
Theses, Dissertations, and Projects

2016

Hospice social work and the Patient Protection and Affordable Care Act

Christine A. Couture
Smith College

Follow this and additional works at: <https://scholarworks.smith.edu/theses>



Part of the [Social Work Commons](#)

Recommended Citation

Couture, Christine A., "Hospice social work and the Patient Protection and Affordable Care Act" (2016).
Masters Thesis, Smith College, Northampton, MA.
<https://scholarworks.smith.edu/theses/1709>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

ABSTRACT

This study was undertaken to explore how hospice social workers based at United States hospice agencies perceive changes in their work responsibilities in relation to the Patient Protection and Affordable Care Act (PPACA). Secondly, this study sought to explore hospice social worker support of the Patient Protection and Affordable Care Act healthcare policy reform.

A nonprobability sample of availability was used to find research participants. The researcher recruited participants through online social and professional networking groups and forums and by snowball sampling methods. Self-selected participants electronically confirmed their eligibility for participation in the study, prior to completing the 20-question online survey. Fourteen hospice social workers, representing 11 separate states, participated.

The findings of the research showed study participants did not identify any substantial changes in their work-related duties after the PPACA took effect. Within the five categories examined—clinical and counseling, case management, management and administration, advocacy, and spiritual and cultural competence—which vary widely in the amount of perceived change, participants reported experiencing the most increase and overall change in case management duties. The study also found that, overall, hospice social workers who responded to the survey supported the PPACA. Many hospice social workers commented on the ethical dilemma of delivering inadequate services within a health care model that does not meet the needs of all end-of-life care recipients and those in need of end-of-life care.

**HOSPICE SOCIAL WORK AND THE PATIENT PROTECTION
AND AFFORDABLE CARE ACT**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Christine Couture

Smith College School for Social Work
Northampton, Massachusetts 01063

2016

ACKNOWLEDGEMENTS

This thesis could not have been accomplished without the assistance of many people whose contributions are gratefully acknowledged.

I wish to thank my research professor, Gail, for brainstorming on the swing; my research advisor, Mary Beth, for her patience and many motivational phone sessions; my editor, Julia, for her attention to detail and Word shortcuts; Cassidy, for her review and feedback; Beka, for Thursdays and baked goods; Helen Marie, for her ever-present support; Jim, for his sacrifice and encouragement; and my father, whose death inspired my interest in hospice.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES	iv
LIST OF FIGURES	v
CHAPTER	
I INTRODUCTION.....	1
II LITERATURE REVIEW.....	4
III METHODOLOGY.....	65
IV FINDINGS	71
V DISCUSSION.....	82
REFERENCES	100
APPENDICES	
Appendix A: Human Subjects Review Application.....	119
Appendix B: Research Project Change of Protocol Submission	128
Appendix C: Electronic Informed Consent to Participate in a Research Study	130
Appendix D: Study Instrument	132
Appendix E: LinkedIn Recruitment Post.....	139
Appendix F: LinkedIn Group Owner/Manager Correspondence.....	140
Appendix G: Facebook Recruitment Post.....	141

LIST OF TABLES

Table

1. States Represented by Survey Participants..... 72
2. Years of Professional Experience in Social Work and in Hospice 73

LIST OF FIGURES

Figures

1. Changes in time spent on work-related responsibilities	75
2. Clinical and counseling-related work responsibilities.....	76
3. Spiritual and cultural competence-related work responsibilities.....	77
4. Case management-related work responsibilities	78
5. Administrative and management-related work responsibilities	79
6. Advocacy-related work responsibilities	80

CHAPTER I

Introduction

The purpose of this study was to explore how hospice social workers working for United States-based hospice agencies perceive changes in their work responsibilities in relation to the Patient Protection and Affordable Care Act. This study examined the relationship of these changes within the following contexts: hospice social workers at for-profit agencies and those at not-for-profit agencies; states that accepted the Medicaid expansion and states that did not; and states that offer the optional Medicaid Hospice Benefit and those that do not.

The Patient Protection and Affordable Care Act (PPACA) HR-3590 (2010), or Affordable Care Act for short, is the federal health care reform statute signed into law in 2010 by President Barack Obama. Often called by its nickname, Obamacare, this reform act includes two pieces of legislation: the Patient Protection and Affordable Care Act (Public Law 111-148, 2010) and the Health Care and Education Reconciliation Act of 2010 (Public Law 111-152, 2010). This historical and highly controversial legislation expanded Medicaid coverage to millions of low-income Americans and made numerous improved changes to both Medicaid and the State Children's Health Insurance Program (SCHIP or CHIP). It also included amendments to other laws like the Food, Drug and Cosmetics Act and the Health and Public Services Act.

Several provisions of the PPACA (2010) are directly relevant to hospice care. For example, hospice facilities are now required to report quality measures to The Centers for Medicare and Medicaid Services (CMS) of the U.S. Department of Health and Human Services

or face a reduction in Medicare and Medicaid payments. Additionally, under the PPACA, children enrolled in Medicare or Children's Health Insurance Program (CHIP) will now be allowed access to both hospice and curative/life-prolonging care (also known as *concurrent care*) at the same time. Lastly, there are provisions for research to evaluate a new model of reimbursable care that allows adult Medicare recipients access to concurrent care. Presently, adults cannot access concurrent care through the highly standardized Medicare Hospice Benefit; patients and their caregivers may only elect to access either curative/life-prolonging care or hospice. Under the PPACA, this new model of reimbursable care will be evaluated for potential expansion (Meier, 2011).

Unlike many terms used to describe phases of end-of-life care, there is consensus on what constitutes *hospice care*. Hospice falls under the umbrella of palliative care; the two are often paired as hospice and palliative care in end-of-life literature (Bausewein & Higginson, 2012; Billings & Block, 1997; Hui, Mori, Parsons, Kwon, Torres-Vigil, & Bruera, 2013). Hospice is predominantly a community-based program that provides interdisciplinary, multidimensional care for patients with terminal illness and their families, working in conjunction with volunteers to provide services ranging from symptom management to bereavement care. Information is limited about current quality measures of palliative care and hospice programs, but the United States and other nations are investing in outcome measures for quality improvement and public reporting (Anderson & Squires, 2010). In fact, PPACA provisions increase quality-measure reporting requirements for hospice agencies that accept Medicaid and CHIP funding.

Many experts have made projections on how the changes dictated by PPACA will affect health care services, including the potential impact on the hospice and palliative care workforce. In the last 15 years, the number of hospice programs in the United States has grown by 47%

(Medicare Payment Advisory Commission, 2009, 2010b; National Hospice and Palliative Care Organization, 2010). This growth in hospice programs, as well as a 74% increase in the number of people served by hospice (Medicare Payment Advisory Commission, 2009, 2010b; National Hospice and Palliative Care Organization, 2010), illustrates a rising demand for hospice care services. Additionally, due to increased regulatory requirements, forecasters have anticipated a large increase in work responsibilities for hospice physicians in a field that already has demonstrated a need for more resources (Lupu, 2010). This need was underscored by a report commissioned by the Health Resources and Services Administration (HRSA) in 2002 that projected significant shortfalls in the nation's number of palliative medicine specialists (Connor, Elwert, Spence, & Christakis, 2007). The 2002 report also called for an examination of the appropriate role of non-physician professionals (such as nurse practitioners, clinical social workers, and physician assistants) in strengthening access to palliative care across health care settings.

The role of social work is still being defined within modern health care, specifically with regard to facing advanced illness and end-of-life care (Brandsen, 2005; Jones, 2005). Bosma et al. (2010) stated that, "The lack of a clearly defined [social work] identity has contributed to other professionals' confusion about what social workers actually do in hospice palliative care." Consequently, other professions often have inadequate knowledge about the complexity and value of social work practice in this area (Oliviere, 2001; Thompson, Rose, Wainwright, Mattar & Scanlan, 2001; Christ & Sormanti, 2000).

CHAPTER II

Literature Review

The Patient Protection and Affordable Care Act (PPACA) HR-3590 (2010), or Affordable Care Act for short, is the federal health care reform statute signed into law in 2010 by President Barack Obama. This historical legislation expanded Medicaid coverage to millions of low-income Americans and made numerous changes to both Medicaid and the State Children's Health Insurance Program (SCHIP or CHIP). To illustrate the current climate of hospice social work since the PPACA was passed into law, this literature review will explore important factors related to the PPACA, health care in the United States prior to the PPACA, hospice care, and the field of social work. First, I will provide a general overview of the PPACA, followed by a broad outline of health care in the United States and issues related to the health care system's policies that led to the PPACA. Then, I will define hospice care and review its history in the United States, including PPACA changes that pertain to hospice services. After exploring hospice care, I will review the role of social work in end-of-life care in the United States. Finally, I will summarize the literature pertaining to the implications of the PPACA for direct service workers, and will provide a theoretical framework to help understand how hospice social workers are impacted by this legislation.

The Patient Protection and Affordable Care Act of 2010

The PPACA is considered the greatest health care reform in the United States since implementation of Medicaid in 1965 and Medicare in 1966 (Cerminara, 2011; Morrison, 2013).

The massive 900-page legislation outlines many significant changes to the current rules and regulations of health care coverage for citizens of the United States (PPACA, 2010). One of the most significant changes as a result of this legislation is a mandate for all individuals in the United States to obtain health insurance coverage (PPACA, §36); otherwise, noncompliant citizens will be required to pay an annual fine to the federal government. Prior to this legislation, the United States was “the only country in the industrial world to depend on employer-based, voluntary health insurance” (Jimenez, 2010, p. 353). This legislation has resulted in a significant nationwide increase in individuals who have health care coverage by removing pre-existing medical conditions and high premiums as barriers for individuals who want to purchase health insurance, and by expanding Medicaid for states that chose to participate (Kaiser Family Foundation [KFF], 2014).

