inclusion criteria before residents in their facility were selected. Resident data were collected from designated personnel of the nursing home identified by the facility as knowledgeable of the resident and their care. The Minimum Data Set (MDS), which is a federal mandated assessment tool for Medicare and Medicaid certified nursing homes, was used along with the resident's medical chart to gather the information for the survey. Data were not collected directly from the residents.

Measures

Variables utilized in this study were selected utilizing prior literature and theory. The variables were defined based on the question text from the NNHS facility, resident, and staffing questionnaires (see Appendix A). Factors specific to the resident were explored through the domains (predisposing, enabling, need, and health behavior) and organizational factors were explored through the health system domain of the behavioral model for health service utilization (Andersen & Newman, 1973).

Predisposing Factors

1. *Resident Age*: Resident's age at time of interview (continuous variable). Acknowledging that use of EOL services and barriers experienced by pediatric patients is much different than the adult population (Knapp et al., 2008), this current study focused on nursing home residents who were ages 35 and above. Variables for the descriptive analyses and multi-level model were coded to select only resident cases that were ages 35 and above.

2. *Resident Gender*: Gender of resident (Male =0 or Female = 1)

3. *Resident Marital Status*: Marital status of resident (Married = 1 or Not married = 0)

4. *Resident Race*: For descriptive purposes, 6 variables (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, White, and Other Race) were categorically coded individually (Yes = 1 or No = 0)

5. *Hispanic or Latino Origin*: Resident was of Hispanic or Latino heritage. (Yes = 1 or No = 0)

Enabling Factors

1. *Resident Advanced Directives*: Identifying if the resident has any Advanced Directives (Yes or No). In addition, four individual variables (Living Wills, Do Not Resuscitate, Do Not Hospitalize, Medication and Feeding Instructions) were also provided to identify which advanced

directives the resident had in place. These variables were coded individually (Yes= 1or No = 0).

2. *Resident Source of Payment*: Source of Payment for the past month or billing period. Four variables (Medicare, Medicaid, Private Insurance, & Self-Pay) were coded individually (Yes =1 or No =0).

Need Factors

1. *Resident Diagnosis*: Resident current primary diagnosis using their first listed ICD-9 code (Neoplasms, Mental Disorders, Circulatory Diseases, Respiratory Diseases, Nervous System Diseases, Endocrine System Diseases, Musculoskeletal, & Other) were coded individually (Yes = 1 or No = 0).

2. *Resident Pain*: Evidence of pain documented in the resident's chart as measured by resident showing or expressing evidence of pain in the last 7 days (Yes = 1 or No = 0).

3. *Resident Indicators of Distressed Mood*: Mood status documented in the resident's chart as identifying whether the resident showed symptoms of depression, sadness, or anxiety were coded as ordinal variables (No mood indicators = 0, Indicators present easily altered = 1, or Indicators present not easily altered =2).

Health Services System-Structure

1. *Nursing Home Ownership*: Nursing home facility ownership categorically coded (For Profit = 1 or Not-for-profit/government & private = 0).

2. *Nursing Home Chain Affiliation*: Identifying whether the facility was part of a nursing home (Yes = 1 or No = 0).

3. *Bedsize of Facility*: Facility size established by the number of nursing home beds. This included the number of beds that were in use, had available staffing, and were available for residents. Size was categorically coded as an ordinal variable (50-99 beds =1, 100-199 beds = 2, 3-49 beds = 3, or 200 or more beds =0). Facilities with 200 or more beds served as the reference category in the logistic regression analysis.

4. *Geographic Region*: For the region of the U.S. in which the facility was located, four variables were categorically coded (Northeast = 0, Midwest = 1, South = 2, or West = 3). Facilities located in the West served as the reference category in the logistic regression analysis.

5. *Metropolitan Status*: For facility location, three variables were categorically coded for the descriptive analyses (Metropolitan = 1, Micropolitan=2, or Neither = 3).

6. *Any Facility Accreditation*: Identifying whether the facility is accredited by Joint Commission on Accreditation of Healthcare Organizations (JCAHO), Commission on Accreditation of Rehabilitation Facilities (CARF), and/or Continuum of Care Accreditation (CCAC) (Yes = 0, No =1).

7. *Medical Director holds Advanced Education in Geriatrics*: Identifying whether the Medical Director had an advanced education in geriatrics (Yes = 0 or No = 1).

8. *Medical Director Certified in Geriatrics*: Identifying whether the Medical Director was certified in Geriatrics (Yes = 1 or No = 2).

9. *Medical Director holds Advanced Education in Palliative/End-of-Life Care:* Medical director had an advanced education in palliative or EOL care (Yes = 0 or No = 1).

10. *Number of Days that the Medical Director works at the Facility*: Days per month that the Medical Director worked at the facility.

11. *Length of Time as a Medical Director*: Length of time (in months) that the medical director had served as a medical director at any nursing home or similar facility.

12. *Length of Time as Medical Director at Current Facility*: Length of time (in months) that the medical director had served as medical director at the current facility.

13. *Nursing Home Administrator's Most Advanced Degree*: The most advanced degree that the nursing home administrator held was coded as an ordinal variable (High School =1, Associate Degree =2, Bachelor Degree =3, Master's Degree or Higher = 4, or Other = 5). For the logistic regression analysis, the variable representing Other degree served as the reference.

14. *Nursing Home Administrator's Degree in Health Care Administration*: This variable was created using the initial variable of Nursing Home Administrator's Most Advanced Degree which from the original data set had categories for health care administration. These categories were combined to create the new variable measuring whether the administrator had a degree in health care administration (Yes = 1 or No = 2).

15. *Nursing Home Administrator's Certifications*: Nursing home administrator held certifications by the Certified Nursing Home Administrator (CNHA) American College of Health Care Administrators or the American Nurses Credentialing Center (ANCC) (Yes = 1 or No =0).

16. *Length of Time as Administrator*: Length of time (in months) that the nursing home administrator served as an administrator at any nursing home or similar facility.

17. *Length of Time as Administrator at Current Facility*: Length of time (in months) that the nursing home administrator served as the administrator at the current facility.

Human Services System-Resources

1. *Residents with Medicare*: Percentage of residents whose primary payment source for the nursing home was Medicare coded as an ordinal variable (0-9% = 0, 10-19% = 1, or 20% or more = 2). For the logistic regression analysis, the category representing 20% or more served as the reference.

2. *Residents with Medicaid*: Percentage of residents whose primary payment source for the nursing home was Medicaid was coded as an ordinal variable (0-19% = 4, 20-39% = 1, 40-59% = 2, 60-79% =3, or more than 80% =0). For the logistic regression, the category representing 80% or more served as the reference.

3. *Residents with other sources of payment*: Percentage of resident whose primary payment source for the nursing home was other than Medicare or Medicaid was coded as an ordinal variable (0-19% =0, 20-39% =1, or more than 40% =2). For the logistic regression, the category representing 40% or more served as the reference.

4. *Participation in End-of-Life Initiatives*: Facility's participation in End-of-Life Initiatives was operationalized by whether the facility offered Five Wishes (advanced directive program), Physician's Orders for Life Sustaining Treatment (standardized medical order form), or Last Acts programs. For descriptive purposes, these initiatives were coded as three individual variables (Yes = 1 or No = 0) and also combined as one variable (Yes = 1or No = 0).

5. *Presence of End-of-Life Services*: For descriptive purposes, the three variables (formal contract with an outside provider, physically distinct beds or units for hospice care, or special programs and trained staff for hospice or palliative services) were coded individually (Yes = 1 or No =0). These variables were also combined to measure as a single outcome

variable. This combined variable representing the presence of EOL services will be coded dichotomously (Yes = 1 or No = 0).

Health Services Utilization

1. *Receiving Services from Hospice/Palliative/EOL Programs*: Resident was receiving services from special programs for hospice/palliative/EOL care (Yes = 1 or No = 0).

2. *Medicare Hospice Coverage Initiated*: Resident had initiated their Medicare hospice coverage (Yes =1 or No = 0).

3. *On a Specialty Unit for Hospice Care*: Resident was assigned to a specialty unit in the facility for hospice care (Yes = 1 or No = 0). Residents who resided in facilities that did not offer a special care unit were not included in the analysis.

4. *Start of Palliative or Hospice Care*: Identifying when the resident started receiving palliative or hospice care and coded categorically (Before Admission to the Facility =1 or After Admission to the Facility = 2).

5. *Types of EOL/Palliative/Hospice Services*: Types of EOL services utilized in the past week (7 days). Seven categorical variables (Symptom help, Pain management, Ethical or legal counseling, Grief/bereavement counseling, Death preparation, Emotional support for family, and Pastoral/spiritual care) were coded individually (Yes = 1 or No = 0).

Data Analysis

This study focused on two research questions utilizing descriptive and multilevel analyses. In exploring the possible predictors for the outcome variables (presence of EOL services in the facility and EOL care service utilization by residents), two analyses were conducted. Descriptive statistics were also utilized to describe the sample of residents, facilities, and the types of EOL services being utilized. A proposal was submitted to the National Center for Health Statistics Research Data Center to access restricted data of the National Nursing Home Survey. Data analyses on the restricted data were conducted on site at the Research Data Center in Hyattsville, Maryland. Analyses using the public data set were conducted off-site. IBM SPSS Statistics 19 for Windows was used for the descriptive and logistic regression (Research Question 1) analyses. MPLUS version 6.11 for Windows was utilized for the multi-level model for Research Question 2. The NNHS is a complex survey sample and required that each of the analyses accommodate for the weighted variables. The stratification, weighting, and cluster variables of the data set were utilized in the complex survey component of IBM Statistics 19 (descriptive and logistic regression analyses) and Mplus (multilevel model analyses).

Preliminary Analyses and Data Cleaning. For the purpose of preparing the data, preliminary analyses including measures of central tendency (mean, median, and mode), frequencies, range, and standard deviation were conducted. Histograms and scatterplots were also constructed. The preliminary analyses were used to explore for any possible coding errors, outliers, or missing data. The facility and resident questionnaires were referenced along with the data and input directory to ensure appropriate coding.

Data cleaning including recoding for dichotomous, categorical, and missing variables was conducted. The preliminary analyses were utilized to ensure that the statistical assumptions were not violated risking bias in the estimates of the regression coefficients and/or the standard errors (Bickel, 2007; Cohen, Cohen, West, & Aiken, 2003). With prior research identifying that pediatric populations approach and utilize EOL care in different ways (Knapp et al., 2008); resident cases were selected for this study only if they were age 35 and above. Using biological, psychological, and social guidelines, selection criteria of the residents was established to allow the current study to focus on utilization of EOL services for individuals in middle or older adulthood (Zastro & Kirst-Ashman, 2013). Preliminary analysis from the National Nursing Home Survey 2004 (National Center for Health Statistics, 2011) estimated that there were approximately 10,236 residents ages 34 and below residing in U.S. nursing homes at the time of their study. From the actual sample, 88 cases were excluded from this analysis.

Descriptive Analyses. Descriptive analyses were conducted on the variables from the predisposing, enabling, need and outcome domains. These analyses were utilized to describe characteristics of the sample of residents and facilities participating in the study. In addition, chi square analyses were conducted to compare facilities with and without EOL services.

Research Question 1 Analysis: What facility and administrative factors predict the presence of EOL services in nursing homes in the U.S.? To explore the possible organizational factors that predict the presence of EOL care services within the facility, a three step logistic regression analysis was conducted on the nursing home variables. Facility variables that were entered in step 1 of the analysis included ownership, size, chain affiliation, percentages of insurance coverage of residents (Medicare, Medicaid, Other), geographic region, and participation in end-of-life initiatives. Medical director variables that were entered at step 2 included certification in geriatrics, advanced education in geriatrics, advanced education in palliative/end-of-life care, number of days that the medical director works at the facility, and length of time as medical director (overall time and time at current facility). Lastly, administrative variables that were entered at step 3 included administrators' most advanced degree, degree in health care administration, nursing home administrator's certification, and length of time served as a nursing home administrator (overall time and time at current facility).

Research Question 2 Analysis: What factors related to the nursing home organization and resident characteristics predict the utilization of EOL care services in nursing homes in the United States? To explore the organizational, administrative, and resident factors that predict the utilization of EOL care services, a multilevel regression analysis was conducted. Because the residents are grouped (i.e., nested) within the individual nursing homes, it is important to acknowledge that there may have been cross-level interactions between and within the facilities. Bickel (2007) suggests that the strength of a multilevel regression is that it allows for the analysis of the possible cross-level and contextual effects. An intraclass correlation coefficient (ICC) was calculated to assess this level of dependence among the observations. Although there is no specific numeric value established for when a multilevel regression analysis would not be needed, it has been suggested that even small ICC values can impact standard errors in a regular regression analysis (Bickel, 2007). Level 1 resident variables included resident factors (age, gender, marital status, advanced directives, race, Hispanic/Latino origin, source of payment, diagnosis, pain, resident indicators of distressed mood, and level of bed mobility). Several Level 2 facility variables (facility, medical director, & administrator) were selected for testing model fit. As suggested by Gelman and Hill (2007), these variables were tested for best model fit to determine the variables that will be included in the final analysis. In testing the model with more than one Level 2 variable, the model did not converge due to being too complex. This resulted in utilizing only one Level 2 variable, facility ownership, for the final model.

Human Subjects Protections

The study was reviewed by the University of Maryland Institutional Review Board (IRB) and given exempt status because there were no identified data. In addition, a research proposal and confidentiality requirements were submitted to the National Center for Health Statistics' Research Data Center for their approval to use restricted NNHS data. The Research Data Center has strict guidelines for researchers to ensure the confidentiality of the facilities, respondents, and residents. The appropriate steps were taken to meet the requirements for requesting use of the non-public data including the integration of the data from the facility, staff, and resident questionnaires. Several of the data analyses were conducted under the supervision of a Research Data Center analyst, all data were de-identified, and restricted data were not permitted to leave the center.

Chapter 4: Results

This chapter presents the demographic and descriptive characteristics of U.S nursing homes and their residents. It also provides descriptive information related to the types of EOL services being provided and their availability in the facilities. The analyses addressing Research Question 1 and Research Question 2 are also presented.

Demographic and Descriptive Analyses

The following presents the basic descriptive characteristics of the U.S. nursing homes in the study. It identifies not only the characteristics of the facility, but also provides descriptive information on the nursing home Medical Directors and administrators. Results of the chi-square analysis testing the relationship of specific facility characteristics on the presence of EOL services are presented. Lastly, demographic information on the residents residing in the facilities is discussed. For those residents that were utilizing EOL services, the specific types of EOL services are further identified.

Facility Characteristics. Table 1 presents the basic demographic information for the estimated 16,100 nursing homes in the United States. Almost two-thirds (61%) were identified as for-profit facilities, and over half (54%) were part of a nursing home chain. The largest percentage of facilities (42%) had 100 to 199 resident beds. Four-fifths of the facilities had 50-199 resident beds. The largest percent of facilities were located in the Midwest (33%) and Southern (34%) parts of the United States. Two-fifths (41%) of the facilities had 60% to 79% of its residents with Medicaid as their primary payment source, and one-fifth (21%) of the facilities had over 80% of residents with Medicaid as primary insurance.

One in six (17%) of the facilities reported participation in EOL planning programs that included directives such as Physicians' Orders for Life Sustaining Treatment (POLST), Five Wishes, or Last Acts. POLST held the highest percentage of participation at 13%. Less than 1 in 10 of the facilities participated in the Five Wishes program or Last Acts program (6% and 4 % respectively). Over three-fourths (78%) of the facilities had formal contracts with outside hospice providers, and less than one-fourth of the facilities had special programs and trained staff (SPTS) for hospice care (19%) and palliative services (17%). More than four out of five (83%) facilities reported the presence of EOL services which combined the variables including those facilities that held contracts with outside hospice providers, and/or SPTS for hospice or palliative services.

Table 1: Facility Characteristics (N=1174)

	Weighted Sample Estimates	%**	Unweighted Sample Count
Nursing Home Ownership			
For Profit	9,889	61.5	707
All others (private and government not-for-profit)	6,192	38.5	467
Chain Affiliation			
Yes	8,709	54.2	616
No	7,372	45.8	558
Bed size of Facility			
30-49 beds	2,242	13.9	174
50-99 beds	6,005	37.3	441
100-199 beds	6,840	42.5	485
200 or more	994	6.2	74
Geographic Region			
Northeast	2,805	17.4	171
Midwest	5,300	33.0	414
South	5,410	33.6	413
West	2,566	16	176
Metropolitan Status			
Metropolitan	10,893	67.7	663
Micropolitan	2,607	16.2	260
Neither	2,581	16.0	251

Table 1 Continued

Percent of Residents with Medicare as Primary *			
0-9%	8,418	52.6	636
10-19%	5,198	32.5	373
20% or more	2,383	14.9	157
Percent of Residents with Medicaid as Primary*			
0-19%	1,491	9.3	99
20-39%	1,215	7.6	81
40-59%	3,330	20.8	242
60-79%	6,531	40.8	484
80% or more	3,432	21.5	260
Percent of Residents with Other Sources of Payment as Primary*			
0-19%	7,996	50.1	590
20-39%	4,882	30.6	359
40% or more	3,084	19.3	214
Any Facility Accreditation *			
Yes	2,435	15.2	164
No	13,552	84.8	1004
Participation in End of Life Initiatives*(yes)	2,762	17.2	200
Five Wishes*(yes)	895	5.6	60
POLST*(yes)	2,130	13.3	155
Last Acts* (yes)	680	4.2	49
Formal Hospice Contract with Outside Provider*(yes)	12,553	78.1	900
SPTS for Hospice*(yes)	3,027	18.8	222
SPTS for Palliative/EOL*(yes)	2,687	16.7	196
Physically Distinct Clusters of Beds for Hospice (yes)	897	5.6	70
Presence of EOL services*(yes) (DV)	13,308	82.8	957

*n is smaller than the unweighted sample of 1174 due to missing data
** percentages are valid percents based on excluding missing data

Facility Medical Director and Administrator Characteristics. Medical Directors had an average of almost 10 years (M = 117 months, SE= 2.80) of overall experience serving as a nursing home medical director. They reported serving an average of 6.5 years (M = 79 months, SE = 2.00) in their current facility. The Medical Directors worked an average of six days a month (SE =0.18) in the facility. Over one-third of the Medical Directors held advanced degrees in geriatrics, and 12% held advanced education in palliative care. Twenty-three percent of the Medical Directors were certified in Geriatrics.

The basic demographics of the nursing home administrators were individuals who held Bachelor's degrees (49%) and had an average of over 11 years (M =138 months, SE = 3.00) serving as a nursing home administrator. These administrators reported being at their current facility an average of 5 years (M =62 months, SE = 2.80). One-third (31%) had degrees in health care administration. One-fourth of the administrators held certifications by the Nursing Home Administration/American College of Health Care Administration. Three percent were certified by the American Nurses Credentialing Center. Descriptive Characteristics are presented in Table 2 and 3.

Table 2: Medical Director and Nursing Home Administrator Time of Service

	M	SE
Medical Director		
Length of time (months) as Medical Director at Any Facility (N=991)	117.11	2.80
Length of time (months) as Medical Director at Current Facility (N=1046)	78.65	2.00
Days Per Month Working at the Facility (N=1057)	5.92	0.18
Nursing Home Administrator		
Length of Time (months) as Administrator at Any Facility (N = 1142)	137.68	3.00
Length of Time (months) as Administrator at Current Facility (N = 1161)	61.56	2.22

Table 3: Facility Medical Director and Administrator Characteristics

	Weighted Estimate	%**	Unweighted Sample count
Medical Director Characteristics			
Medical Director has Advanced Degree in Geriatrics (N = 1021)			
Yes	5,599	39.9	389
No	8,439	60.1	632
Medical Director has Advanced Degree in Palliative/EOL Care (N = 1021)			
Yes	1,742	12.4	122
No	12,296	87.6	899
Medical Director Certified in Geriatrics (N=1057)			
Yes	3,385	23.3	230
No	11,168	76.7	827
Administrator Characteristics			
Nursing Home Administrator's Most Advanced Degree (N = 1151)			
High School	904	5.7	67
Associates	1,755	11.1	142
Bachelor's Degree	7,670	48.5	565
Master's Degree	4,920	31.1	336
Other	551	3.5	41
Administrator Holds Degree in Health Care Administration (N = 1151)			
Yes	4,833	30.6	350
No	10,967	69.4	801
Administrator Holds Certifications (N = 1148)			
Certified Nursing Home Admin.			
American College of Health Care Admin.			
Yes	3,999	25.4	289
No	11,767	74.6	859
American Nurses Credentialing Center			
Yes	481	3.1	35
No	15,285	96.9	1113

** Percentages are valid percents based on excluding missing data

Facility Variables and Presence of EOL Services. Results from the chi-square analyses testing the relationship of facility variables with the presence of EOL services are represented in Table 4. Four significant associations (nursing home ownership, chain affiliation, facility bedsize, and region) were identified. Over 4 out of 5 (86%) of for-profit facilities offered EOL services compared to 78% of facilities that were private/government not-for-profit (χ^2 = 11.778, p < .001). Eighty-five percent of nursing home facilities that were part of a chain identified as offering EOL services compared to 80% of facilities that were not affiliated with a chain (χ^2 = 5.673, p < .021). The analysis also identified an association between the region where the facility was located and whether they offered EOL services or not. Eighty-seven percent of the facilities in the Northeast offered EOL services versus 84% in the Midwest, 85% in the South, and 72% in the West. In addition, the size of facility also was associated with the presence of EOL services. Eighty-seven percent of facilities that have 100-199 resident beds offered EOL services compared to 86% of facilities with 200 or more beds, 84% of facilities with 50 to 99 beds, and 63% of those facilities that were below 49 resident beds. There was not an association between facility accreditation status, participation in EOL initiatives, and any of the Medical Director or Nursing home administrator characteristics.

Table 4: Chi-square analysis Nursing Home Factors*

	Presence of EOL Services				
	Yes	No			
	f (% of Total)	f (% of Total)	χ^2	df	p
Nursing Home Ownership			11.778	1	.001
For Profit	8477 (85.8)	1404 (14.2)			
Not-for-Profit (Private & Government)	4831 (78.0)	1361 (22.0)			
Chain Affiliation			5.673	1	.021
Yes	7421 (85.2)	1288 (14.8)			
No	5887 (79.9)	1477 (20.1)			
Accreditation Status			2.431	1	.145
Yes	1919 (78.8)	516 (21.2)			
No	11322 (83.6)	2222 (16.4)			

Table 4 Continued

Facility Bedsize			52.923	3	<.001
49 or below	1414 (63.3)	820 (36.7)			
50-99 beds	5042(84.0)	963(16.0)			
100-199 beds	6002(87.7)	838 (12.3)			
200 or more beds	850 (85.5)	144(14.5)			
Geographic Regions			18.646	3	.001
Northeast	2425(86.5)	380(13.5)			
Midwest	4466(84.4)	826 (15.6)			
South	4569 (84.5)	841 (15.5%)			
West	1848 (72%)	718 (28%)			
Participation in EOL Initiatives			1.793	1	.204
Yes	2375 (86.0)	387 (14.0)			
No	10886 (82.1)	2378 (17.9)			
Medical Director has Advanced Degree in Geriatrics			.684	1	.422
Yes	4766 (85.1)	833 (14.9)			
No	7013 (83.2)	1418 (16.8)			
Medical Director has Advanced Degree in Palliative/EOL care			.267	1	.615
Yes	1490 (85.5)	252 (14.5)			
No	10289 (83.7)	1999 (16.3)			
Medical Director Certified in Geriatrics			.969	1	.355
Yes	2894 (85.5)	491 (14.5)			
No	9244 (82.8)	1916(17.2)			
Administrator has certification from CNHA			.683	1	.420
Yes	3393 (84.8)	606 (15.2)			
No	9731 (82.8)	2028 (17.2)			
Administrator has certification from ANCC			1.653	1	.153
Yes	439 (91.3)	42 (8.7)			
No	12685 (83.0)	2592 (17.0)			

* Complex survey analysis weighted estimates

Resident Characteristics. Results of the descriptive analysis indicate that the majority of residents in U.S. nursing homes are female, white, non-Hispanic descent, and not married (see Table 5). The average resident's age was 81 years (SE = 0.200) with a sampling range of ages 35 to 110. Circulatory Diseases (25%) and Mental Disorders (21 %) were listed as the most frequently charted primary diagnoses of the residents at the time of interview. Sixty-six percent were identified as having at least one advanced directive on file. These advanced directives included living wills (19%), do not resuscitate orders (57%), do not hospitalize (4%), feeding restrictions (11%), and medication restrictions (3%). Over three out of five (62%) of the residents were utilizing Medicaid as their primary payment source for the nursing home fees. Similarly, 67% of the residents were reported as paying out of pocket for costs. Less than 1 in 7 (13%) of the residents were reported as having Medicare as their primary payment source.