The PPACA helped to address several critical barriers to obtaining coverage for many Americans. First, the legislation made denying patients health care coverage for pre-existing conditions illegal. Second, the legislation forced insurers to remove the lifetime cap for insured individuals. Third, the legislation lowered the threshold for individuals to qualify for Medicaid in participating states by removing the requirement that the individual, in addition to being poor, be in a particular category, such as disabled, a child, a parent, or elderly. Thus, for the first time since the creation of Medicaid in 1965, all poor, childless, able-bodied adults are eligible for Medicaid in states that are participating in the expansion (KFF, 2014). Fourth, the law created a federal subsidy for documented citizens earning between 100% and 400% of the Federal Poverty Limit to make the insurance premium more affordable for those purchasing insurance on the individual market (KFF, 2014). After the Supreme Court decision in *National Federation of Independent Business v. Sebelius* (2012), states were able to opt out of the Medicaid expansion

that, up until that point, had been mandatory. As of November 2015, 30 states and the District of Columbia had voluntarily expanded Medicaid (KFF, 2015). One state, Utah, was considering expanding Medicaid (KFF, 2015). The remaining 19 states had not adopted Medicaid expansion (KFF, 2015).

By addressing the previously mentioned critical barriers to basic coverage, the PPACA helped to make health insurance more accessible to individuals who previously could not afford, or were denied, coverage. Health insurance coverage helps citizens save money on health care costs, which is important considering that 62.1% of all bankruptcies in 2007 were medical-related (Himmelstein, Thorne, Warren, & Woolhandler, 2009). In addition, having insurance could improve individuals' overall health and provide access to benefits otherwise unavailable to uninsured patients—for example, hospice care.

Health care in the United States prior to the Patient Protection and Affordable Care Act

Health care in the United States is a complicated system of policy regulations and funding streams largely based on a market economy dominated by private insurance coverage programs. While many Americans remain uninsured, individuals who do receive health insurance obtain their coverage largely through private insurance providers or public insurance known as Medicare and Medicaid (Jimenez, 2010). These private and public insurance plans vary in their costs for coverage, criteria for eligibility, access to benefits, and quality of service.

Private health insurance. Individuals who are employed can often obtain private insurance through their employer-sponsored health care benefit plans. In 2007, approximately 59% of insured individuals were covered through an employer-based health insurance plan (Jimenez, 2010). Individuals who are unemployed or self employed can purchase insurance directly from private health insurance providers if they can afford to pay for the cost of the health

plan(s) offered; however, these non-employer sponsored plans can be cost prohibitive for many individuals and families. For example, in 2007, private health insurance for a family of four in an urban area in the United States costs an average of \$20,000-40,000 a year (Jimenez, 2010).

Both employer-sponsored health plans and plans offered directly through a private health insurance provider may not be affordable for many workers. These plans usually require recipients to pay a portion of their premium costs, deductibles, and co-payments for services. For services not covered under their plan, many people are faced with the decision to pay for the cost out-of-pocket, forgo care, or incur debt to pay for the service.

Additionally, employers providing insurance can change the plans they offer as frequently as every year, which can disrupt the continuity of care for an individual, potentially resulting in a decreased quality of care. In order for employees to have their health insurance covered for their health care needs (either at full cost until they meet a deductible, partial-cost, or no-cost), they need to see a health care provider who is in their insurance company's provider network, and thus might need to switch from their previous providers if their employer changes insurance plans.

United States Census Bureau (2010) figures show that in 2009, the year before the passage of PPACA, 63.9% of the population reported they had private health insurance, 55.8% of which reported they had obtained their health insurance through their employer. In 2014, the percentages of people who had private health insurance (including plans purchased with federal subsidies on health insurance exchanges) or employer-sponsored health insurance were 66% and 55.4%, respectively (U.S. Census Bureau, 2015).

Public health insurance. Uninsured individuals can participate in public health care insurance if they meet eligibility criteria. The largest programs are Medicare and Medicaid, and

the Veterans Health Administration (VHA), which provides health care to military veterans. Under these programs, the majority of a person's essential health care costs are subsidized by the government. Medicare is limited to people who are either disabled or older than 65 years and who have paid into the Medicare system through payroll taxes. Prior to the PPACA, the eligibility criteria for Medicaid varied from state to state, effectively making 51 different Medicaid programs in the country; coverage was limited to people who were poor and were either a child, a parent, pregnant, disabled, or elderly. Though Medicaid benefits are fairly comprehensive, including prescription drugs and long-term care, many enrollees found it difficult to locate providers who accepted Medicaid due to its low reimbursement rate (Jimenez, 2015; Morrison, 2013). Some state and local governments had programs that provided limited health care for people who did not qualify for Medicare or Medicaid, such as undocumented immigrants and people categorized as poor, childless, able-bodied adults; most of these people are now eligible for Medicaid if they live in states participating in the Medicaid expansion authorized by the PPACA.

A 2010 United States Census Bureau report showed that the percentage of the population with government health insurance in 2009, the year prior to the signing of the PPACA, was 30.6%. That same year, the percentage of people receiving Medicaid or Medicare was 15.7% and 14.3%, respectively (U.S. Census Bureau, 2010). Individuals who have Medicare and are poor according to eligibility criteria can also receive Medicaid. In 2014 the percentage of the population that received government health insurance rose to 36.5%, with 19.5% receiving Medicaid benefits and 16% receiving Medicare (U.S. Census Bureau, 2015).

Uninsured individuals. There are many reasons why a person might forgo having health insurance. Some individuals do not have access to insurance through an employer because they

are either unemployed, or self-employed and cannot afford to pay the high costs of private health insurance. Others may be employed, but either their employer does not offer insurance or the employee is unable to afford the options provided to them by the employer (Jimenez, 2015). Other individuals choose not to purchase health insurance due to religious or political reasons. However, some insurers have denied coverage to individuals who want to purchase insurance for having pre-existing health conditions (Jimenez, 2015). Individuals no longer covered by insurance because they reached the lifetime financial cap of their insurance coverage are also effectively uninsured. These caps set a maximum dollar amount an insurer will provide during the lifetime of a payee. Others who are uninsured may be eligible to enroll in a government-provided health plan but have limited health literacy and thus do not enroll because they do not know where or how to enroll, have difficulty completing the paperwork involved in enrollment, or assume they are ineligible and thus do not attempt to enroll (Sentell, 2012).

With the implementation of the PPACA, the United States has seen a decrease in number of uninsured individuals. According to the United States Census Bureau, in 2009, the year before the PPACA was signed into law, 16.7% of people were uninsured (U.S. Census Bureau, 2010). In 2014, this percentage decreased to 10.4% (U.S. Census Bureau, 2015).

Hospice Care in the United States

Definitions of hospice care, palliative care, and end-of-life care

Hospice care. According to the National Hospice and Palliative Care Organization, hospice care is considered “the model for quality compassionate care for people facing a life-limiting illness” (National Hospice and Palliative Care Organization [NHPCO], 2015, p. 3). Similarly, the National Association of Social Workers defines hospice care in terms of *hospice and palliative care*, calling it, “the model for quality, compassionate care for people facing life-

limiting illnesses or injuries” (National Association of Social Workers [NASW], 2004, p. 11). A health care service offered during a dying patient’s end-of-life phase of treatment, hospice provides comprehensive, interdisciplinary, team-based medical care, pain management, and emotional and spiritual support to the patient, their families, caregivers and loved ones, based on the patient’s needs and wishes, regardless of their terminal illness, age, religion, or race (NHPCO, 2015). The United States Department of Health and Human Services (HHS) Centers for Medicare & Medicaid Services (CMS) defines hospice care as “a comprehensive set of services . . . identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care” where terminally ill means that “the individual has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course” (Centers for Medicare & Medicaid Services [CMS], 2008, p. 32204). Commonly, patients, caregivers, providers, and the general public do not know the difference between *hospice* and *nonhospice palliative care* (Unroe & Meier, 2011).

Palliative care. While palliative care is a primary and predominant service of hospice care, it sometimes is offered outside of the context of hospice services, and occasionally is considered nonhospice palliative care (Unroe & Meier, 2011). For persons who are living with serious, complex, and life-threatening illnesses, nonhospice palliative care may be offered simultaneously with life-prolonging and other curative treatments (Unroe & Meier, 2011). The NASW defines palliative care as “an approach that improves quality of life for patients and their families facing the problems associated with life-limiting illness” (2004, p. 10). The definition of palliative care, according to the National Quality Forum and Centers for Medicare & Medicaid Services, states:

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. (National Quality Forum [NQF], 2006; CMS, 2008)

Independent of an individual's prognosis, palliative care aims to assist and support patients, their families, and caregivers in improving the patient's quality of life by matching their established goals with treatment (Meier, 2011); minimizing pain and discomfort; relieving patient suffering; helping to mobilize community resources to support patients, their families and caregivers in their homes; and collaborating to coordinate care across settings (Unroe & Meier, 2011). In addition, palliative care encompasses assessment and treatment of symptoms such as pain, nausea, and shortness of breath.

End-of-life care. The NASW defines end-of-life care as a “multidimensional assessment and interventions provided to assist individuals and their families as they approach end of life” (2004, p. 9). The term end-of-life refers to the phase or stage of medical treatment when an individual is diagnosed with a life-limiting or terminal illness. Interventions and types of assessments during this phase can vary greatly and include curative care or palliative care, with or without advance directives. During this phase of medical treatment, when the patient is facing advanced stages of the disease, the patient and/or his caregivers determine whether they want to continue with non-hospice life-prolonging, curative care or with palliative, hospice care. However, end-of-life care usually denotes hospice care or palliative care, and, oftentimes, both. Life-prolonging, curative care is medical team-directed treatment that often includes invasive interventions, using whatever means necessary to increase the potential for extending the

patient's life to its maximum duration, regardless of how that treatment may affect the patient's quality of life. For example, the use of a ventilator for an individual who cannot breathe on his or her own, and thus would die without the aid of a ventilator, would be considered life-prolonging care. Often these interventions can be invasive and can have severe, sometimes fatal, side effects; for example, surgery or chemotherapy treatment. Decisions on types of interventions and treatments can be influenced by psychosocial, spiritual, and cultural factors, as well as insurance coverage and medical team consultation.