Over 3 out of 5 residents (63%) were listed as needing extensive assistance, total dependence, or having no activity at all for bed mobility. Pain was reported in the last seven days by over 1 in 5 (23%) of the residents. Two out of 5 residents reported indicators of distressed mood (depression, sadness, or anxiety). Only 2.5% of the residents in the sample were identified as receiving services from hospice/palliative care or end-of-life programs in the facilities.

Table 5: Resident Demographics (N = 13,419)

	Weighted estimates	%	Unweighted Sample count
Resident Gender			
Male	424,421	28.6	3815
Female	1,057,543	71.4	9604
Resident's Race[1]			
American Indian or Alaska Native	7,864.00	0.5	101
Asian	14,442	1.0	100
Black or African American	183,356	12.4	1385
Native Hawaiian or Pacific Islander	5,991	0.4	44
White	1,271,728	85.8	11799
Hispanic or Latino Origin*	54,643	3.7	428
Resident Source of Payment[1*]			
Medicare	189,182	13.3	1,680
Medicaid	882,561	62.0	7,811
Self/Out of Pocket	947,231	66.6	8,769
Other Source	31,853	2.2	266

Table 5 Continued

Resident's Primary Diagnosis*			
Neoplasms	33,701	2.3	298
Mental Disorders	325,529	22.2	2,886
Circulatory Diseases	372,675	25.4	3,393
Respiratory Diseases	73,770	5.0	677
Nervous System Diseases	238,810	16.3	2195
Endocrine System Diseases	109,595	7.5	1000
Musculoskeletal	77,390	5.3	725
Other diseases	236,625	16.1	2154
Advanced Directives			
Any Advanced Directives[1*]	970,635	66.2	9020
Living Will	271,197	18.5	2,544
Do not Resuscitate	832,615	56.8	7,877
Do not Hospitalize	51,810	3.5	406
Medication Restrictions	44,972	3.1	425
Feeding Instructions	154,936	10.6	1,381
Pain in past 7 days *			
Yes	336,069	23.4	3,402
No	1,100,576	76.6	9,658
Indicators of Distressed Mood (Depression, Sadness, or Anxiety)*			
No Mood Indicators	828,537	56.8	7453
Indicators Present but Easily Altered	375,134	25.7	3403
Indicators Present not Easily Altered	255,536	17.5	2403
Resident Level of Bed Mobility*			
Independent	458,734	31.3	4,354
Supervision	85,341	5.8	753
Limited Assistance	264,708	18.0	2,448
Extensive Assistance	414,918	28.3	3,610
Total Dependence	241,073	16.4	2,147
No activity reported in last 7 days	1,923	0.1	17
Receiving Services from Hospice/Palliative care/EOL Programs			
Yes	36,429	2.5	331
No	1,431,384	97.5	12,998

Percentage totals more than 100% because respondents could mark more than one category.
*N is smaller than the unweighted sample of 13,419 due to missing data.

EOL Care Utilization and Types of EOL Services Accessed. Table 6 provides further descriptive information specific to only those residents identified as utilizing EOL services in the nursing homes. One in a 100 of the residents was assigned to a bed on a specialty unit focusing on hospice care. Two-thirds (67%) of those receiving EOL services activated their Medicare Hospice Benefit. Those receiving EOL services were further categorized as to when they started the programs. Seventeen percent had started receiving hospice or palliative care before admission and 83% started services after they had been admitted to the facilities.

Of the 2.5% of the residents utilizing EOL services, the most frequently utilized type of services were symptom help (57%) and pain management (60%). Emotional support for their family was received by over half (53%) of those residents, and spiritual care was provided to 41%. Death preparation was utilized by 18% of these individuals and over 1 in 4 of the residents or families accessed ethical or legal counseling (28%) and grief or bereavement counseling (29%).

Table 6: EOL Care Utilization and Types of EOL Services Accessed [1]

	Weighted Estimates	%	Unweighted Sample Count
EOL Care Utilization			
Start of Palliative or Hospice care			
Before Admission	6,354	17.2	63
After Admission	30,683	82.8	269
On a Specialty Unit for Hospice**			
Yes	1,498	1.0	9
No	154,014	99.0	1111
Medicare Hospice Coverage Initiated			
Yes	21,960	67.1	214
No	10,776	32.9	83
Types of EOL Services Accessed*			
Ethical or Legal Counseling			
Yes	10,118	27.7	83
No	26,377	72.3	242
Grief, Loss and Bereavement Counseling			
Yes	10,481	28.7	89
No	26,014	71.3	236

Table 6 Continued

Death Preparation			
Yes	6,541	17.9	54
No	29,954	82.1	271
Emotional Support for Family			
Yes	19,456	53.3	170
No	17,039	46.7	155
Pastoral/Spiritual Care			
Yes	14,911	40.9	132
No	21,584	59.1	193

[1]Representing only the residents identified as receiving EOL services in the study.
[*] N is smaller than the unweighted sample of 331 residents identified as receiving EOL care due to missing data.
** N represents only those residents in facilities that offered specialty units.

Research Question 1: Facility and Administrator Factors Predicting the Presence of EOL Services

What facility and administrative factors predict the presence of EOL services in nursing homes in the U.S.? In answering research question one, a three step logistic regression was conducted. At level one, the facility demographic characteristics were entered and revealed a significant model at $p < .001$ with an overall model classification of 84 %. The second step of the hierarchical model introduced variables specific to the medical director at the facility. The second model remained significant at $p < .001$ with the overall model classification improving to almost 86%. The final model was also significant at $p < .001$ and revealed an improvement of model fit at 86.8% (see Table 7a, 7b, & 7c for the logistic regression analysis results by step).

Table 7a: Model 1 Logistic Regression using Facility Characteristics (N = 1174)

Facility Characteristics	df	Model 1 Wald F	B	Exp(B)	C.I.	
Ownership (For-profit)	1	3.837	.000[a]	1		
Not-for-profit (gov't or private)			-.359	0.699*	0.488	1.001
Chain affiliation (Yes)	1	0.788	.000[a]	1		
No			-.163	.850	0.593	1.218
Bedsize (3-49 beds)	3	5.113	.000[a]	1**		
50-99 beds			0.728	2.072**	1.320	3.250
100-199 beds			0.891	2.438**	1.532	3.878
200 or more beds			0.675	1.964	0.837	4.608
Region (West)	3	4.459	.000[a]	1**		
Northeast			0.927	2.526**	1.376	4.637
Midwest			0.722	2.059**	1.303	3.254
South			0.706	2.025**	1.277	3.213
Medicare Percent (20% +)	2	1.013	.000[a]	1		
0-9%			0.283	1.326	0.689	2.553
10-19%			0.441	1.554	0.834	2.895
Medicaid Percent (0-19%)	4	3.141	.000[a]	1*		
20-39%			1.343	3.831**	1.451	10.119
40-59%			0.738	2.092*	1.052	4.161
60-79%			0.929	2.532*	1.134	5.655
80% or more			0.475	1.609	0.618	4.191
Other Insurance Percent (40% +)	2	0.516	.000[a]	1		
0-19%			-0.386	0.680	0.318	1.451
20%-39%			-0.278	0.757	0.405	1.416
Participation in EOL initiatives (Yes)	1	5.863	.000[a]	1		
No			-.589	.555*	0.345	0.894
Overall Model Significance		p < .005				
Wald F		4.848				
Df		17				
Pseudo R Square						
Cox and Snell		.079				
Nagelkerke		.132				
Classification Percent		84.0				

p< . 05*, p < .01**
[a] reference category

Table 7b: Model 2 Logistic Regression (N = 1174)

	Model 2					
	df	Wald F	B	Exp (B)	C.I.	
Facility Characteristics						
Ownership (For-profit)	1	4.011	.000[a]	1		
Not-for-profit (gov't and private)			-0.441	0.643*	0.417	0.991
Chain affiliation (Yes)	1	0.000	.000[a].	1		
No			-0.002	0.998	0.649	1.536
Bedsize (3-49 beds)	3	5.921	.000[a]	1**		
50-99 beds			0.925	2.522**	1.486	4.281
100-199 beds			1.123	3.073**	1.771	5.331
200 or more beds			0.755	2.129	0.835	5.428
Region (West)	3	2.921	.000[a]	1*		
Northeast			0.878	2.407*	1.203	4.816
Midwest			0.647	1.909*	1.100	3.312
South			0.710	2.034*	1.185	3.492
Medicare Percent (20% +)	2	0.510	.000[a]	1		
0-9%			0.285	1.330	0.622	2.845
10-19%			0.388	1.474	0.693	3.137
Medicaid Percent (0-19%)	4	3.253	.000[a]	1*		
20-39%			1.445	4.240**	1.452	12.377
40-59%			0.904	2.470*	1.105	5.525
60-79%			1.124	3.078*	1.223	7.748
80% or more			0.543	1.722	0.581	5.100
Other Insurance Percent (40% +)	2	0.137	.000[a]	1		
0-19%			-0.163	0.850	0.353	2.047
20%-39%			-0.195	0.823	0.395	1.716
Participation in EOL initiatives (Yes)	1	6.247	.000[a]	1		
No			-0.722	.486*	0.276	0.856
Medical Director Characteristics						
Certified in Geriatrics (No)	1	0.360	.000[a]	1		
Yes			0.135	1.145	0.736	1.781
Certified in Palliative Care (No)	1	0.000	.000[a]	1		
Yes			-0.007	0.993	0.522	1.887
Days working at facility/month	1	1.993	-0.024	0.976	0.944	1.010
Months at current facility	1	1.735	-0.003	0.997	0.991	1.002
Months at any facility	1	0.689	0.002	1.002	0.998	1.006

Table 7b Continued

Overall Model Significance	p<.005
Wald F	3.455
Df	22
Pseudo R Square	
Cox and Snell	0.099
Nagelkerke	0.170
Classification Percent	85.6

p< . 05*, p < .01**
[a] reference category

Table 7c: Model 3 Logistic Regression (N = 1174)

	df	Model 3 Wald F	B	Exp(B)	C.I.	
Facility Characteristics						
Ownership (For-profit)	1	5.090	.000[a]	1		
Not-for-profit (gov't and private)			-0.517	0.596*	0.380	0.935
Chain affiliation (Yes)	1	0.215	.000[a]	1		
No			0.107	1.112	0.708	1.747
Bedsize (3-49 beds)	3	5.424	.000[a]	1**		
50-99 beds			0.969	2.636**	1.536	4.524
100-199 beds			1.04	2.830**	1.618	4.948
200 or more beds			0.649	1.915	0.745	4.923
Region (West)	3	4.431	.000[a]	1**		
Northeast			1.019	2.770**	1.353	5.671
Midwest			0.866	2.377**	1.340	4.217
South			0.939	2.557**	1.466	4.460
Medicare Percent (20% +)	2	0.575	.000[a]	1		
0-9%			0.377	1.458	0.662	3.215
10-19%			0.413	1.511	0.699	3.268
Medicaid Percent (0-19%)	4	3.300	.000[a]	1*		
20-39%			1.524	4.589**	1.557	13.524
40-59%			1.023	2.780*	1.221	6.333
60-79%			1.107	3.025*	1.180	7.756
80% or more			0.547	1.728	0.571	5.228
Other Insurance Percent (40% +)	2	0.122	.000[a]	1		
0-19%			-0.063	0.939	0.387	2.280
20%-39%			-0.158	0.854	0.402	1.815
Participation in EOL initiatives (Yes)	1	6.040	.000[a]	1		
No			-.709	0.492*	0.279	0.867

Table 7c Continued

Medical Director Characteristics						
Certified in Geriatrics (No)	1	0.062	.000[a]	1		
Yes			0.058	1.059	0.672	1.669
Certified in Palliative Care (No)	1	0.079	.000[a]	1		
Yes			0.096	1.100	0.564	2.147
Days working at facility/month	1	2.373	-0.027	0.974	0.941	1.007
Months at current facility	1	0.962	-0.003	0.997	0.992	1.003
Months at any facility	1	0.183	0.001	1.001	0.997	1.005
Administrator Characteristics						
Months at current facility	1	3.175	-0.003	0.997	0.993	1.000
Months at any facility	1	4.050	0.003	1.003*	1.000	1.006
Degree (other)	4	0.626	.000[a]	1		
High School			0.227	1.255	0.372	4.234
Associates Degree			0.248	1.281	0.457	3.590
Bachelor’s Degree			0.350	1.419	0.568	3.546
Master’s Degree or Higher			0.620	1.859	0.717	4.819
Degree in Health Care Admin.(yes)	1	0.340	.000[a]	1		
No			-0.141	0.869	0.541	1.394
Overall Model Significance		p <.005				
Wald F		2.949				
Df		29				
Pseudo R Square						
Cox and Snell		0.111				
Nagelkerke		0.191				
Classification Percent		86.2				

$p < .05$*, $p < .01$**
[a] reference category

The facility characteristics that were found to be significant in step one of the model remained significant throughout the other two final steps. Facility bed size (p = .001), type of ownership (p = .024), region of the facility (p = .004), percent of residents with Medicaid (p = .011), and participation in EOL programs such as Five Wishes, Physicians Orders for Life-Sustaining Treatment, and Last Acts (p = .014) were all characteristics that were identified as predictors for the presence of EOL services in the nursing homes. Medical director variables entered at step two were not significant predictors. One facility administrator characteristic, length of time (months) as administrator at any facility, was significant ($p = .044$) when entered at step three of the hierarchical model. Therefore, only the results of the final model (Model 3) will be reported.

The findings indicated that private or government not-for-profit facilities were less likely (OR = 0.596, B =-0.517) to offer EOL services compared to for-profit facilities. Compared to smaller facilities with bed sizes less than 49 beds, those facilities with 50 to 99 beds (OR = 2.636, B =0.969) and 100 to 99 beds (OR = 2.830, B = 1.040) were more likely to offer EOL services. Facilities that were larger than 200 or more beds were found to be not significantly different than the smaller facilities. The location of the facility in the United States also predicted the presences of services. Those facilities located in the Northeast (OR = 2.770, B = 1.019), Midwest (OR =2.377, B = 0.866), and South (OR = 2.557, B = 0.939) were more likely to report the presence of EOL services compared to those facilities in the West. The percentage of residents with Medicaid within the facilities was also a predictor of presence of EOL services. Facilities with 20 to 39% (OR = 4.589, B = 1.524), 40 to 59% (OR = 2.780, B = 1.023), and 60-79% (OR = 3.025, B = 1.107) of residents with Medicaid as their primary payment source were more likely to report the presence of EOL services than facilities that had less than 19% of their residents with Medicaid. However, facilities that had over 80% or more of their residents with Medicaid were found to not be significantly different from those facilities that had a small percentage (19% or less) of residents with Medicaid. Facility participation in EOL planning programs such as Five Wishes, Physicians Orders for Life Sustaining Treatment, and Do Not Hospitalize was also found to be a significant predictor with facilities. Those facilities that did not participate in the EOL initiatives were less likely (OR = 0.492, B = -0.709) to report specialized EOL services in their facilities. Lastly, the administrators' length of work experience as an administrator was found to be a predictor of presence of services as well. The longer the administrator had been serving in an administrative position, the more likely (OR = 1.003, B = 0.003) the facility in which they were currently employed had EOL services available.

Research Question 2: Resident and Facility Factors Predicting the Use of EOL Services

What factors related to the nursing home organization and resident characteristics predict the utilization of EOL care services in nursing homes in the United States? A multilevel regression analysis was conducted to explore the predictors of EOL service utilization. As suggested by Bickel (2007), an intraclass correlation coefficient (ICC) was first calculated to explore the regression assumption of dependence among observations for those residents nested within the nursing home facilities. The ICC for this analysis showed that 18.8% of the variance in use of EOL services is due to the differences in the nursing homes. Bickel (2007) does not identify an ICC cut point of determining when a multilevel model is needed, however, he suggests that even small amounts of dependency among groups can still inflate the standard errors. Gellman and Hill (2007) suggest that multilevel models should always be utilized to address these potential groupings. Multilevel analyses were conducted for this study to control for the dependency among those groups of residents nested within the facilities.

Multilevel Model Analysis

Two multilevel analyses were conducted utilizing the resident public data set. The dependent variable measured residents who were identified as receiving hospice, palliative, or EOL care in the facilities. Model 1 included resident variables at level one. Model 2 included the same resident variables at level one, but also added a facility variable (ownership) at level 2 (see table 8 for the list of variables). The clustering variable in both models was the 1151 individual nursing homes in the study. The Akaike (AIC) and Bayesian (BIC) information criteria did not demonstrate improvement in the model fit between Model 1 and Model 2. For Model 1, the AIC and BIC information criteria were 256,661.270 and 257,006.474, respectively. Model 2 information criteria were 477,809.620 (AIC) and 478,169.832 (BIC) demonstrating less parsimony and poorer fit for the model after adding the level 2 facility variable.

Table 8: Summary of Multilevel Regression Analysis on Public Data Set (N = 13,419)

	Model 1			Model 2		
Level 1 Fixed Variables						
Age	0.024	3.186**	1.024	0.024	3.224**	1.025
Gender (female)	-0.226	-1.491	0.798	-0.224	-1.477	0.800
Race (white)	-0.157	-0.600	0.855	-0.151	-0.581	0.860
Hispanic (yes)	-0.205	-0.580	0.814	-0.209	-0.590	0.811
Marital Status (yes)	0.157	1.003	1.170	0.155	0.988	1.167
Private Insurance	-0.303	-1.185	0.739	-0.302	-1.194	0.739
Out of Pocket Payment	-0.249	-1.532	0.780	-0.250	-1.529	0.779
Medicare Insurance	-0.821	-3.298**	0.440	-0.823	-3.314**	0.439
Medicaid	-0.701	-4.227**	0.496	-0.715	-4.391**	0.489
Advanced Directives (yes)	1.807	7.578**	6.094	1.817	7.645**	6.152

Table 8 Continued

Pain (yes)	0.816	5.692**	2.262	0.819	5.718**	2.268
Distressed Mood (ordinal)	0.212	2.534*	1.237	0.219	2.623**	1.244
Bed Mobility (ordinal)	0.425	8.062**	1.529	0.424	8.055**	1.528
Neoplasms	2.768	9.092**	15.932	2.776	9.073**	16.048
Mental Disorders	0.039	0.150	1.039	0.044	0.172	1.045
Cardiac	0.126	0.558	1.135	0.126	0.559	1.135
Respiratory	1.005	3.200**	2.732	1.010	3.212**	2.745
Nervous System	-0.173	-0.669	0.841	-0.161	-0.620	0.852
Endocrine	-1.519	-2.797**	0.219	-1.513	-2.787**	0.220
Musculoskeletal	-0.567	-1.426	0.567	-0.559	-1.407	0.572
Level Two Variables						
Ownership				-0.188	-0.968	
Information Criteria						
AIC	256,661.279			477,809.620		
BIC	257,006.474			478,169.832		

N = 13,419, p< .05*, p < .01**

The resident variables that were found to be predictors in Model 1 remained significant in Model 2. The facility level variable (ownership) in Model 2 was found not to be a significant predictor of EOL use in nursing home residents. With the significant resident variables remaining the same from Model 1, only the results of the final Model 2 will be presented. The following variables were found significant in predicting residents' receipt of hospice, palliative, or EOL services:

Demographics. Age was the only resident demographic found to predict the receipt of EOL care in facilities. As age increased, the odds of a resident accessing EOL services also increased by 1.022 (t = 3.224, p = 0.001). The resident's race, sex, and marital status were not significant predictors in the models.

Insurance. Both models supported that a resident's insurance coverage could also predict use of services. Residents were less likely to access EOL services if they had Medicare (OR = 0.439, $p = 0.001$, $t = -3.314$) or Medicaid (OR = 0.489, $p < .001$, $t = -4.391$) identified as their primary payment sources. Out of pocket payments and private insurances were not found to be significant predictors of use of services.

Advanced Directives. Advanced directives were found to be significant predictors of EOL service utilization in the facilities. Residents who were identified as having advanced directives had an odds of 6.152 of utilizing EOL services compared with those who did not have advanced directives ($p < 0.001$, $t = 7.645$).

Physical Condition. There were several variables that were used to identify the status of the resident's physical condition. Residents who were identified as reporting pain in the last seven days of service were more likely to be utilizing EOL services than those residents not reporting pain (OR = 2.268, $p < 0.001$, $t = 5.718$). Indicators for distressed mood (depression, sadness, or anxiety) were measured as ordinal variables identifying those residents who had (1) no mood indicators present, (2) depression indicators present but easily altered, and (3) indicators of depression present but were not easily altered. The results of the analysis indicated that as the resident's depression increased the likelihood that they were utilizing EOL services also increased (OR = 1.244, $p = 0.009$, $t = 2.623$). Finally, as resident's bed mobility decreased the likelihood of utilizing EOL services also increased (OR = 1.528, $p < .001$, $t = 8.055$).

Primary Diagnosis. Using the ICD-9 coding for primary diagnosis, three categories of diseases or health problems were identified as predictors of EOL service utilization. Individuals with the primary diagnosis of neoplasms (including tumors that are malignant, pre-malignant, or benign) had an odds of 16.048 of utilizing EOL services ($p < 0.001$, $t = 9.073$). Individuals with the diseases of the respiratory system had an odds of 2.745 of also accessing services ($p = 0.001$, $t = 3.212$). In contrast, residents who had the primary diagnosis related to the endocrine system (including immunity, nutritional, and metabolic diseases) were less likely ($OR = 0.220$, $t = -2.787$) to receive specialized EOL care.

Facility Ownership. The between level variable of facility ownership was not found to significantly predict resident use of services.

Chapter 5: Discussion

This chapter reviews the descriptive characteristics of the nursing homes and the residents residing in those facilities. The results of the analyses will also be discussed as they relate to answering the research questions and how they apply to the conceptual framework of the behavioral model of health service utilization (Andersen & Newman, 1973). The strengths and limitations of the study will also be explored and a discussion will be offered on how these findings can be utilized to inform practice and future research.

Facility Characteristics

Three out of five of the facilities participating in the 2004 National Nursing Home Survey were for-profit facilities. Over half were part of a nursing home chain, and two out of five of the facilities had a bedsize of 100 to 199 beds. In exploring services related to EOL care, over 75% of the facilities identified having contracts with outside hospice providers. These findings are similar to a prior study conducted by Miller and Mor (2004) identifying that 76% of U.S. nursing homes hold formal collaborations or hospice contacts with outside hospice providers. Similarly, Miller and Han (2008) merged the 2004 NNHS with 2004 Area Resource File (ARF) and the Nursing Home 2004 Online Survey and found that 78% of the nursing homes held hospice contracts.

This current study also found that over one in four of the facilities reported having special programs and trained staff (SPTS) for hospice and palliative care. Nineteen percent of the facilities reported SPTS for hospice, and 17% for palliative services. Overall, four out of five facilities reported having some form of EOL care services (contract with outside hospice and/or SPTS for hospice or palliative care). These findings also matched those in the study conducted by Miller and Han (2008). The findings of the current study indicate that the main source of EOL services in U.S. nursing homes remains with formal contracts with an outside hospice provider. The benefits of offering hospice care in nursing homes has been supported in prior research indicating fewer hospitalizations (Gozalo & Miller), improved pain management (Miller, et al., 2002), and practices ensuring resident's comfort (Miller, Gozalo, & Mor, 2000).

Resident Characteristics

Research has identified that pediatric and young populations face different barriers to accessing EOL services (Knapp et al., 2008) and survival durations and medical conditions are often not the same in older adults (Feudtner et al., 2011). Acknowledging these differences, the current study focused on nursing home residents that were ages 35 and above. The demographics of the residents were white, female, and not married. The average age of the resident was 81 years old. The two primary diagnostic categories for this population were circulatory diseases and mental disorders.

Of the residents in the study, 2.5% were identified as receiving services from hospice/palliative or EOL programs in those facilities. These findings match the study by Bercovitz et al. (2008), which utilized the entire resident sample of the 2004 NNHS. This current study further explored the specific types of EOL services that residents were utilizing. Of those residents that were identified as receiving EOL services in the original sample, management of symptoms (57%), management of pain (60%), emotional support to family (53%), and pastoral/spiritual care (41%) were identified as the primary types of EOL services being utilized.