History of hospice in the United States

Hospice care in the United States began as an international multidisciplinary movement in the mid-1950s to mid-1970s inspired, in large part, by Dr. Cicely Saunders in the United Kingdom (D. Clark, 2001; Connor, 2007; Reese, 2013). In the late 1950s, Saunders was working as a research fellow studying terminally ill cancer patients at the Catholic church-affiliated St. Joseph's Hospice in Hackney, London (D. Clark, 2001). Before obtaining her physician status, Saunders was trained as both a nurse and medical social worker, which likely grounded her support and philosophy of interdisciplinary teamwork in providing care for the dying. Saunders believed there were five main areas important to understanding and working in end-of-life care that lacked the focus and attention they deserved in contemporary practice: problems with medication pain management, psychological problems of dying patients, cooperation with and training of hospital chaplains, the problems of the bereaved, and hospice centers or "homes" (C. Saunders, personal communication to Mildred Allen, September 6, 1962, as cited in D. Clark, 2001, p.18).

While touring the United States to collaborate with others on her interest in end-of-life care, Saunders met with the dean of the Yale School of Nursing, Florence Wald, MS, RN, and

delivered a series of lectures on hospice care to the Yale School of Medicine's students' council and the faculty of post-graduate nursing (D. Clark, 2001; Connor, 2007). Saunders reported that Wald was highly moved by her lecture, reportedly remarking, "This is what we have lost and this is what we need" (C. Saunders' Report of Tour in the United States of America, Spring 1963, unpublished, as cited in D. Clark, 2001, p. 20). A friendship and long-term collaborative relationship formed between Saunders and Wald, and concurrently with Yale University; Saunders was invited to return to Yale School of Nursing to continue her lectures (D. Clark, 2001). After this visit, Saunders began writing for American journals on the topics of facing death, the meaning of life itself, the last stages of life, and life's fulfillment. She also laid out plans to create a hospice with international links to the United States in the United Kingdom (which later became St. Christopher's Hospice in London) focused on research, teaching, and caring for the dying.

Across the United States, editors, professionals, and readers enthusiastically endorsed her published work (D. Clark, 2001). Saunders' American popularity and wide notice of her published works gained media attention leading to a *Time* magazine article with her as the subject, stimulating public interest in the care of the terminally ill. In 1966, during her third visit to Yale University, Saunders met with Dr. Elizabeth Kübler-Ross and Dr. Colin Murray Parkes, a collaboration considered to be "a remarkable early triad of those whose names were to become synonymous with the modern care of the dying and bereaved" (D. Clark, 2001, p. 22).

In 1969, Dr. Elizabeth Kübler-Ross published one of the first United States-based studies on death and dying. She interviewed dying patients in hospitals and observed them in their environments, typically the hospital, to understand their unmet needs in the end-of-life process (Kübler-Ross, 1969). Her work on the five stages of dying is considered pioneering work by

other researchers in the psychology and end-of-life fields. Researchers who criticized her model noted a lack of theoretical foundation and omission of sociocultural contexts as limiting factors to the validity of its modern day application, and her hierarchical status as a physician as the basis for the model's widespread acceptance and praise (Hart, Sainsbury, & Short, 1998).

The first United States hospice—The Connecticut Hospice, founded by Wald—began serving patients in their homes in 1974 (Connor, 2007), “which stimulated the development of hospices across the country” (Unroe & Meier, 2011, p. 417). Less than a decade later in 1982, Wald and other advocates for hospice organized and lobbied the government to expand hospice services to patients insured by public assistance via the Medicare hospice benefit.

Hospice care delivery. By choosing hospice care, the patient—or, when appropriate, the primary caregiver—chooses to forgo life-prolonging interventions of treatment and instead use treatments that are exclusively palliative in nature. By entering hospice, the patient and his caregivers are eligible to receive counseling and support to help prepare for the patient's pending death. Interdisciplinary hospice team members assess the patient regularly and provide additional care or refer to other services, as needed. The interdisciplinary hospice team facilitates communication with patients and families to establish appropriate and realistic goals of care, known as “care plans,” in order to meet each patient's individual needs for pain management and symptom control (NHPCO, 2015; Unroe & Meier, 2011), as well as “support families in crisis and plan for safe transitions out of hospitals to more supportive settings” (Meier, 2011, p. 349).

The hospice team is on-call 24 hours a day, seven days a week; it “usually consists of the patient's personal physician, hospice physician or medical director, nurses, hospice aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists, if needed” (NHPCO, 2015, p. 3). For Medicare and

Medicaid certified hospices, the core standard of hospice services includes physician, nursing, medical social work, and counseling (bereavement, dietary, and spiritual) services (CMS, 2008, p. 32204). The hospice team supports the family caregiver(s) throughout the hospice delivery process and, after the patient's death, offers bereavement services to family members (Meier, 2011, p. 346). Hospice services can also include the coordination of care for the patient (Nelson, Gale, Naierman, & DeViney, 2014). Hospice care services are provided in home-based hospice, inpatient hospice care, freestanding hospice centers, hospitals, acute care hospitals, skilled nursing facilities, residential facilities, or long-term care facilities (Meier, 2011; Morrison, 2013; NHPCO, 2015).

The National Quality Forum (NQF) and the National Consensus Project for Quality Palliative Care (NCPQPC), confirm the aforementioned components of hospice delivery as some of the essential structural elements of quality palliative care, while adding that the staffing ratios are determined by the nature and size of the population to be served and that the staff are trained, credentialed, and/or certified in palliative care (Meier, 2011; NQF, 2006; National Consensus Project for Quality Palliative Care [NCPQPC], 2013).

Insurance coverage for hospice. There are multiple ways that individuals can pay for hospice benefits through their health insurance. In 1982, the United States government created the Medicare hospice benefit (Tax Equity and Fiscal Responsibility Act of 1982, §122). In 1986, a similar hospice benefit was added to Medicaid (Consolidated Omnibus Budget Reconciliation Act of 1985). While the Medicare hospice benefit is a federal benefit, the Medicaid hospice benefit is optional, meaning each state can choose whether or not to offer this benefit to people enrolled in Medicaid in their state. For individuals who are covered through an employer-sponsored insurance plan or through private insurance, hospice is not a required benefit that

insurers must offer; however, most insurers provide this benefit (NHPCO, 2014). The percentage of total Medicare expenditures made in the last year of a patient's life was 27.3% in 2012 (Medicare Payment Advisory Commission [MedPAC], 2015).

Process of eligibility for hospice care. The goal of hospice care is to maximize “comfort and quality of life, when curative treatments are no longer beneficial, when the burdens of these [curative] treatments outweigh their benefits, or when patients are entering the last weeks or months of life” (Meier, 2011, p. 346). Under most health insurance plans, in order to be eligible for hospice patients need to undergo a multi-step process and meet specific criteria. First, a patient must be diagnosed, or certified, with a terminal illness by a physician or nurse practitioner and have a prognosis of six months of life remaining. To be eligible for the Medicare hospice benefit, a Medicare patient must meet both general criteria (e.g., weight loss, frequent hospitalizations) and disease-specific criteria for a physician to make a prognosis of less than six months of life remaining (CMS, 2016). Second, the patient must sign a waiver removing his or her rights to access curative, life-prolonging treatment in exchange for the palliative care of hospice. Under most, if not all, health insurance plans, concurrent care, which is the coverage of both life-prolonging care and palliative hospice care, is not available as an option; the patient must choose between the two.

Barriers to hospice services. Insurance coverage does not seem to be the only barrier to people enrolling in hospice. For more than three decades, hospice care for terminally ill Medicare patients has been fully covered by their insurance; and yet, as of 2002, “less than one third of dying patients use [hospice] services” (Friedman, Harwood, & Shields, 2002, p. 73). There are numerous barriers to patients accessing hospice services; the most common barriers to qualifying patients receiving hospice services are a lack of public knowledge pertaining to the

value of palliative care and hospice care (Friedman et al., 2002; Meier, 2011); workforce shortage of clinical hospice professionals as a result of an increased demand (Meier, 2011); delayed referrals (Friedman et al., 2002; Meier, 2011); issues within the hospice system (Friedman et al., 2002); access issues due to geographic location (Fisher, Bynum, & Skinner, 2009; Friedman et al., 2002; Goldsmith, Dietrich, Du, & Morrison, 2008; Meier, 2011); and racial, ethnic and cultural disparities in health care (Del Rio, 2004).

Public knowledge. One barrier to hospice utilization pertains to the lack of knowledge about hospice by the patient and/or the primary caregiver (Friedman et al., 2002; Meier, 2011). Despite being a fixture of health care in the United States for more than 30 years, hospice care is largely misunderstood by the public (Dinger, 2005; Nelson et al., 2014; Sofaer, Hopper, Firminger, Naierman, & Nelson, 2009). A public opinion survey by the National Hospice and Palliative Care Organization in 1999 revealed that “80% of respondents do not know what the word *hospice* means and 90% are unaware that Medicare pays for hospice services” (as cited in Friedman et al., 2002, p. 74).

Workforce shortage. In addition to a lack of public knowledge of hospice care, another primary barrier to receiving quality palliative and hospice care is “an inadequate workforce and workforce pipeline to meet the needs of patients and their families” (Meier, 2011, p. 354). In the last decade, the number of hospice programs in the United States grew by 47% while the number of persons served by hospice increased by 74% (Meier, 2011, p. 354). From 2000 to 2009, the decade before the PPACA was passed into law, the percentage of Medicare decedents who used hospice for end-of-life care rose from 23% to more than 40% (MedPAC, 2010b; NHPCO, 2010; Meier, 2011).

Key barriers to access of hospice care services as they relate to workforce shortages are related to insufficient hospice and palliative care education and training for key members of the interdisciplinary team—especially primary and specialist-level physician, nursing, social work, and pharmacy education and training (Billings & Block, 1997; Meier, 2011; Weissman & Blust, 2005; Weissman, Mullan, Ambuel, & von Gunten, 2002). In addition, inadequate compensation and minimal student loan forgiveness opportunities serve as key barriers to meeting workforce capacity in hospice and palliative care (Gelfman & Morrison, 2008; Meier, 2011). In order to address the access barriers related to workforce shortages and to attract professionals into the field, hospice and palliative care agencies and government policies should provide financial incentive options encouraging workforce development and organizational commitment (Gelfman & Morrison, 2008; Meier, 2011).

Later in this section, the literature on workforce shortages in rural settings as a critical barrier to hospice care utilization will be reviewed in more detail. However, shortages exist even in settings where a palliative care team is available. Variability in accessible service staff for patients can range from part-time medical staff to a full interdisciplinary team (MedPAC, 2010b; Meier, 2011).