The use of EOL services identified in this study is low when considering the number of individuals dying in U.S. nursing homes. Miller, Gozola, and Mor (2000) conducted a retrospective study using the nursing home Minimum Data Set (MDS) from 1992-1996. They identified all the residents that had died in that 5 year time frame and found that only 5.6% elected to use their hospice benefit. In a longitudinal study conducted by Miller, Lima, Gozalo, and Mor (2010), the use of hospice for Medicare beneficiaries residing in nursing homes had increased to 33% in 2006. These findings are promising as it indicates that nursing homes are becoming more open to utilizing hospice services for their residents possibly due to the severity of illnesses that they are seeing in their residents, acknowledging the benefits of the hospice approach to care, and navigating some of the previous barriers to accessing the Medicare Hospice Benefit.

Insurance Benefits and Barriers

The findings of this current study showed that out of the 2.5% of the residents who were utilizing EOL services, approximately 2 out of 3 were due to activating their Medicare hospice coverage. However approximately 30% of those utilizing EOL services in the study were identified as not accessing the Medicare benefit. This may be due to not being eligible or other barriers. In most cases, the main insurance provider for accessing hospice care is through the Medicare Hospice Benefit. Prior research and literature, however, have identified several barriers to individuals accessing that benefit. One barrier is related to the financial restrictions of Medicare reimbursement (Miller, Teno, & Mor, 2004). Many residents may be in the nursing home using their Medicare skilled days. These skilled days generally cover the entire episode of care for the resident at the facility. When residents elect the Medicare Hospice Benefit, however, they are then waiving the rest of their eligible skilled days for that admission. Both benefits can't be utilized at the same time (Miller, Intrator, Gozalo, Roy, Barber & Mor, 2004). The Medicare Benefit would cover their referral to the hospice services, but the dilemma that is often presented is that the room and board costs at the facility are then the responsibility of the resident and/or another insurance provider. Often this financial responsibility prevents referral due to the resident not having other avenues for covering the nursing home costs.

For residents that are Medicaid or dual (Medicare and Medicaid) eligible, Medicaid provides coverage for the room and board costs in the facilities. Since 1986, Congress allowed individual states to provide hospice care under their Medicaid programs. Medicaid payment for the room and board costs is not submitted directly to the nursing home. Payment is submitted to the contracted hospice, which under the contract pays the nursing home 95 – 100% of the Medicaid allowable room and board costs (DHHS, 1997).

This study found that residents who identified Medicaid as a primary payment source for the care they received in the facility were less likely to access EOL services than those residents who had other sources of payment. The Long term care Medicaid is often available to residents who have been in the facilities for extended periods of times. This may indicate that individuals who have been in the nursing facilities for longer periods of time may not be referred to EOL services once their condition changes, and that the treatment plan often remains the standard nursing home care. Most importantly the current study indicates that little is still known on the use of EOL care in residents not eligible for Medicare or Medicaid and identifies that many residents may not have accessed services at all due to insurance or payment barriers.

Facility Characteristics Predicting the Presence of EOL Services

This study identified several characteristics of the nursing homes that predicted whether they offered EOL services in their facilities. Facilities that were for-profit were more likely to report offering these specialized EOL services. These findings are supported by the study conducted by Temkin-Greener, Zheng, and Mukamel (2012) that identified that for-profit nursing homes reported a higher likelihood of utilizing hospice. Miller and Han's (2008) study however found that not-for-profit facilities were more likely to offer special programs and trained staff for hospice or palliative care. Although Miller and Han also utilized the 2004 NNHS, it is important to identify that the coding of profit status included three categorical variables (for-profit, private not-for-profit, and government). The current study utilizing the public data set had the not-for profit facilities combined (government and private). In addition, Miller and Han were only exploring SPTS and did not include facilities that identified the existence of hospice contracts. These outcome and variable differences could explain the difference in the findings between this study and the early Miller and Han study.

Prior literature indicated that size of facilities also impacted whether EOL services were offered in facilities. Miller and Han (2008) identified that larger facilities were more likely to offer special programs and trained staff for hospice or palliative care. This current study identified that those facilities that ranged in bed sizes of 50 to199 beds were more likely than smaller facilities to offer EOL services. The larger facilities (over 200 beds) were found to not be significantly different than the small facilities. Hodgson et al. (2006) found that nursing homes that were larger in size were more likely to offer palliative services in nursing homes in the State of Pennsylvania. It is important to note that Hodgson and colleagues (2006) identified nursing home size into two categories (small or large). This may explain the differences between this current study with the size of facilities being defined into 4 separate categories with the two middle categories of the analysis (50-99 & 100-199) also found to be more likely to offer EOL services.

Prior literature indicates that administrative characteristics influence EOL care service delivery in the individual facilities (Hanson, Sengupta, & Slubicki, 2005; Miller & Han, 2008; Rice et al., 2004). This current study explored several administrative characteristics and identified that the longer they had been an administrator (at any facility) the more likely that they would be at a facility offering EOL services. All the other Medical Director and nursing home administrator variables that were explored in this current study were found to not be significant predictors. These findings are not consistent with a study conducted by Rice et al. (2004) that identified length of time as an administrator had a negative relationship on whether EOL services would be considered in the facilities. This difference may be explained in the region in which the sample was recruited. Rice and colleagues' study consisted of administrators in the Denver, Colorado metropolitan area. The regional differences may explain the difference in findings due to the characteristics of nursing homes in that area. The implications that Rice et al. (2004) offer is still important to consider. Rice et al. identified the need for further education not only among the administrators, physicians, staff, and families, but stressed that improving EOL service models in the facility would require attention on the organizational and administrative culture in order to encourage a “top down” approach for successfully implementing these new practices (p. 674).

Geographic location was also a predictor of whether nursing homes were offering EOL services. The chi-square analysis in this study indicated that facilities in each of the regions (Northeast, Mid-west, and South) reported more than a 12% difference in offering EOL services compared to those facilities in the West. The logistic regression analysis indicated that facilities in the West were less likely to offer EOL services in the facilities compared to the Northeast, Mid-west, and South. In looking at Hospice use in general, Conner, Elwert, Spence, and Christakis (2007) reported that hospice utilization was highest in the South and Southwest with Arizona being the state with the highest percent of hospice use. The Conner et al. (2007) study, however, did not specifically identify percentages of use within the nursing homes only. Miller and Han’s (2008) focus on SPTS for hospice and palliative care only identified that facilities in the South were more likely to report those special programs. This current study offers new regional differences for consideration combining not only hospice, but also SPTS for hospice and palliative care. Generalizing these findings, however, should be considered with caution. Understanding state level differences in EOL care may offer more information in understanding the individual state policies and funding practices.

This study identified that those facilities that participated in planning initiatives such as Five Wishes, Physicians Orders for Life Sustaining Treatment, and Last Acts were more likely to also have EOL services in their facilities. Tilly and Folk (2008) identified that lack of advanced care discussions often create barriers to effective EOL care. They suggested the importance of programs such as Five Wishes to allow for a thorough discussion of the wishes of the individuals. This current study found that only 1 in 4 of facilities in the U.S. participate in formal EOL care planning initiatives such as Five Wishes, Physician's Orders for Life Sustaining Treatment, or Last Acts. The benefits of these initiatives offer a formal way of communicating and discussing the wishes of their residents at the end of life. These results indicate a need for education and set practices in the facilities for avenues to be established that would allow for improved EOL care discussions and planning with their residents.

Resident and Facility Factors Predicting the Use of EOL Services

Residents' age was found to be a predictor of receiving EOL services in the facilities. These findings are also supported in prior research that residents receiving hospice coverage were more likely to be older (Buchanan et al., 2004; Cassarett, Hirshman, & Henry, 2001). These prior studies, however, also identified that gender (being female) and marital status (not married) were predictors of use of services. However this current study did not identify these additional resident demographics as being significant predictors for EOL service use in the facilities. Cassarett and colleagues (2001) explored a sample of 167 nursing home residents in hospice care affiliated with the University of Pennsylvania. The study conducted by Buchanan et al. (2004) compared residents in the facility that were utilizing hospice with those residents who were not referred to hospice, but also had been identified with an end-stage (6 months or less) disease. The current study compared residents receiving EOL care in the nursing homes with those residents receiving the routine nursing home care. A distinction between the general residents and ones who had a possible terminal diagnoses was not made. These differences in sample and in the focus of comparison may explain the differences in findings.

Residents who had advanced directives on file were more likely to utilize EOL services in the facilities. These findings support the prior research conducted by Bercovitz et al. (2008), Buchanan et al. (2004) and Parker-Oliver et al. (2003) all identifying that those residents utilizing hospice services were more likely to have completed some form of advanced directive including durable power of attorney, DNR orders, or other forms of living wills.

Resident insurance coverage was also found to predict the use of EOL services. Those residents with Medicare and Medicaid as their primary payment source were found to be less likely to utilize EOL services in this analysis. Although reports suggest that use of Medicare Hospice Benefit has seen an increase for those residing in nursing homes (Department of Health and Human Services, 2007), payment barriers in Medicare continue to be identified as a barrier to accessing services due to losing Medicare Part A benefits when electing the hospice benefit (Huskamp et al., 2001; Lu & Johantgen, 2010). The coding of the variables in this study, however, limit the ability to clearly identify those residents who were dual eligible, and whether they utilize EOL services differently due to not facing some of the payment barriers for coverage of room and board fees at the nursing home. This study did identify that both the residents with Medicare and Medicaid as their primary payment source were less likely to access services, but the current analysis did not account for those residents who held both insurances.

Several resident physical factors were found to predict whether they were utilizing EOL services in the facilities. This study identified that those residents who reported pain, had indicators of depression, and decreased bed mobility were more likely to utilize EOL services. There were also several diagnoses that were found to be predictors of use as well. Residents with Neoplasms (including tumors that were malignant, pre-malignant, or benign) and respiratory diagnoses were more likely to be accessing services. Those residents with diseases of the endocrine system, however, were less likely to utilize services. The findings of this study match the need factors identified in prior research such as pain and cancer diagnosis (Buchanan et al., 2004; Parker-Oliver et al., 2003; Lu & Johantgen, 2010). Kwak and colleagues' (2008) study found that residents with the diagnosis of cancer and dementia were more likely to utilize hospice services compared to residents with heart disease or other diagnoses. Although this current study did not identify dementia as a predictor or use, it is important to note that the diagnosis of dementia was included in the categorical variable with other mental disorders. Dementia as a separate diagnosis was not explored. Consistent with the current study's findings, Lu and Johantgen's (2010) study also identified that residents with higher functional dependence including decreased bed mobility were at an increased likelihood of utilizing hospice care. Lu and Johantgen (2010) further identified that those residents in their study located in for-profit facilities were less likely to receive hospice care. Although the current study identified that for-profit facilities were more likely to report the presence of EOL services in the facilities (not only hospice, but other EOL services), the final multilevel analysis found that facility ownership status did not serve as a predictor to whether the residents accessed those services.

Behavioral Model Conceptual Framework

A modified version of Andersen and Newman's (1973) behavioral model for health service utilization provided a framework for understanding the results of this study. Components in the health care system were first explored in research question one identifying the facility and administrative factors that predict the presence of EOL services in the nursing home. This is following the assumption identified by Andersen and Newman (1973) that resource and structure components of the health care organization often mold if and how the services are provided to the individuals. In exploring the factors within the nursing home health care system, barriers and catalysts may be identified to help improve resource availability. Within the health care system component of the model, structure factors that were identified as predictors of presence of EOL services in the nursing home were for-profit status, size of the facility, geographic location, and administrator's length of time as a nursing home administrator.

Research question two utilized the entire modified behavioral model for health service utilization (health care system and individual determinants) to explore receipt of EOL services. Age was the only descriptive factor identified in exploring the predisposing components of the model. Existence of advanced directives and resident insurance coverage issues were identified as enabling components that impacted use. Pain, presence of depressive symptoms, limited bed mobility, and certain diagnoses were identified in exploring the need component of the model. The health care system domain of the model was entered by utilizing the multilevel analysis.

The modified version of the Andersen and Newman's behavioral model for health service utilization (1973) helps to explain the impact of these results identifying that there remain several barriers and catalysts for not only the nursing home facilities in offering EOL services, but also for the resident. Contracts with hospice providers are in over 75% of facilities. However, the results of this study show that fewer than 3 out of 100 residents in the NNHS sample actually receive services. In addition, special programs and trained staff (SPTS) for hospice and palliative care are still not offered in 75% of nursing homes. Prior research has identified many barriers and catalysts to the presence and utilization of EOL services. The results of this study also identified some of these same issues including insurance coverage, advanced care planning/EOL initiatives, geographic location, facility characteristics, and residents' diagnostic and physical needs. As Andersen and Newman (1973) indicate, all these factors come together to inform health care utilization at EOL.