Delayed referrals. Late referrals make it more challenging for patients and their families to get the full benefit of what hospice care has to offer (Friedman et al., 2002), especially when coming to closure with end-of-life issues; patients and families can miss out, for example, on counseling, pain and symptom management, timely referral to resources, and nursing care (Casey, Moscovice, Virnig, & Durham, 2005, p. 364). Short lengths of stays can be detrimental to hospice organizations. A short stay can have a negative financial impact on an agency, since the services provided in the first and last few days of hospice care are usually the most costly.

Data from 2012 highlight the range of late referrals nationwide, with a low of 7.3 hospice days in the last six months of life for decedents in Alaska to a high of 36.1 hospice days in the last six months of life for decedents in Delaware (Dartmouth Institute for Health Policy and Clinical Practice, 2015a). These delays in hospice referrals can be attributed to physicians and other health care professionals, but also to patients, their primary caregivers, and the hospice system itself (Casey et al., 2005; Friedman et al. 2002; MedPAC, 2004; United States General Accounting Office, 2000).

Physicians and other health care professionals. Referral delays on the part of physicians or other health care professionals can be attributed to several factors, including postponement of either educating the patient about the hospice option or triggering the process of transition to hospice care, inability to prognosticate the course of a disease, and training. Physicians and other health care professionals can delay educating the patient and their families about hospice services or postpone triggering the process of entering the patient into the hospice care system in lieu of a viable curative treatment. Based on research by Friedman et al., “Physicians often do not refer to hospice or delay referring to hospice because they maintain an optimistic view of the patient’s prognosis weeks and even days before death” (2002, p. 74).

Additionally, despite current advanced medical technology, there is no way to accurately prognosticate the course of a disease, especially in cases of chronic illness (Friedman et al., 2002; Kramer, 2013). At the end of the 21st century, 53% of hospice patients died from cancer; in the last decade, 31% of hospice decedents had cancer while 69% died from chronically debilitating diseases such as frailty, atherosclerotic and respiratory disease, and dementia (MedPAC, 2010b). Predicting prognosis of the majority of current hospice patients’ diseases is difficult and nearly uncertain (Meier, 2011).

Another major contributor to the variability of patients' access to hospice is associated with the variability in physician practice patterns, awareness, and training (Meier, 2011). Traditionally, physician training suggests that the overall goal of treatment is to improve the health of the patient by all means necessary. Once a physician has determined that an illness is terminal and the patient's death is imminent, it is implied that the physician's treatment and the available technology have failed the patient.

Patients and their primary caregivers. Similar to physicians and other health care professionals, the patient and their primary caregivers can have a difficult time accepting that every possible treatment option has been attempted or considered, and that further treatment would be at best futile, at worst harmful. This resistance to accept that all treatment has been considered could be attributed to a historical distrust of the health care system and medical professionals, especially from patients with marginalized identities, which will be discussed further in this chapter. For example, Stein and Sherman (2005) describe a scenario where a patient's cultural beliefs or religion could delay seeking help from a doctor for a life-threatening illness. "Many cultures seek help from local healers or places of worship before looking to Western medicine for care" (Stein & Sherman, 2005, p. 1279).

Avoiding acceptance of death by the patient or patient's family can get in the way of an accurate prognosis and result in a delayed referral to hospice. In 2013, the median length of service for a patient in hospice care was 18.5 days, with almost a third, 34.5%, of patients dying or being discharged within 7 days of admission (NHPCO, 2014). These numbers suggest that a large number of patients are referred late, when the fate of the patient has become very clear.

Hospice system. Delays in patient hospice referrals are related to the *hospice system* (Fisher et al., 2009; Freidman et al., 2002; Goldsmith et al., 2008; Meier, 2011), which Freidman

et al. (2002) refer to as “regulations, financing, and hospice administration” (p. 75). Delayed referrals as a result of the hospice system can be linked to great variability and lack of standardization in the regulatory and accreditation requirements to access palliative care and hospice services. This variability has been associated with insurance coverage, agency financial issues, hospital size, ownership, and attending-physician biases. These barriers in the hospice system have been further complicated by tighter admissions policies and managed care directives, and narrowed definitions of what constitutes end-of-life among health care providers (Freidman et al., 2002).

The literature supports variability in hospice system guidelines due to insurance coverage and agency size. While some insurance plans do not provide a long-term hospice benefit, one study participant in Freidman et al. (2002) referred to confusing and inconsistent policies across hospice agencies. One inconsistent policy of hospice agencies is admission of patients with specific treatment needs; a participant in the study stated that, “Doctors recognize that some hospices will or won’t accept patients (receiving) certain treatments or that some types of medicine are or are not covered” (p. 80). Another reason for denying admission to hospice can be related to agency size and hospice guidelines; a study participant stated, “Many smaller hospices use the NHPCO guidelines as cut-offs because they do not have the census to afford more expensive treatments” (p. 80). These policies pertaining to reimbursement issues are not consistent across hospices, which can lead to confusion and physician discouragement in making hospice referrals.

Another reason for delayed referrals to hospice pertains to limitations in managed care plans. In managed care environments, health care providers can only use specific hospice agencies, which may have a reputation for inadequate care. Physicians are then forced to refer to

specific hospices covered under managed care despite the hospice's poor reputation. One participant stated that "hospices sometimes that are contracted with those specific HMOs—they don't provide the best care, but their patients don't have any other choice—they've got to use that agency" (Friedman et al., 2002, p. 80).

Acting as a last hospice-system barrier to appropriate referrals, Friedman et al. (2002) found that delayed referrals to hospice could be based on the attitudes and assumptions of hospice personnel. Qualitative data from the study quote one participant as stating, "Hospices can be fairly missionary about assuming their care is wonderful" (p. 80). Another participant stated, "Hospices are fairly aggressive in recommending care which sometimes leads to clashes with doctors" (p. 80). Casey et al. (2005) also support this discord between hospice staff and referring medical teams, which they suggest can make it difficult to build and maintain relationships, for example, when coordinating patient care.

Racial, ethnic, and cultural health care disparities. Disparities in health care treatment access and the quality of health care for the poor and people of color have been widely studied (KFF, 2012). Marginalized ethnic groups and people identifying with devalued non-mainstream cultures encounter serious health access problems. These racial, ethnic, and cultural populations experience explicit and implicit discrimination and often live in underserved communities where marginalized patients are struggling for greater access within a health care system with historic economic inequality and systematic oppression. Quality end-of-life care is yet another example of health care's pervasive inequality for non-White, marginalized racial, ethnic, and cultural groups (Del Rio, 2004). Current models of hospice care delivery are criticized for not serving all dying persons and for their lack of cultural sensitivity and relevance (Jennings, Ryndes, D'Onofrio, & Baily, 2003), which poses another critical barrier to access. In addition, Jennings

et al. (2003) specifically identified prisoners, refugees and immigrants, those with severe physical and mental disabilities, and homeless persons as not having sufficient access to suitable end-of-life care.

At the turn of the 21st century, two studies identified evidence of historical barriers that people of color have faced in accessing and receiving hospice services (Brenner, 1997; Gordon, 1996). Gordon (1996) found that hospice admission criteria blocked access for Blacks. Gordon also demonstrated that Hispanics faced the most hospice access and service problems primarily due to language needs, reimbursement, and severity of illness issues. In another study, Brenner (1997) examined statistics published by the National Hospice and Palliative Care Organization (NHPCO) of hospice usage from the previous year and argued that based on these statistics, hospice was relatively successful in serving middle-class, elderly White persons with cancer who had family members available and willing to care for them at home. Del Rio (2004) advanced Brenner's argument stating, "Hospices as a whole have not been successful in providing access to end-of-life care . . . to persons and illnesses which diverge from this basic profile" (p. 445). Hospices have not historically served a sizeable percentage of non-white decedents, despite being a model of care most incorporated into community settings (Del Rio, 2004; Jennings et al., 2003).

In nearly two decades, the statistics supporting Brenner's argument have not changed considerably. According to current information available from NHPCO (2015), hospices continue to serve a patient base comprised of 76% White, 24% non-White. Eighty-six percent of all patients served were covered by Medicare; 5% of all patients were covered by Medicaid; 84% of all patients were 65 years or older; 37% of all care provided by all hospice programs was provided to persons with cancer; and less than 1% of the total persons cared for by hospice had

AIDS. Although palliative care and hospice programs have experienced progress and evolution, many vulnerable populations continue to be underserved in end-of-life care.

Geographic location. Disparities in access to palliative and hospice care can be linked to patients' geographic location, especially in very rural areas, which impacts utilization rates of services (Casey et al., 2005; Connor et al., 2007; Meier, 2011; Reese, 2013). Based on data from 2012, a low of 24% hospice enrollment in the last six months of life existed for all decedents in Alaska and spanned a high of 65.4% in Arizona (Dartmouth Institute for Health Policy and Clinical Practice, 2015b). Though the gap in utilization rates across the United States has narrowed in the last decade, indicating an increase in access, in 2010 there were still “approximately 35 million individuals living in communities more than 30 minutes from a hospice and 6 million individuals in communities [living] more than 60 minutes from a hospice” (Carlson, Bradley, Du, & Morrison, 2010, p. 1335). The greatest challenges facing hospices that serve rural populations are primarily financial, staffing, physician referrals and coordination of care (Casey et al., 2005).

For multiple reasons, hospices in rural locations have a notably difficult time making ends meet. One study found that Medicare and insurance reimbursements were not sufficient to cover rural hospice costs, which forced struggling hospices to rely on fundraising and donations to help cover operating expenses (Casey et al., 2005). The participating rural hospices in this study listed their primary costs as the travel to patients' homes, the time spent traveling limiting time available for direct patient care, and medication costs. Despite the burden of additional travel expenses, the Medicare reimbursement rate for rural hospices is lower than non-rural hospices (Casey et al., 2005; Cerminara, 2011; Reese, 2013).

However, one of the greatest challenges facing rural hospices is recruiting and retaining staff in order to meet the hospice coverage requirement of 24 hours a day, seven days a week (Casey et al., 2005; Cerminara, 2011). Hospices in rural communities have claimed they do not have access to social workers with the required social work degrees for Medicare and Medicaid qualification (Reese, 2013). This challenge is exacerbated when rural hospices compete for talent with other health care facilities, resulting in staffing shortages, high staff turnover, and a large percentage of patients obtaining medical care outside the local community (Casey et al., 2005). The coordination of patient care becomes increasingly difficult for agencies where the staff is overworked, where there is considerable turnover, and where significant portions of its county's residents receive health care from providers outside of the community.