Strengths and Limitations

This current study has a number of limitations that should be noted. Several of these limitations have also been identified by prior research utilizing the NNHS (Bercovitz et al., 2008; Choi, 2010; Miller and Han, 2008). The measurement instrument utilized in the NNHS relied on responses from nursing home staff. The instrument was not developed based on a theoretical framework and the psychometric properties of the instrument were not tested (Choi, 2010). Miller and Han (2008) identified that although the study was able to report the existence of services, the data do not allow for elaboration on the actual "scope of practices in those programs" (p. 876). This limitation in the data prevented further exploration of the services. In addition it is important to acknowledge that prior research identified several barriers to EOL services in the nursing homes such as education of nursing staff, facility resources, administrative attitudes, etc.

(Brazil et al., 2006; Brazil & Vohr, 2005; Greiner, Buhr, Phelps, & Ward, 2003). The NNHS dataset does not provide information on these specific variables so the potential barriers could not be explored in the current study.

Nursing homes can provide several avenues for residents to receive EOL services in their facilities. These options can include services from outside hospice contracts, offering specialty units for EOL care, and identifying special programs and trained staff for providing hospice/palliative interventions. Each of these avenues of providing EOL care could possibly have different standards, approaches, and benefits. This current study explored receipt of EOL services as one grouping which limited its ability to explore the individual benefits of the different approaches.

Bercovitz et al. (2008) acknowledge that the sample recruitment of the NNHS creates errors in estimates for those residents receiving EOL care. This is due to the study being more likely to capture long-stay residents creating an underestimation of the number of residents receiving EOL care and an overestimation of the length of EOL care in the facilities. In addition, the cross sectional design of the NNHS provides data at one point in time, which prevents a thorough exploration of the care that those residents received during their full length of stay at the facilities. Therefore the results of this study were interpreted with caution. A final limitation of this study is the use of a secondary data set. With the research being conducted by the National Center for Health Statistics, the full operationalized definitions of the variables being collected by the NNHS interviewees was not always identified in the Data Dictionary. This implies a limitation in the validity of the instrument identifying whether the question was measuring what it intended to measure.

The National Nursing Home Survey (NNHS) provided a large data set that was specifically designed with the purpose to be able to explore the characteristics of residents, facilities, and health care services (National Center for Health Care Statistics [NCHS], 2011). The NCHS (2011) identified that the NNHS study not only offered the ability to assess the specific services that are provided, but also to identify the types of residents who receive those services. Although the data were collected in 2004 and potential changes in policies and nursing home practices should be acknowledged, the 2004 NNHS continues to be utilized in current research due to its strength of being a large nationally representative sample. Prior studies in EOL have focused on certain regional areas. This limits the ability to generalize findings to the United States. This current study utilized the nationally representative sample of both the nursing home facilities in the United States and also the residents residing within them. A benefit of using the NNHS dataset was its sample size of 1,174 nursing homes and 13,507 residents. This offered a sufficient sample for each of the analyses in the current study. In addition, the data collection throughout the United States also afforded a thorough review of EOL care across the country and not limited to only certain States or regions.

This study was also one of the first to not only consider the resident variables impacting use of services, but also explore the organizational components of the nursing home facility. Using the advanced methodological design of a multilevel regression analysis, this study allowed for consideration to be given to residents who were grouped within the nursing home facilities. A final strength of this study is that it is also one of the first that links facility, administrative, and resident factors to explore EOL care access and utilization using a modified version of Andersen and Newman's (1973) behavioral model for health service utilization. Many prior studies have only utilized the individual determinant component of the model. This study maintained the health service system component of the framework to explore its impact as well on the outcomes for health services utilization.

Implications for Nursing Home Care and Policy

This study offers several implications for nursing home organizations. Although this study did not directly measure the role of education, it is suggested that education is a key component for making change in the facilities. This current study has indicated that facility characteristics may influence the availability of EOL services. Acknowledging the benefits of hospice and palliative services for dying nursing home residents, administrators need to implement policies and practices that remove obstacles for referral and resident use of services.

Insurance and payment issues were also identified as barriers to accessing services. A prior study on the use of the Medicare Skilled Nursing Benefit found that 1 in 11 elderly nursing home residents died while receiving Skilled Nursing Facility (SNF) care and most within the first month of services (Aragon, Covinsky, Miao, Boscardin, Flint & Smith, 2012). Aragon et al. (2012) identified that the many nursing home residents are admitted to a SNF after receiving acute care in the hospital. With the Medicare Skilled Nursing Benefit providing room and board coverage for the nursing home care, many residents may be choosing the skilled services for financial need rather than choosing services that address EOL care goals. Skilled nursing facilities should acknowledge that many of their skilled care residents may need EOL or palliative care. In addition, government policies could be established to address these payment challenges so that residents' choices for care are not limited because of financial restrictions. Policy changes in the Medicare Hospice Benefit or Medicare Skilled Nursing Benefit could be initiated to allow newly admitted nursing home residents with a terminal prognosis to utilize hospice care while still accessing their skilled benefits during the transition periods from hospital acute care to the nursing home. This would help address one of the barriers facing patients in early access to EOL services.

Implications for Social Work Practice

The benefits of hospice services in nursing homes have been supported in prior research identifying improved comfort care for residents (Gozalo & Miller, 2007; Miller, Gozalo, & Mor, 2000). Studies have shown that when nursing homes offer leadership and training for palliative services, quality improvement practices are noted such as increased pain assessment, increased referrals for hospice care, and more EOL discussions (Hanson, Reynolds, Henderson, & Pickard, 2005). The current study has identified that there may be facility and resident characteristics that serve as possible barriers and catalysts for the presence and use of EOL care in the nursing homes. In addition, this study identified several areas where types of EOL care services (emotional support, spiritual care, and death preparation) could be utilized more often to improve the quality of EOL services by using a holistic approach addressing not only physical needs, but also the psychological, social, and spiritual needs of the residents. By the nature of their training, social workers can help to facilitate the changes needed to draw on the incentives and remove the possible barriers of EOL services in nursing homes. They can serve as advocates on behalf of residents who face insurance barriers for payment. They can serve as educators to help nursing home staff, family members, and residents identify the many benefits to receiving EOL services. They can help in identifying eligibility for services that often are needed in initiating timely referrals for services. This will require social workers within the facilities to actively utilize their assessment skills identifying not only physical needs for EOL services, but also psychological, social, and spiritual needs. Social workers should also be active in creating changes in policy and practices related to advanced care planning or EOL initiatives in their facilities. Not only can they lead these program initiatives in the organizations, but they can develop the standards for practice in the facilities for conversations and discussions with residents and families about their end-of- life wishes. These implications are directly connected with the field of social work's Code of Ethics that calls for the profession to advocate, serve, and address the needs of the vulnerable (NASW, 2008).

Future Research Implications

It is concerning that EOL care is not considered a standard of practice for many nursing homes in the United States despite the fact that many individuals spend their last days in these facilities. More research needs to be conducted on the benefits of implementing comprehensive EOL practices in U.S. nursing homes including a focus on organizational and policy barriers. This study identified that a large percentage of nursing homes in the country hold existing hospice contracts. However, only a small percentage of residents actually utilize the services. Identifying the barriers for hospice referrals are essential in providing quality EOL care in the facilities. Research on staff education needs, facility resource limitations, and policy barriers would help to inform future program planning. In addition, this current study identified that only a small percent of the facilities offer SPTS for hospice and palliative care. Researching the benefits of these programs (especially for those residents that cannot activate a hospice insurance benefit) in the facilities will also help to identify any catalysts or barriers to program implementation. Much research has focused on hospice care in nursing homes, but little is still known about other EOL practices and their benefits within the facilities (Miller, Lima, Gozola, & Mor, 2010).

Additionally, more research needs to be conducted focusing further on the individual determinants for access to care for residents. Predisposing variables such as those residents who are not in late adulthood should be explored. There may be specific barriers for people under the age of 65 who are characteristically different than the general nursing home population, and do not qualify yet due to their age for the Medicare Hospice Benefit. Exploration of the enabling factors related to understanding the various insurance barriers is also needed. Research has shown that insurance can serve as a barrier for residents having EOL service coverage. In addition, insurance reimbursement constraints have also been found to serve as a disincentive for nursing homes to refer residents for EOL services with the concern of losing some financial income for the facility (Miller, Teno, & Mor, 2010). Finally, specific determinants related to specific diagnoses that often do not illicit a referral for EOL services could be explored further.

With the prediction of 40% of deaths happening in nursing home facilities by the year 2040 (Ersek et al., 2005), it is integral for policy changes to be made so that accessing quality EOL services are feasible for these individuals. The 2004 NNHS provides comprehensive data on nursing home facilities and residents throughout the United States. However, there is a need for further research on EOL practice and utilization utilizing more recent data sources. Finally, intervention research is needed focusing on EOL education and quality EOL program implementation in the facilities. The current study explored the presence and use of services, but further research on quality EOL care practices would be beneficial. Development and testing of evidence-based interventions that can be implemented in the facilities to provide quality EOL services and improve staff EOL education are next steps in changing current EOL care practices in nursing home facilities.

Conclusion

The study had two primary purposes in researching EOL care in U.S. nursing homes. First, it attempted to understand factors about the facility (administratively and structurally) that impact the availability of EOL services. Second, this study focused on factors (resident and facility) that impacted receipt of EOL services. There was a dual focus of not only exploring whether services were available, but also whether they were being utilized. Interestingly one of the major findings is that although a major portion of facilities in U.S. nursing homes offer outside contracts to hospice care, only a small percentage of residents are accessing those services. This study also identified that EOL services other than outside hospice contracts, such as special programs or trained staff for hospice or palliative care, remain limited in the facilities. This indicates a major gap in offering palliative care for individuals who may not be eligible for hospice care due to having a prognosis of more than 6 months, but would benefit from the comfort care that are offered in palliative programs.

This is one of the first studies that merged both facility and resident factors to identify possible barriers and catalysts for accessing care. It utilized a nationally representative sample on nursing homes in the United States and the residents that reside within them to explore the potential factors that prevent or encourage the presence or use of EOL services in the facilities. Knowledge of these barriers is essential in being able to take the needed steps to conduct further research, change policies, and implement new programs to meet the needs of dying residents in nursing homes.

Appendix A: Variable and National Nursing Home Survey (NNHS) Question Text*

Variable	NNHS Question Text
Source: Resident Questionnaire	
Resident Age (Predisposing)	What is resident's date of birth? Coded (Month, Day, & Year).
Resident Gender (Predisposing)	Is resident male or female? Coded (Male = 1; Female = 2)
Resident Marital Status (Predisposing)	When resident was admitted to the facility, was he/she married, widowed, divorced, separated, or never married? Originally coded (Married = 1; Widowed = 2; Divorced = 3; Separated = 4; Never Married = 5; Significant Other = 6; Single = 7).
Resident's Race (Predisposing)	What is resident's race? Coded (American Indian or Alaska Native = 1; Asian = 2; Black or African American = 3; Native Hawaiian or Other Pacific Islander = 4; White = 5; Another Race [Specify] = 91)
Resident Advanced Directives (Enabling)	Which of the following Advanced Directives were listed in resident's current record or chart? Coded (Living Will = 1; Do Not Resuscitate = 2; Do Not Hospitalize = 3; Organ Donation = 4; Autopsy Request 5; Feeding Restrictions = 6; Medication Restrictions = 7; Other Treatment Restrictions = 8; No Advanced Directives Provided = 9)
Resident's Source of Payment (Enabling)	What were all the sources of payment that covered or will cover the cost of resident's care for the past month or billing period? (Private insurance = 1; Life care = 2 ; Self/private pay/out-of-pocket = 3; Medicare = 4, Medicaid = 5, Welfare or other Government Assistance= 6, Department of Veterans Affairs Contract or other Department of Veterans Affairs Programs = 7; Other = 8)
Resident Pain (Need)	Since admission/in past 7 days, has resident reported or shown evidence of pain (include grimacing or other non-verbal signs that suggest pain)? (Yes = 1; No = 0)
Resident Diagnosis (Need)	Resident's primary diagnosis. Respondents were asked to list the resident's current diagnosis (open coding).
Resident Level of Mobility (Need)	What is Resident's level of self-performance in bed mobility? Coded (Independent = 0; Supervision = 1; Limited Assistance = 2; Extensive Assistance = 3; Total Dependence = 4; Activity Did not Occur During Entire 7 Days = 8)

*Coding represents the original codes in the CDC dataset. Recoding of the variables for this current study is represented in Chapter 3: Methods (NCHS, 2011).

Appendix A: Variable and National Nursing Home Survey (NNHS) Question Text*

Variable	NNHS Question Text
Source: Resident Questionnaire	
Resident Indicators of Distressed Mood (Need)	Does resident show any indicators of depressed, sad or anxious mood that are not easily altered by attempts to "cheer up", console, or reassure? Coded (No Mood Indicators = 0; Indicators Present, Easily Altered = 1; Indicators Present, Not Easily Altered = 2)
Receiving EOL care (Health Services Utilization)	Is resident currently receiving services from a special program for any of these conditions on this card? Survey has other options for other special programs. This study is only considering the Hospice/Palliative Care/End of Life (End Stage/Terminal Condition) option. Coded (Hospice/Palliative Care/End of Life [End Stage/Terminal Condition] = 1)
Type of EOL Care Service Utilized	Please look at this card and tell me what type of end-of-life, palliative, or hospice services the resident has received during the past week (7 days). Coded (Symptom Management = 1; Pain Management = 2; Counseling/Assistance with Ethical/Legal Issues = 3; Grief, Loss, & Bereavement counseling for Resident or Family = 4; Death Preparation = 5; Emotional Support for Family = 6; Pastoral/Spiritual Care =7; Other = 8)
On a Specialty Unit for Hospice Care	Is resident assigned to a specialty bed for hospice? This study focused on only one of the categories (Hospice coded 6 in the questionnaire).
Medicare Hospice Coverage Initiated	Has Medicare hospice coverage been initiated for resident's hospice care? Categorically coded (Yes = 1; No = 2; Not eligible for Medicare = 3)
Start of Palliative or Hospice Care	Did the resident start receiving palliative or hospice care before or after admission to the facility? Coded (Before Admission = 1; After Admission = 2).
Source: Facility Questionnaire	
Nursing Home Ownership (Structure)	Which of these categories on this card best describes the ownership of this facility? Coding (For profit = 1; Private Nonprofit = 2; City/County Government = 3; State Government = 4; Department of Veterans Affairs = 5; Other Federal Agency = 6; Other (Specify) = 91; DK; RF)

*Coding represents the original codes in the CDC dataset. Recoding of the variables for this current study is represented in Chapter 3: Methods (NCHS, 2011).

Appendix A: Variable and National Nursing Home Survey (NNHS) Question Text*

Variable	NNHS Question Text
Size of Facility (Structure)	How many beds are currently available for residents (including all beds set up and staffed for use whether or not they are in use by residents at the present time)?
Chain Affiliation (Structure)	Is facility part of a chain? Coding (Yes = 1; No = 2)
Geographic Region (Structure)	What is the correct address of this facility?
Residents with Medicare (Resources)	Based on most recent daily census, what is the number of current residents who have Medicare as their primary source of payment?
Residents with Medicaid (Resources)	Based on most recent daily census, what is the number of current residents who have Medicaid as their primary source of payment?
Residents with Other Payment (Resources)	Based on your most recent daily census, what is the number of current residents who have other source of payments?
Participation in End-of-Life Initiatives (Resources)	Does facility participate in any of the following End-of-Life programs on this card ? (Five Wishes = 1; Physician's Orders for Life-Sustaining Treatment = 2; Last Acts = 3; No End Of Life Initiatives = 4)
Presence of End-of-Life Services	This variable will be a combined variable from the following question texts. Does facility have special, physically distinct or designated clusters of beds, or segregated wings or units, used exclusively for conditions listed on this card? This study is only looking at option for Hospice. Coded (Hospice = 6) Does facility have formal contracts with any of the outside services providers on this card? This study is only looking at option for Hospice. Coded (Hospice = 6) Please tell me if facility has a special program that has specially trained personnel dedicated to the program for anything listed on this card. Survey has other options. This study is only looking for Hospice and Palliative care/End of Life (End Stage/Terminal Condition-Not Hospice). Coded (Hospice = 1; Palliative care/End of Life (End Stage/Terminal Condition-Not Hospice = 2)

* Coding represents the original codes in the CDC dataset. Recoding of the variables for this current study is represented in Chapter 3: Methods (NCHS, 2011).

Appendix A: Variable and National Nursing Home Survey (NNHS) Question Text*

Variable	NNHS Question Text
Nursing Home Administrator Most Advanced Degree (Structure)	Most advanced degree or program of the Nursing Home Administrator. Coded (High School Diploma = 1; Associate Degree in Health Care Administration or Long-Term Care = 2; Associate Degree-Other = 3; Bachelor Degree in Health Care Administration/Long-Term Care = 4; Bachelor Degree-Other = 6; Master's Degree in Health Care Administration/Long-Term Care = 6; Master's Degree-Other = 7; Doctoral Degree in Health Care Administration/Long-Term Care = 8; Doctoral Degree-Other = 9, Other = 10).
Nursing Home Administrator Certifications (Structure)	Does Nursing Home Administrator hold any of these certifications? (Certified Nursing Home Administrator (CNHA) American College of Health Care Administrators = 1; American Nurses Credentialing Center (ANCC) = 2; No Certification = 3)
Length of Time As Administrator	About how long has the administrator served as an administrator at any nursing home or similar type of facility? Coded (Months)
Length of Time As Administrator at Current Facility Source: Staffing Questionnaire	About how long has the administrator served as an administrator at this (current) facility? Coded (Months).
Medical Director Certified by the American Medical Director's Association (Structure)	Does the Medical Director have an American Medical Director's Association (AMDA) certification? Coded (Yes = 1; No = 2)
Medical Director- Advanced Education (Structure)	Does the Medical Director have advanced education in any of the following areas? Coded (Geriatrics = 1; Palliative/End-of-Life Care = 2; Management = 3; None of the Above = 4)
Number of Days that the Medical Director Works at the Facility (Structure)	How many days a week or month does the Medical Director spend working in this facility? Coded (Days a Week or Days a Month)
Length of Time as a Medical Director (Structure)	How long has medical director been the medical director at any nursing home or similar facility? Coded (Weeks, Months or Years)
Length of Time as Medical Director at Current Facility (Structure)	How long has medical director been the medical director at this facility? Coded (Weeks, Months, or Years)

* Coding represents the original codes in the CDC dataset. Recoding of the variables for this current study is represented in Chapter 3: Methods (NCHS, 2011).

References

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it really matter? *Journal of Health and Social Behavior, 36*(1), 1-10.

Andersen, R. M., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly, 51*, 95-124.

Aragon, K., Covinsky, K., Miao, Y., Boscardin, W. J., Flint, L., & Smith, A. K. (2012). Use of the medicare posthospitalization skilled nursing benefit in the last six months of life. *Archives of Internal Medicine, 172*(20), 1573-1579. doi: 10.1001/archinternmed.2012.4451.

Baer, W. M. & Hanson, L. C. (2000). Families' perception of the added value of hospice in the nursing home. *Journal of the American Geriatrics Society, 48*(8), 879-882.

Bercovitz A., Decker F.H., Jones A., Remsburg R.E. (2008). End-of-life care in nursing homes: 2004 National Nursing Home Survey. *National Health Statistics Reports*,(9). Hyattsville, MD: National Center for Health Statistics. Retrieved from http://www.cdc.gov/nchs/data/nhsr/nhsr009.pdf.

Bern-Klug, M. (2009). A framework for categorizing social interaction related to end-of-life care in nursing homes. *The Gerontologist, 49*, 495-507. doi: 10.1093/geront/gnnp098

Bern-Klug, M. (2010). *Transforming palliative care in nursing Homes: The social work role,* (Ed.). New York, NY: Columbia University Press.

Bickel, R. (2007). *Multilevel analysis for applied research: It's just regression!* New York, NY: The Guilford Press.

Black, B. S., Fogarty, L. A., Phillips, H., Finucane, T., Loreck, D. J., Baker, A., …. Rabins, P. V., (2009). Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *Journal of Aging and Health, 21*(4), 627-650. doi: 10.1177/0898264309333316

Brazil, K., Bédard, M., Krueger, P., Taniguchi, A., Kelley, M. L., McAiney, C., & Justice, C. (2006). Barriers to providing palliative care in long-term care facilities. *Canadian Family Physician*, *52*, 473-473.

Brazil, K., & Vohra, J. U. (2005). Identifying educational needs in end-of-life care for staff and families of residents in care facilities. *International Journal of Palliative Nursing*, *11*(9), 475-480.

Buchanan, R. J., Choi, M. A., Wang, S., & Ju, H. (2004). End-of-life care in nursing homes: Residents in hospice compared to other end-stage residents. *Journal of Palliative Medicine, 7*(2), 221-232. doi: 10.1089/109662104773709341

Caffrey C. (2010) Potentially preventable emergency department visits by nursing home residents: United States, 2004. *NCHS Data Brief*, (33). Hyattsville, MD: National Center for Health Statistics. Retrieved from http://www.cdc.gov/nchs/data/databriefs/db33.pdf.

Casarett, D. J., Hirshman, K. B., & Henry, M. R. (2001). Does hospice have a role in nursing home care at end of life? *Journal of the American Geriatrics Society, 49*(11), 1493-1498.

Casarett, D., Karlawish, J., Morales, K., Crowley, R., Mirsh, T., & Asch, D. A. (2005). Improving the use of hospice services in nursing homes: A randomized controlled trial. *Journal of the American Medical Association*, *294*(2), 211-217.

Center to Advance Palliative Care (2011). *Making the case for hospital-based palliative care*. Retrieved from http://www.capc.org/building-a-hospital-based-palliative-care-program/case.

Chan H. Y.L. & Pang S. M. C. (2007). Quality of life concerns and end-of-life care preferences of aged persons in long term care facilities. *Journal of Clinical Nursing*, *16*(11), 2158-2166. doi: 10.1111/j.1365-2702.2006.01891.x

Chappell, N. L. & Blandford, A. A. (1987). Health service utilization by elderly persons. *Canadian Journal of Sociology*, *12*(3), 195-215.

Chatterjee, S. Mehta, S., Sherer, J. T., & Aparasu, R. R. (2010). Prevalence and predictors of anticholinergic medication use in elderly nursing home residents with dementia: Analysis of data from the 2004 National Nursing Home Survey. *Drugs Aging*, *27*(12), 987-997.

Chiatti, C., Barbadoro, P., Lamura, G., Pennacciettie, L., Di Stanislao, F. D'Errico, M. M. & Prospero, E. (2011). Influenza vaccine uptake among community-dwelling Italian elderly: results from a large cross-sectional study. *BMC Public Health*, *11*, 207-213. doi: 10.1186/1471-2458-11-207

Choi, J. (2010). Work-related and personal factors influencing job satisfaction and intent to leave among certified nursing assistants in nursing homes. Retrieved from ProQuest Digital Dissetations. (AAT 3433836)

Cohen, J., Cohen, P., West, S. G., Cohen, and Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Conner, S. R. (2007). Development of hospice and palliative care in the United States. Omega: *Journal of Death & Dyin, 56*(1), 89-99. doi: 10.2190M.56.1.h

Department of Health and Human Services, Office of the Inspector General. (2007) *Medicare hospices; Certification and centers for Medicare & Medicaid services oversight* (DHHS *Publication No*. OEI-06-05-00260). Washington, DC: Daniel Levinson, Inspector General.

Department of Health and Human Services, Office of Inspector General. (1997). *Hospice patients in nursing homes* (DHHS Publication No. OEI- 05-95-00250). Washington, DC: U.S. Government Printing Office. Retrieved from https://oig.hhs.gov/oei/reports/oei-05-95-00250.pdf

Dobbs, D.J., Hanson, L., Zimmerman, S., Williams, C. S., & Munn, J. (2006). Hospice attitudes among assisted living and nursing home administrators, and the long-term care hospice attitudes scale. *Journal of Palliative Medicine, 9*, 1388-1400. doi:0.1089/jpm.2006.9.1388

Ersek, M., Grant, M. M., & Kraybill, M. (2005). Enhancing end-of-life care in nursing homes: palliative care educational resource team (PERT) program. *Journal of Palliative Medicine*, *8*, 556-566.doi: 10.1089/10966210360510118

Ersek, M., & Wilson, S. A. (2003). The challenges and opportunities in providing end-of-life care in nursing homes. *Journal of Palliative Medicine, 6*(1), 45-57. doi: 10.1089/jpm.2005.8.556

Feudtner, C., Kang, T. I., Hexem, K.R., Friedrichsdorf, S. J., Osenga, K., Siden, H., …Wolfe, J. (2011). Pediatric palliative care patients: A prospective multicenter cohort study. *Pediatrics, 127*(6), 1094-1101. doi: 101542/peds2010-3225.