Hospice Social Work

History of social work in health care and hospice. Social workers have been providing services in end-of-life care for nearly half a century and have been providing health care services, which can include end-of-life care, for much longer. Before hospice was introduced in the United States, a period the literature frequently refers to as *the hospice movement*, social workers providing end-of-life care were working in other medical social work specializations. Researchers initially focused their attention on the roles, tasks, and responsibilities of social workers in medical settings (Lister, 1980; Olsen & Olsen, 1967). Literature summarizing changes in hospital social work sheds some light on the shifting climate of social work in hospital settings (Reisch, 2012), but does not specifically focus on hospice, palliative, or end-of-life care. Literature further supported hospital social work departments increasingly shifting from a social action and an advocacy focus in the mid-1970s, when the United States hospice movement gained momentum, to the development of productivity, outcome measures, and

specialization of function (Reisch, 2012; Ross, 1995; Rosenberg, 1987), which resulted in tension between the counseling and discharge planning functions of hospital social work (Davidson, 1978).

The historical literature documents ill preparedness and role overlap of hospice social workers in end-of-life care. In addition, a scarcity of research supporting positive outcomes of social work involvement has existed (Reese, 2013). Some literature highlights the threatened viability of social work in health care as having been considered a displaceable or ancillary resource by health care management (Kulys & Davis, 1987; Reisch, 2012). Some studies supported the notion that social workers were underprepared for roles in end-of-life care, especially with regard to ethics (Csikai, 2004) and their work with patients who did not meet the profile of the typical hospice patient (Huff, Weisenfluh, Murphy, & Black, 2006). Other research supported the view that hospital employees' perceptions of social workers' qualifications can depend largely on the relationships social workers have with key clinical staff (Landau, 2000).

The literature emphasizes how social workers can increase their influence by raising team members' awareness of social work's distinctive role (Landau, 2000; Lister, 1980), thus improving their relationships with team members and boosting the social work profession's reputation. Consequently, literature has documented social work leaders in end-of-life care as having made purposeful efforts to distinguish the field in its professional identity (Reese, 2011; Reese, 2013). These turn-of-the-century efforts have included studies supporting positive outcomes of social work involvement that will be discussed later in this chapter, outcomes which ultimately reflect the enduring role of hospice social work in addressing the biopsychosocial needs of patients and their families.

Ill-preparedness and role overlap. Many social workers and students of social work feel ill-prepared in serving clients in end-of-life care (Berzoff, Dane, & Cait, 2005; Berzoff et al., 2006; Christ & Sormanti, 2000; Csikai, 1997; Csikai & Bass, 2000; Csikai & Raymer, 2005; Dickinson, Sumner, & Frederick, 1992; Huff et al., 2006; Kovacs & Bronstein, 1999; Kramer, 1998; Sormanti, 1994), a sentiment underscored by a dearth of social work textbooks covering issues that would aid in preparing social workers in end-of-life care (Kramer, Hovland-Scafe, & Pacourek, 2003). One study, on ethical dilemmas in end-of-life care (Csikai, 2004), illustrates that social workers participating in ethics committees on the institutional level often struggle to assume a prevalent role in affecting end-of-life care policy and practice, despite the profession's advocacy for high standard of bioethical principles (NASW, 2004). Hospital ethics committees review difficult hospital cases in order to better serve future patients, educate staff, and formulate hospital policy (Stein & Sherman, 2005), which includes hospice care needs. Although social workers were members of approximately 75% of hospital ethics committees (Csikai, 1997; Skinner, 1991), Csikai reported that their "participation was moderate, with greatest involvement in 'traditional' social work activities, such as providing knowledge of community resources and acting as liaisons among patient, family, and providers" (2004, p. 68). In another study, on social work student preparedness with end-of-life care clients who do not meet the stereotypical demographic profile, social work students felt undereducated on the cultural needs of clients (Huff et al., 2006). Fifteen percent to 20% of social work students placed in end-of-life care internships reported they were engaged in services with clients of Hispanic and/or African-American decent. Each of these cultural and racial groups can have specific death practices important to them and these social work students reported feeling undereducated in the culture of each group.

However, ill-preparedness is only one criticism of social work involvement in health care and end-of-life care services; role overlap with the discipline of nursing and underutilization of social workers in hospice has motivated some researchers to investigate social work's distinctive function in medical settings. The literature (Hodgson, Segal, Weidinger, & Linde, 2004; Kramer, 2013; Kulys & Davis, 1987; Lister, 1980; Olsen & Olsen, 1967; Reese, 2011) identified an overlap in roles and responsibilities with other health care professionals, most often nurses. This role overlap between social workers and other health care professionals likely prompted these researchers to try to avoid bias by designing their research to survey interdisciplinary team members' perspectives of which role, task and responsibility social workers were most qualified to fill; they also surveyed volunteers, family members, primary caregivers, and patients (Hodgson et al., 2004; Kramer, 2013; Kulys & Davis, 1987; Lister, 1980; Olsen & Olsen, 1967; Reese, 2011).

One study found that social workers' impact on hospital wards depended on how key clinical staff viewed social work's role (Landau, 2000). If the social worker's role was limited in scope (for example, to discharge planning) he or she had less influence than if important clinical staff understood their role as more broad. For example, when principal staff viewed social workers as a resource for valuable knowledge or for having insightful perspectives, then social workers were seen by others as playing a more meaningful role.

Establishing a professional identity in hospice. Social work naturally responded to the field's changing political climate, the regulation of hospice care, and other health care initiatives affecting social workers in hospice and palliative care. Over time, leaders in the field have chosen to distinguish social work in end-of-life care from other social work specialties and professionals doing similar work by establishing a distinct professional identity in hospice and

palliative care. Although, the historical literature documented underutilization of hospice social workers (Hodgson et al., 2004; Kramer, 2013; Kulys & Davis, 1987; Lister, 1980; Olsen & Olsen, 1967; Reese, 2011) and ill preparedness of social workers in end-of-life care (Berzoff et al., 2005; Berzoff et al., 2006; Christ & Sormanti, 2000; Csikai, 1997; Csikai & Bass, 2000; Csikai & Raymer, 2005; Dickinson, Sumner, & Frederick, 1992; Huff et al., 2006; Kovacs & Bronstein, 1999; Kramer, 1998; Sormanti, 1994), including a dearth of social work textbooks covering issues that would aid in preparing social workers in end-of-life care (Kramer et al., 2003), recent literature and a history of deliberate efforts in the field have aimed to advance the professional identity of end-of life care social workers (Christ & Sormanti, 2000; Csikai & Raymer, 2005; Reese, 2011/2013; Reese & Raymer, 2004).

Understanding professional identity. The literature outlines different ways to understand professional identity. Sullivan (2005) conceives professional identity as a relational concept where an individual or group of individuals categorize themselves with a community of colleagues in a specific profession who share a collective value base (or purpose) and engage in joint efforts towards shared goals with a public value. Gustafson (1982) distinguishes three principal characteristics incorporated into all professions: people-oriented purpose, extensive knowledge base, and mechanisms of control. By creating people-oriented purpose, a profession ascertains that within the context of a greater environment or community it exists to meet others' needs (Gustafson, 1982). Through the institution of an extensive knowledge base, a profession requires individuals who identify with the greater purpose to gain an advanced understanding of theoretical, research-based, and technical knowledge specific to that profession. Last, with mechanisms of control, a profession safeguards capacities, obligations, and assessment on

professional activities through structured and consistent communal regulations (Netting, Kettner, McMurtry, & Thomas, 2012).

Since the mid-1990s, the field of hospice social work has set out to create a specialized profession and professional identity in response perhaps to role overlap with other professionals and underutilization of social work's unique skills and training on the interdisciplinary team (Reese, 2011). Reese describes these efforts:

. . . through improving social work education, increasing the number of social work scholars devoted to hospice research, defining the social work role in hospice, documenting social work outcomes, disseminating knowledge and providing continuing education to practitioners, and promoting the social work role in other disciplines. (pp. 387-389)

The social work profession has taken steps to clearly define its purpose in end-of-life care, expand its knowledge base, secure mechanisms of control, and propagate its specialized and valuable role.

Purpose. The literature supports social work's accomplishment of several professional milestones in clearly defining a purpose and promoting leadership roles for the professional advancement of social work in hospice and palliative care. First, in 1999, researcher Dr. Grace Christ created the Social Work Leadership Development Awards within the Project on Death in America (PDIA), which awarded 42 practice and research awards to advance social work leaders in the field of palliative care (Christ & Sormanti, 2000; Reese, 2011). Second, social workers established a consortium of organizations at the National Social Work Summit on End-of-Life and Palliative Care in 2002 (Reese, 2011). Its goal was to explore issues in the field of end-of-life and palliative care and develop an agenda to focus the profession's purpose on the public

good in subsequent meetings. The consortium identified social work education content as one of its top priorities (Kramer et al., 2003), including a focus on new social work curricula and continuing education programs in end-of-life care. This new focus led to identifying other needs in national research and standards in the field. Third, the Society for Social Work and Research created an End-of-Life Care Researchers Interest Group in 2003. Fourth, the profession founded two specialized collaborative groups specific to social workers in end-of-life care: in 1994, the Social Worker Section of the National Council of Hospice and Palliative Professionals, under the National Hospice and Palliative Care Organization; and in 2008, the Social Work in Hospice and Palliative Care Network, which grew out of the PDIA Social Work Leadership Development Awards Program (Reese, 2011).

Knowledge base. A review of the literature recognizes social work's professional successes in aggregating, disseminating, and expanding a knowledge base of historical research and designing new research for the professional advancement of social work in hospice and palliative care. For example, in 2003, Csikai established "the first and only [journal] specifically for social workers in the field of end-of-life and palliative care," the *Journal of Social Work in End-of-Life & Palliative Care*. The journal focuses on "social work standards for practice, research results, needs for further research, ethical issues, and policy and practice updates" (Reese 2011). Then, in 2004, Berzoff and Silverman co-edited the first social work textbook on end-of-life care, *Living with Dying: A Comprehensive Resource for End-of-Life Care*. That same year the NASW published the Standards for Social Work Practice in Palliative and End of Life Care, "which included ethics and values, knowledge, assessment, attitude and self-awareness, empowerment and advocacy, documentation, interdisciplinary teamwork, cultural competence, continuing education, and supervision, leadership, and training" (Reese, 2011, p. 388). Next,

Reese and Raymer published the results of their research known as the National Hospice Social Work Survey (2004), supporting the positive outcomes of social work involvement in hospice service outcomes. This study gained the recognition of the Center for Medicare and Medicaid Services (CMS) on the importance of MSW-prepared social workers on interdisciplinary teams and in hospice services (Reese, 2011). The study was one of the largest of its kind; it “surveyed a stratified random sample of 330 patient cases within 66 hospices” (p. 388). The results of this study will be discussed later in this chapter. Last, roughly one year later in 2005, two Project on Death in America (PDIA) Social Work Leaders conducted research on the educational preparation needed for social workers in end-of-life care called The Social Work End of Life Care Education Project (Csikai & Raymer, 2005).

Mechanisms of control. The field of social work already upholds the standards and controls of state-credentialing and licensing boards, accreditation activities carried about by the Council on Social Work Education (CSWE) to ensure the quality and consistency of degree programs in social work, the sanctioning capacity of the NASW, and the NASW Code of Ethics (Netting et al., 2012). The NASW Code of Ethics (2008), which Netting et al. state “provides basic value guidelines through which professional judgment is applied” (2012, p. 28), lists six core values on which the ethical principles of social work are based: “service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence” (NASW, 2008, para. 3). Additionally, by creating a specialized professional identity, leaders in end-of-life social work collaborated in outlining specific standards and guidelines to ensure an advanced level of competency and a higher quality of service.

First, in 1994, social workers established the first social work guidelines in the field of end-of-life care through the Social Worker Section of the National Council of Hospice and

Palliative Professionals (NCHPP), an NHPCO professional liaison committee founded in 1984 (Reese, 2011). The group updated its social work guidelines in 2007 with new Medicare Conditions of Participation. In 2000, the Society for Social Work Leadership in Health Care also developed end-of-life care standards (Reese, 2011). In 2003, both the related fields of health care and oncology, the Association of Oncology Social Work (AOSW) and the NASW, followed suit in setting advanced professional standards for social work certification in health care social work and oncology social work, with a specific focus on psychosocial oncology. The AOSW believed that by creating advanced standards and establishing new certifications, it would demonstrate to clients as well as employers and the health care system that oncology social workers are committed to a higher level of competency and dedicated to a high quality of service (Reese 2011). By including a specialized training and furthering their professional identity, social workers would not only better prepare other social work professionals interested in end-of-life care, but could serve in improving hospice directors' views and the views of other hospice professionals, of social work's capacity to provide a valuable and distinctive role (Reese, 2011).

Social worker role in hospice and recognition from other professionals. Through social workers' involvement in establishing a professional purpose, knowledge base, and mechanisms of control, the field of social work has arguably built a stronger, positive reputation with other hospice and end-of-life-care professionals on interdisciplinary teams and within the field. As a legally required member of the interdisciplinary hospice team for CMS certified hospices (CMS, 2008, p. 32204; Tax Equity and Fiscal Responsibility Act of 1982, §122), social workers engage in collaboration with other team members. In addition, they establish their role with the patients they serve and those patients' families or primary caregivers. In this subsection, the literature will provide an overview of research establishing social work's demonstrated role in hospice and

end-of-life care, as determined by other members of their teams, by their patients, by the patient's families, and by social workers themselves.

Researchers have conducted studies to understand, differentiate, and establish the role of social work in end-of-life care. The literature supports the view that end-of-life-care social workers play a unique, dynamic, specialized, and multidimensional role (Blacker, 2004; Kramer, 2013; Taylor-Brown, Blacker, Walsh-Burke, Altilio, & Christ, 2001). These studies explored other health care professionals' and clients' perceptions about social work's role in end-of-life care by surveying the opinions of social workers (Heller, 1998; Jones, 2005; Kramer, 2013; Kulys & Davis, 1987; Sheldon, 2000), hospice directors, nurses, volunteers (Kulys & Davis, 1987), administrators (Reese, 2011), patients and family members receiving services in end-of-life care (Kramer, 2013). Outcomes of these studies isolate the tasks that other end-of-life care professionals perceive social workers to be most qualified to complete and the client needs most frequently addressed by social work.

The findings of these studies indicate that social workers help patients and families manage and deal with complex medical, psychological, legal, social, and ethical issues associated with advanced illness. Their role in hospice and palliative care involves clinical care, advocacy, education, administration, and research, especially in facilitating and supporting the patients' and families' interactions with the health care system (Blacker, 2004). In a recent study where social workers were asked to identify additional roles they serve on the end-of-life care team, along with the roles already listed, the workers said they address the spiritual and cultural needs of their patients (Kramer, 2013).

In addition, social workers help their interdisciplinary team members adjust, modify, or expand their overall perspectives of their professional work with clients. For example, social

workers encourage colleagues to see their clients' cases from a macro perspective, remind their colleagues to pay attention to the patient's requests, and help them to understand patients and their families. Social workers also provide emotional support to the team, back-up relief, and help to teach other team members effective communication skills (Kramer, 2013). In the same study, when social workers were asked to identify additional roles they serve on the end-of-life care team, they added that they help their team members to facilitate acceptance of "non-action."

Recent qualitative research, surveying team members' perceptions of the end-of-life social worker role, added that social workers are particularly adept at eliciting patients' wishes for end-of-life care and advocating for the patient (Kramer, 2013). Patients identified social workers as having seven primary roles that helped them: they ensured that the patient's basic needs were met; provided meaningful, caring relationships; completed organization tasks; helped the patient make informed decisions; prepared the patient for future and for death; solved problems; and watched over the patient (Kramer, 2013). The patients' family members not only agreed with those roles, but also identified six additional ways that end-of-life care social workers offered support: they provided the patient with intellectual and social stimulation, as well as emotional support; addressed grief and bereavement; facilitated transitions; facilitated independence; and served as a central manager of patient care (Kramer, 2013).

Qualitative data from the study of social worker's team members' perceptions further endorsed social workers' skill at initiating and helping facilitate family meetings and addressing and identifying family conflict and challenges (Kramer, 2013). Patients identified social workers as having three primary roles that helped their family caregivers: providing their families with information, offering their families emotional support, and helping alleviate family burdens. Family members also added three primary roles in which end-of-life care social workers served

in helping the family caregivers: facilitating transitions, facilitating family communications, and preparing the family members for the future and for death (Kramer, 2013).

Social work-related responsibilities in hospice. Though limited in number, previous research in hospice social work (Kulys & Davis, 1987; Reese, 2011) and end-of-life care (Kramer, 2013), addresses a wide range of tasks often assigned to hospice social workers, detailing a minimum of 14 work-related responsibilities. Outcomes of these studies isolate the tasks and work-related responsibilities that social workers are perceived to be most qualified to complete and the client needs most frequently addressed by social work in an end-of-life care settings.

These social work-related responsibilities include: psychological and emotional responses of family members and patients (which includes depression, agitation, and anxiety); caregiver support/system involvement; funeral planning; grief issues; caregiver involvement; spiritual issues; and coordination with community facilities (Kramer, 2013); program development, staff development, provision of staff support, volunteer and staff training, use of community resources, assurance of adequate support systems, facilitation of family communication, discharge planning, counseling, referrals to community resources, crisis intervention, advocacy, financial assistance or provision of financial information, assessment of emotional and social problems, provision of information to other facilities, and coordination of services (Kulys & Davis, 1987); financial counseling, referrals, assessment of emotional and asocial problems, counseling about suicide or wanting to hasten death, facilitating social support, counseling about denial, promoting cultural competence, community outreach, counseling about anticipatory grief, crisis intervention, bereavement counseling, counseling about death anxiety (Reese, 2011); completing psychosocial assessments, developing comprehensive treatment plans, participating

as a member of the interdisciplinary team, and providing psychosocial interventions with individuals, families, groups, organizations, and communities (AOSW, 2012; Blacker, 2004; Taylor-Brown et al., 2001); psychosocial interventions include providing individual counseling and psychotherapy, family counseling and family therapy, facilitation of psycho-educational, support, and therapy groups, and crisis intervention (Blacker, 2004; Blum, Clark, & Marcusen, 2001; Taylor-Brown et al., 2001); and psychosocial screening, assessment, counseling, referral, and practical assistance with financial resources (Huff et al., 2006).

For the purposes of this study, the aforementioned tasks were aggregated into five main areas of work-related responsibilities in hospice social work: clinical and counseling support, case management, management and administrative support, advocacy work, and spiritual and cultural support. Research supporting each area of hospice social work related responsibilities are outlined below.

Clinical and counseling support. The first work-related responsibility of hospice social workers is clinical and counseling support. Health care social workers have reported in previous research that knowledge directed at addressing psychological and social needs of patients and their families as the most essential skills necessary for competent end-of-life care practice (Csikai & Raymer, 2005). Examples of clinical and counseling support in end-of-life care include assessment of psychosocial issues, crisis intervention, counseling in the areas of suicide or wanting to hasten death, denial, anticipatory grief, bereavement, death anxiety, safety issues, on-call responsibilities, caregiver support, and family counseling. For patients receiving hospice services, clinical and counseling end-of-life care needs most frequently addressed by social workers were depression, agitation, anxiety, and addressing psychological and emotional responses of clients and their family members (Kramer, 2013), financial counseling (Reese,

2011), counseling about safety issues, crisis intervention (Kulys & Davis, 1987; Reese, 2011), grief issues, and bereavement counseling (Kulys & Davis, 1987; Kramer, 2013; Reese, 2011). Coluzzi, Grant and Doroshov (1995) reported that based on data from various agencies that offer services to people who are terminally ill, social workers provided 75% of the supportive counseling to individuals with cancer.