Gelman, A. & Hill, J. (2007). *Data analysis using regression and multilevel/hierarchical models.* New York, NY: Cambridge University Press.

Gozalo, P. L., & Miller, S. C. (2007). Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. *Health Research and Educational Trust, 42*(2), 587-610. doi: 10.1111/j.1475-6773.2006.00623.x

Greiner, L., Buhr, B., Phelps, D., & Ward (2003). A palliative care needs assessment of health care institutions in Wisconsin. *Journal of Palliative Medicine, 6*(4), 543-556. doi: 10.1089/109662103768253650

Hanson, L. C., & Henderson, M. (2000). Care of the dying in long-term care settings. *Clinics in Geriatric Medicine, 16*(2), 225-237.

Hanson, L. C., Henderson, M., & Menon, M. (2002). As individual as death itself: A focus group study of terminal care in nursing homes. *Journal of Palliative Medicine, 5*(1), 117-125. doi: 10.1089/10966210252785088

Hanson, L. C., Reynolds, K. S., Henderson, M., & Pickard, C. G. (2005). A quality improvement intervention to increase palliative care in nursing homes. *Journal of Palliative Medicine, 8*(3), 576-584. doi: 10.1089/jpm.2005.8.576

Hanson, L. C., Sengupta, S., & Slubicki, M. (2005). Access to nursing home hospice: Perspectives of nursing home and hospice administrators. *Journal of Palliative Medicine, 8*(6), 1207-1213. doi: 10.1089/jpm.2005.8.1207

Hodson, N., Landsberg, L., Lehning, A., & Kleban, M. (2006). Palliative care services in Pennsylvania nursing homes. *Journal of Palliative Medicine, 9*, 1054-1058. doi: 10.1089/jpm.2006.9.1054

Hill, T. E., Ginsburg, M., Citko, J., & Cadogan, M. (2005). Improving end-of-life care in nursing facilities: The community state partnership to improve end-of-life care in California. *Journal of Palliative Medicine*, *8*(2), 300-312. doi: 10.1089.jpm.2005.8.300

Huskamp, H. A., Buntin, M. B., Wang, V., & Newhouse, J. P. (2001). Providing care at the end of life: Do Medicare rules impede good care? *Health Affairs*, *20*(3), 204-211. doi: 10.1377/hlthaff.20.3.204

Institute for the Advancement of Social Work Research (2005). *Evaluating social work services in nursing homes: Toward quality psychosocial care and its measurement. (*A Report to the Profession and Blueprint for Action.). .Washington D.C: Vourlekis, B., Zlotnik, J. L., & Simons, K. Retrieved from www.iaswresearch.org.

Jang, Y., Chiriboga, D. A., Allen, J.Y., Kwak, K., & Haley, W. E. (2010). Willingness of Older Korean-American Adults to Use Hospice. *Journal of the American Geriatrics Society*, *58*, 352-356. doi: 10.1111/j.1532-5415.2009.02684.x

Johnson, V. M. P., Teno, J. M., Bourbonnier, M., & Mor., V. (2005). Palliative care needs of cancer patients in U.S. nursing homes. *Journal of Palliative Medicine*, *8*(2), 273-279. doi: 10.1089/jpm.2005.8.273

Keay, T. J., Alexander, C., McNally, K., Crusse, E., & Eger, R. E. (2003). Nursing home physician educational intervention improves end-of-life outcomes. *Journal of Palliative Medicine, 6*(2), 205-213. doi: 10.1089/109662103764978452

Knapp, C.A., Madden, V. L., Curtis, C. M., Slyer, P. J., Huan, I., Thompson, L. A., Shenkman, E. A. (2008). Partners in care: Together for kids: Florida's model of pediatric palliative care. *Journal of Palliative Medicine, 11*(9), 1212-1220. doi: 10.1089/jpm.2008.0080.

Kwak, J., Haley, W. E., & Chiriboga, D. A. (2008). Racial differences in hospice use and in-hospital death among Medicare and Medicaid dual-eligible nursing home residents. *The Gerontologist, 48*(1), 32-41.

Lepore, M. J., Miller, S. C., & Gozalo, P. (2011). Hospice use among urban black and white U.S. nursing home decedents in 2006. *The Gerontologist, 51*(2), 251-260. doi: 10.1093/geront/gnq093

Levy, C. Morris, M., & Kramer, A. (2008). Improving end-of-life outcomes in nursing homes by targeting residents at high-risk of mortality for palliative care: Program description and evaluation. *Journal of Palliative Medicine, 11*(2), 217-225. doi: 10.1089/jpm.2007.0147

Lu, C., & Johantgen, M. (2010). Factors associated with treatment restriction orders and hospice in older nursing home residents. *Journal of Clinical Nursing, 20,* 377-387. doi: 10.1111/j.1365-2702.2010.03346.x

McDonnell, M. M., McGuigan, E., McElhinney, J., McTeggart, M., & McClure, D. (2009). An analysis of the palliative care education needs of RGNs and HCAs in nursing homes in Ireland. *International Journal of Palliative Nursing, 15*(9), 446-455.

Meier D.E., Lim B., & Carlson M.D. (2010). Raising the standard: palliative care in nursing homes. *Health Affairs*, *29*(1), 136-140. doi: 10.1377/hlthaff.2009.0912.

Miller, S. C., Gozalo P., & Mor, V. (2000). Outcomes and utilization for hospice and non-hospice nursing facility decedents. *Synthesis and analysis of Medicare's Hospice Benefit,* Washington, DC: U.S. Department of Health and Human Services. Retrieved from http://aspe.hhs.gov/daltcp/reports/2000/oututil.htm.

Miller, S. C., & Han, B. (2008). End-of-life care in U.S. nursing homes: Nursing homes with special programs and trained staff for hospice or palliative/end-of-life care. *Journal of Palliative Medicine, 11*(6), 866-877. doi: 10.1089/jpm.2007.0278

Miller, S. C., Intrator, O., Gozalo, P., Roy, J., Barber, J., & Mor, V. (2004). Long-stay nursing home residents: Differences by hospice enrollment status. Journal of the *American Geriatrics Society, 52*, 1284-1292.

Miller, S. C., Lima, J., Gozalo, P. L., & Mor, V. (2010). The growth of hospice care in U.S. nursing homes. *Journal of the American Geriatrics Society, 58*, 1481-1488. doi: 10.1111/j.1532-5415.2010.02968.x

Miller, S. C., Mor, V., Wu, N., Gozalo, P., & Lapane, K. (2002). Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *Journal of the American Geriatrics Society, 50*(3), 507-515. doi: 10.1046/j.1532-5415.2002.50118.x

Miller, S. C., Teno, J.M., & Mor, V. (2004). Hospice and palliative care in nursing homes. *Clinics in Geriatric Medicine*, 20, 717-734. doi: 10.1016/j.cger.2004.07.005

Munn, J., & Adorno, G. (2008). By invitation only: Social work involvement at the end of life in long term care. *Journal of Social Work and End of Life and Palliative Care*, *4*(4), 333-357.

Munn, J. C., Zimmerman, S., Hanson, L. C., Williams, C. S., Sloane, P. D., Clipp, E. C., … Steinhauser, K. E. (2007). Measuring the quality of dying in long-term care. *Journal of the American Geriatrics Society, 55*(9), 1371-1379. doi: 10.1111/j.1532-5415.2007.01293.x

National Association of Social Workers (2008) *Code of ethics*. Washington, DC.

National Center for Health Statistics (2008). *2004 National Nursing Home Survey: Nursing Home Current Residents* [Data file]. Retrieved from http://www.cdc.gov/nchs/data/nnhsd/Estimates/nnhs/Estimates_Diagnoses_Tables.pdf

National Center for Health Statistics (2011) *2004 National Nursing Home Survey and National Nursing Assistant Survey* [Data file]. Retrieved from www.cdc.gov/nchs/data/nnhsd/2004NNHS_DesignCollectionEstimates_072706tags.pdf

National Hospice and Palliative Care Organization (2010a). What is hospice and palliative care? Retrieved from www.nhpco.org/i4a/pages/index.cfm?pageid=4648

National Hospice and Palliative Care Organization (2010b). *History of hospice care.* Alexandria, VA. Retrieved from www.nhpco.org/i4a/pages/index.cfm?pageid=3285

National Hospice and Palliative Care Organization (2010c). *NHPCO facts and figures: Hospice care In America*. Alexandria, VA. Retrieved from http://www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf

Nasvadi, G. E. & Wister, A. V. (2006). Informal social support and use of a specialized transportation system by chronically ill older adults. *Environment and Behavior, 38*(2), 209-225. doi: 10.1177/0013916505277605

Parker-Oliver, D., Porock, D., Zweig, S., Ranitz, M., & Petroski, G. F. (2003). Hospice and nonhospice nursing home residents. *Journal of Palliative Medicine, 6*(1), 69-75.

Phillips, J., Davidson, P.M., Jackson, D., Kristjanson, L., Daly, J., & Curran, J. (2006). Residential aged care: The last frontier for palliative care. *Journal of Advanced Nursing, 55*(4), 416-425. doi: 10.1111/j.1365-2648.2006.03945.x

Reynolds, K., Henderson, M., Shulman, A., & Hanson, L.C. (2002). Needs of the dying in nursing homes. *Journal of Palliative Medicine, 5*(6), 895-901.

Rice, K., Coleman, E. A., Fish, R., Levy, C. & Kutner, J. S. (2004). Factors influencing models of end-of-life care in nursing homes: Results of a survey of nursing home administrators. *Journal of Palliative Medicine, 7*, 668-675.

Stevenson, D. G. & Bramson, J. S. (2009). Hospice care in the nursing home setting: A review of the literature. *Journal of Pain and Symptom Management, 38*(3), 440-451. doi: 10.1016/j.jpainsymman.2009.05.006.

Temkin-Greener, H., Zheng, N., Norton, S. A., Quill, T., Ladwig, S., & Veazie, P. (2009). Measuring end-of-life care processes in nursing homes. *The Gerontologist, 49*, 803-815. doi: 10.1093/geront/gnp092

Tilly, J. & Folk, A. (2008). Policy barriers to quality end-of-life care for residents with dementia in assisted living residences and nursing homes. *Alzheimer's Care Today, 9*(2), 103-112.

U.S. Department of Health and Human Services. (2006). *The Supply and Demand of Professional Social Workers Providing Long-Term Care Services*. Report to Congress. Washington, DC. Retrieved from http://aspe.dhhs.gov/daltcp/reports/2006/SWsupply.htm.

Wallace, S. P., Levy-Storms, L., Kington, R. S., & Andersen, R. (1998). The persistence of race and ethnicity in the use of long-term care. *Journal of Gerontology, 53B*(2), S104-S112.

Welch, L. C., Miller, S. C., Martin, E. W., & Nanda, A. (2008). Referral and timing of referral to hospice care in nursing homes: The significant role of staff members. *The Gerontologist, 48*(4), 477-484. doi: 10.1093/geront/48.4.477

Wister, A. V., Malloy-Weir, L. J., Rootman, I., & Desjardins, R. (2010). Lifelong educational practices and resources in enabling health literacy among older adults. *Journal of Aging and Health, 22*(6), 827-854. doi: 10.1177/0898264310373502.

Wowchuk, S. M., McClement, S., & Bond, J. (2007). The challenge of providing palliative care in the nursing home part II: Internal factors. *International Journal of Palliative Nursing, 13,* 345-350.

Zastrow, C.H. & Kirst-Ashman, K.K. (2013). *Understanding human behavior and the social environment* (9th Edition). Belmont, CA: Cengage.

Zerzan, J., Stearns, S., & Hanson, L. (2000). Access to palliative care and hospice in nursing homes. *Journal of American Medical Association, 284*(19), 2489-2494.