Case management. The second work-related responsibility of hospice social workers is case management. Examples of case management are financial counseling, insurance navigation, referrals to bereavement counseling and follow-up care, resource attainment discharge planning, facilitating social supports, community outreach, case coordination, and intake interviews (Blacker, 2004; Taylor-Brown et al., 2001). Case management end-of-life care needs most frequently addressed by social workers were caregiver involvement, coordination with facilities, and funeral planning, initiate and help facilitate family meetings (Kramer, 2013), referrals, and facilitating social supports (Kulys & Davis, 1987; Reese, 2011). Other research findings support this literature; hospice directors determined social workers as most qualified to fulfill the responsibilities of using and making referrals to community resources and providing financial information to clients (Reese, 2011).

In addition, the literature supports that social workers make important contributions to the palliative care team through the provision of education for the patient and family (Blacker, 2004; Blum et al., 2001; Hedlund & Clark, 2001). Typical social work practice in end-of-life care involves working with patients and their families to impart information about resources, advance care planning, caregiving tasks and supports, and the normal grief response. Furthermore, when the social worker identifies barriers to understanding complex medical information such as

language barriers, low literacy levels, and cognitive or memory deficits, the practitioner will intervene (Blacker, 2004).

Management and administrative support. The third work-related responsibility in hospice social work is management and administrative support. Examples of management and administrative support include supervising hospice social workers, training, volunteer management, directing the agency, planning, program assessment and management, creating agency policy, and data reporting. One management and administration support need most frequently addressed by end-of-life care social workers is supervising workers (Kulys & Davis, 1987; Reese, 2011). Literature demonstrates that 30 empirical articles on clinical supervision were published between the time the first hospice opened in the United States and the turn of the century (Tsui, 1997); clinical supervision is considered to be an “important and unique enabling social work process,” (Zilberfein & Hurwitz, 2004).

In addition to clinical supervision of other social workers, hospice social workers sometimes manage and oversee volunteer programs, train volunteers (Skoglund, 2006; Forsyth, 1999), as well as train other staff members (Blacker 2004). The management and administration support tasks on which hospice social workers spend time and effort include orienting, training, and monitoring volunteers, as well as volunteer retention (Skoglund, 2006; Forsyth, 1999). But volunteer retention and training can be equally as important as retaining and educating other interdisciplinary team members when it comes to providing quality end-of-life services for the dying. According to L. Clark et al. (2007), “The infrastructure for maintaining high quality care [for the dying] is contingent upon having continuity and uninterrupted care services provided by a dedicated team of professionals working in [interdisciplinary teams]” (p. 1322). Social workers and social work practice are being recognized in end-of-life care by other disciplines as being

uniquely valuable and is becoming more incorporated into educating other staff. Blacker (2004) states that “many of the skills that have historically been unique to social work training, such as interviewing techniques and communication skills, are being incorporated in the training of the disciplines of nursing and medicine” (p. 420), creating an opportunity for social workers in management and administrative support to use their unique professional skills to develop the training of other disciplines. These trainings could serve as an important role to staff retention and continuity of services.

Another management and administration support need addressed by end-of-life care social workers is directing the hospice (Kulys & Davis, 1987; Reese, 2011). End-of-life care social workers who direct the agency will be expected to engage in practice evaluation, program development, administration, supervision, and social change (Blacker, 2004; NHPCO, 2001; Taylor-Brown et al., 2001). Netting et al. (2012) address the macro practice goals of all social workers to look beyond the issues that their clients face; similarly, social workers in end-of-life care must address the macro level factors shaping and systematically oppressing their clients. Netting et al. state, “If social workers are to be effective in serving their clients, many problems must be recognized and addressed at the agency, community, and policy levels. Some of these problems require changing the nature of services, programs, or policies” (p. 4-5).

Advocacy work. The fourth work-related responsibility in hospice social work is advocacy work. Examples of advocacy include upholding principles of self-determination and autonomy (Blacker, 2004), preference of environment, advocating on behalf of the client, ethical dilemmas, research, and civil and legal assistance (Kulys & Davis, 1987; Reese, 2011). Blacker (2004) adds that upholding justice and access for all within the care delivery system, including health care policy creation and reform and insuring access to quality care for the dying, are

important areas where social workers have demonstrated a history of their commitment to their professional responsibilities of social action and advocacy. Interdisciplinary team members stated that end-of-life care needs most frequently addressed by social workers were advocating on behalf of the client, and civil legal assistance, including patient autonomy, advanced directives, physician-assisted suicide, and cessation of life supports (Kulys & Davis, 1987; Reese, 2011; Kramer, 2013). As engaged patient advocates, social workers may be part of ethics committees or consult teams (Csikai, 1997; Taylor-Brown et al., 2001); though their advocacy begins with understanding the individual and family's needs, it also extends to the institutional, community, and health care policy arenas (Blacker, 2004; Csikai & Bass, 2000).

Reese and Raymer (2004) state that, “communication and advocacy for client self-determination are two of the most highly stressed areas in social work training” (p. 420), as compared to the training of other health care professionals. The National Association of Social Workers (NASW) has long upheld that the social work profession working in end-of-life care is committed to, “the right of the individual to determine the level of his or her care” (2003, p. 47) and “the opportunity to make their own choices but only after being informed of all options and consequences” (p. 48). Moreover, the NASW Standards for Palliative and End of Life Care upholds the incorporation of bioethics principles into professional decision-making and practice:

Social workers working in palliative and end of life care are expected to be familiar with the common and complex bioethical considerations and with legal issues such as the right to refuse treatment; proxy decision-making; withdrawal or withholding of treatment, including termination of ventilator support and withdrawal of fluids and nutrition; and physician aid in dying. (2004, p. 16)

Research supports the need for social workers in palliative care to understand the principles of bioethics and their relationship to dilemmas that result from end-of-life care (Blacker, 2004; Csikai & Bass, 2000). The NASW's professional commitment through its policies and guidelines of fostering the support of all individual's self-determination and social justice demonstrates social worker's longstanding care of patients and their communities (Luptak, 2004; Stein & Sherman, 2005).

One way social work practice advocates for patients and their communities is by facilitating interactions between them and their environments. These interactions include modifying the environments surrounding clients and their communities to be more responsive to client needs and preferences (Germain, 1991). Reese and Raymer (2004) identified in their research of hospice and palliative care, that social workers modify clients' environments by both advocating for patients' active participation in their own care and by representing patients interests when communication breaks down between the client and their family or between the client and end-of-life care staff. This advocacy is important within the United States where some families may not feel supported in performing, or may not be able to perform, traditional rituals or customs, or where families may feel pressure to conform to Western cultural practices that diverge from their own fundamental beliefs and values (Wiener, McConnell, Latella, & Ludi, 2013; Laungani, 1996), especially at the end of life.

Csikai and Bass (2000) labeled end-of-life decision-making as one of the most difficult practice situation facing social workers who work in health care, partially due to the exceptionally complex ethical dilemmas they encounter. Some literature explored social workers participation on ethics committees in care delivery systems and found that, though they are participants in these committees, social workers do not tend to take an active or leadership role

within them (Landau, 2000; Stein & Sherman, 2005). Promotion of social work participation in committee leadership may be an area of further growth and development for social work practice.

Spiritual and cultural support. The final work-related responsibility for end-of-life care social workers is addressing cultural and spiritual end-of-life care needs, which researchers have identified as responsibilities important to the work of end-of-life care social work (Kramer, 2013). The practices and spiritual beliefs of patients' cultures are the foundations on which their lives are based and are especially important during the vulnerable period of end-of-life (Wiener et al., 2013; Levetown, 1998; Contro, Davies, Larson, & Sourkes, 2010); thus, quality end-of-life care requires service providers to be both culturally sensitive and culturally competent (Wiener et al., 2013).

Palliative health care professionals must have knowledge and sensitivity on the role of culture in decision making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and suffering, the meaning of death, and location of end-of-life care (Wiener et al., 2013). The National Association of Social Work (NASW) outlines standards for palliative and end-of-life care practice especially in the areas of cultural competence:

“[Social workers should] identify barriers to effective palliative and end of life care at the macro level by addressing issues of financial inequities, lack of culturally competent services, and other access issues and to address those barriers so that individuals experience the highest quality of life possible to the end of life. (NASW, 2004, p. 23)

Examples of cultural and spiritual support work-related responsibilities for social workers in end-of-life care include cultural competence, ensuring culturally competent end-of-life decisions, supporting direct spiritual experience, and discussing the meaning of life. Cultural competence and spiritual end-of-life care needs most frequently addressed by social workers were spiritual issues (Kramer, 2013), ensuring cultural competent end-of-life decisions, discussing the meaning of life, and supporting direct spiritual experience (Reese, 2011).

Cultural practices must be considered within the patient and their family's sociocultural context, especially with regard to end-of-life care communication. Factors that may be highly relevant to patients and family cultural norms and customs include age, gender, class, English language fluency, literacy, normative family and community hierarchical structure, family and community values around autonomy and independence or boundaries and interdependence, and relationship to environment, including one's sense of control over the environment (Taylor, 2003; Wiener et al., 2013). These factors can effect family members' expectations about who is responsible for caring for an ill family member and vary from culture to culture. These factors and varying expectations may also influence the family's understanding of the role of hospice services and symptom management interventions (Blacker, 2004; Jennings et al., 2003); research supports racial and economic disparities, especially in the treatment of pain and physical suffering, which are highly prevalent symptoms at the end of life (Kramer, 2013; Altilio, 2004).

Research demonstrates that cultural competence spans beyond a health care practitioner's accumulated knowledge of cultural practices; it requires them to consider their own constructs of bias and belief (Wiener et al., 2013; Surbone, 2008; Kumagai & Lypson, 2009). Practitioners providing end-of-life care services must be aware of the effect of propagating rigid stereotypes about particular cultures and how it can change the provision of care. Cultural

competence, especially during palliative end of life care, stresses flexibility in providers' abilities to understand and differentiate individuals within their cultural norms and tie together patients and families' unique needs with the provisions of care (Wiener et al., 2013). Social workers are trained and professionally urged to maintain the standard of bridging communication with the patients and their families with other end-of-life care providers within the system of palliative and end-of-life care (NASW, 2004).

Hospice outcomes of social work involvement. Measurements for hospice outcomes based on social work involvement have expanded since just before the turn of the 21st century. Many of these studies have been used to support the cost effectiveness of social work involvement in hospice, given that they have demonstrated that increased social work involvement in hospice is related to reduced costs (Cherin, 1997; Mahar, Eickman, & Bushfield, 1997; Paquette, 1997; Reese & Raymer, 2004). These studies were designed with pre- and posttest measures, where beneficial differences between the measures indicated fewer patient hospitalizations, on-call visits, and nursing visit hours (Mahar et al., 1997; Paquette, 1997). In addition, increased social work involvement was connected with lower pain medication costs (Cherin, 1997; Mahar et al., 1997; Reese & Raymer, 2004), less frequent use of IVs, and a reduction in staff turnover (Paquette, 1997).

A landmark study previously mentioned in this chapter (Reese & Raymer, 2004), built on the research of Cherin (1997), Mahar et al. (1997), and Paquette (1997), outlines the positive outcomes of social work involvement in hospice services. Published in 2004 and one of the largest of its kind, the National Hospice Social Work Survey denoted that increased social work services in hospice care projected lower home health aide, nursing, pain control, labor, and overall hospice costs, as well as a lower average cost per patient (Reese & Raymer, 2004). Social

work involvement in hospice services also predicted better team functioning, fewer home health aide visits, better client satisfaction, fewer nights of continuous care, fewer patient hospitalizations, and a lower severity rating of the hospice case (Reese & Raymer, 2004). Social work involvement was able to accomplish these outcomes with an average of two social work visits per client. This study gained the recognition of the Centers for Medicare and Medicaid Services (CMS) on the importance of MSW-prepared social workers on interdisciplinary teams and in hospice services (Reese, 2011).

Reese et al. (2006) developed the first tool to measure hospice and palliative care social work outcomes based on social work research called the Social Work Assessment Tool (SWAT). In the past, nonsocial workers assessed social work services by conducting process evaluations, which have been criticized for their limitations (Reese, 2011). The SWAT measures the major psychosocial and spiritual variables known to predict hospice outcomes for clients. Those variables are cultural and religious beliefs, suicidal ideation, desire to hasten death, death anxiety, preference about environment, social support, financial resources, safety issues, comfort issues, complicated anticipatory grief, denial, and spirituality (Reese, 2011). The national study indicated that patients' SWAT scores improved considerably between the first two social work visits (Reese, 2011).

The Patient Protection and Affordable Care Act and Hospice Care

The PPACA has two provisions that allow for the reimbursement of concurrent hospice care and life-sustaining treatment (PPACA, §§2302, 3140). The first is a requirement that children who are terminally ill and enrolled in public insurance either through Medicaid or the Children's Health Insurance Program (CHIP) can concurrently receive life-sustaining treatment while also receiving hospice care (PPACA, §2302). The second is a provision for the "Medicare

Hospice Concurrent Care Demonstration Program”, a three-year pilot study to test the viability of concurrent care for Medicare patients (PPACA, §3140). This demonstration program would allow Medicare patients who are eligible for the hospice benefit to concurrently receive all other Medicare covered services. Up to fifteen hospice programs in both rural and urban areas can participate and an evaluations of the demonstration program would be based on the impact on patient care, quality of life and Medicare spending.

The PPACA has made significant changes to how and when health care benefits are made accessible to patients; however, changes directly applying to the direct services of hospice care are relatively minimal. In addition to the two provisions mentioned above, the PPACA specifically addressed hospice care in three other ways (PPACA, §§3004, 3132, 3401). These changes include increased quality reporting requirements to the federal government, a new requirement prior to recertification for patients that have been in hospice for 180 days, payment reforms, and productivity improvements.

Section 3004 of the 2010 Patient Protection and Affordable Care Act (PPACA, §3004), requires hospices to report to CMS on quality measures. This quality reporting applies to long-term care hospitals, inpatient rehabilitation hospitals, and hospice programs. The goal of these quality-reporting measures is to establish a path toward value-based purchasing. Providers under this section who do not successfully participate in the program will face a two percent reduction in payments in their annual market basket update.

Section 3132 of the 2010 Patient Protection and Affordable Care Act (PPACA, §3132), is considered the Hospice Reform provision. The majority of this provision is dedicated to updates to Medicare hospice claims forms and cost reports and changes to the hospice payment system to improve payment accuracy. Certain hospices will be medically reviewed for their long-stay

patients. However, one significant change this provision makes for direct service providers is the inclusion of a new requirement mandating hospice physicians or nurse practitioners to re-enroll or recertify their patients in hospice care prior to the maximum 180 days and only after a face-to-face assessment. Previously physicians and nurse practitioners were allowed to recertify clients by reviewing medical records and other documentation without meeting with the client. This imposed requirement on hospice service providers is designed to increase accountability in the Medicare hospice program.

Last, section 3401 of the 2010 Patient Protection and Affordable Care Act (PPACA, §3401) revises certain market basket updates to incorporate productivity improvements where they do not currently exist. In addition to hospice providers, these productivity adjustments are incorporated into the market basket updates for inpatient hospitals, home health providers, nursing homes, inpatient psychiatric facilities, long-term care hospitals and inpatient rehabilitation facilities. In addition, the provision implements market basket reductions for certain providers and a productivity adjustment into payment updates for Medicare Part B providers who do not already have such an adjustment.

Impact of PPACA on Hospice Service Providers. Unfortunately, a gap exists in the literature on how the Patient Protection and Affordable Care Act (PPACA) has changed the role of social workers in hospice. While several recent studies have investigated the potential impact the PPACA will have on social workers in health care fields (Mason, 2013; Reardon, 2011; Reisch, 2012; Zabora, 2011), but not specifically in end-of-life care. Reardon (2011) states that while it is unclear how the PPACA will impact social workers, it is certain that the new rules will change the ways social workers in health care will provide direct services. Laura W. Groshong, LICSW, lobbyist and director of government relations for the Clinical Social Work Association,

stated, “The [PPACA] changes that are going to take place are going to change how [social workers] practice. Some of it may be better, some of it may be harder, but it’s going to be different” (as cited in Reardon, 2011). Previous studies explored the perspectives of social workers and their roles in end-of-life care (Heller, 1998; Jones, 2005; Sheldon, 2000), but none have explored this area since the passage of the PPACA. One study explored how other hospice service providers, not social workers, will be impacted by the new legislation, but the study mostly highlights those who work in rural areas and where a workforce shortage already exists (Cerminara, 2011).

Impact of the PPACA on social workers in other health care disciplines. Reisch (2012) claims that the PPACA legislation has “several broad potential consequences for hospital social work staff” (p. 886). These potential consequences are outlined in four areas of social work: greater demand for advocacy, increases in social work caseloads, a shift in work-related responsibilities, and a rise in potential job insecurity.

One potential consequence for hospital social workers as a result of the PPACA could be a greater demand for social work advocacy. Given that each state has a choice to opt into the Medicaid expansion or to create an insurance exchange, and that some states will choose not to expand, thus leaving many of its citizens without access to affordable public health insurance, individual and class advocacy will be essential for increasing health care access (Reisch, 2012; Zabora, 2011). However, another outcome of the variations of states’ responses to the legislation is that since individual states will have more influence on how PPACA programs will be designed and implemented, as well as who will be engaged to provide those services (Mason, 2013), could be expanded opportunities for social workers.

The second potential consequence for hospital social workers as a result of the PPACA could be an increase in social work caseloads. One focus of the PPACA is on health care spending and cost efficiencies (PPACA, § 2718, 1104). The increased focus on health care spending could potentially lead to shrinking hospital budgets resulting in staffing cuts, increases in caseloads, or growing workload requirements (Reisch, 2012; Zabora, 2011). Furthermore, Reisch states that “attempts to reduce costs have often resulted in cuts in funding for ‘ancillary’ hospital services, such as social work, which places increased burdens on social work staff” (2012, p. 881). Another focus of the PPACA is on individual and employer mandates, premium subsidies, and the expansion of Medicaid (PPACA, 2010). These changes could predictably increase access to outpatient and inpatient care, surging caseloads in both clinic and hospital settings (Reisch, 2012, p. 886).

The third potential consequence for hospital social workers as a result of the PPACA could be a shift in work-related responsibilities and the role of social workers on interdisciplinary teams. The PPACA emphasizes cost control, community-based care, and the promotion of independence at home, as part of home-based primary care teams, and will lead to an increased complexity of health care delivery (PPACA, 2010). These emphases of the PPACA will naturally require hospital social workers to exercise their enhanced skill in inter-organizational collaboration and their brokerage role (Reisch, 2012; Zabora, 2011). Areas where work-related responsibilities could shift are an increase in the health education and information and referral components of their role, the speed of assessment completion, the time spent on discharge planning, the coordination of services, the consultation and collaboration with other professionals, and the attention given to the environmental and socioeconomic factors that affect patients’ illnesses and lead to readmission into the hospital (Reisch, 2012; Zabora, 2011).

The fourth potential consequence for hospital social workers as a result of the PPACA could be a rise in potential job insecurity. Current and past research supports the concerns of job insecurity for social workers at times of financial constraint and cost cutting focus in health care. As mentioned earlier in this section, more current research suggests that hospital cost cutting measures can result in decreases in funding for ancillary services, such as social work (Reisch, 2012). More specifically, past research documents previous trends of viewing social work as displaceable in hospice care (Reese, 2011); in Kulys and Davis' discussion of their study they questioned social work's ability to maintain its hard-earned position in hospice care when cost reduction becomes a focus (1987). However, one recent study outlining the implications of the PPACA on social work (Mason, 2013), suggests that while unclearly defined, an indirect upturn in social work utilization may be in the future. Mason states that "although [the PPACA] does not specify the inclusion of licensed social workers in its implementation, it does call for increased grants to schools of social work, thus indirectly indicating the utilization of social work services" (2013, p. 67).

Other hospice service providers. Studies have supported that physicians in hospice and palliative medicine are experiencing a substantial workforce shortage (Casey et al., 2005; Lupu, 2010; Maison, 2010). Additionally, given their travel challenges and staffing concerns, rural hospices, in particular, are forced to overcome unique and challenging barriers to hospice access for their patients (Casey et al., 2005; Cerminara, 2011; Reese, 2013). Given the PPACA's changed regulation for face-to-face recertification when the 180-day duration has been reached (PPACA, §3132), rural hospices may suffer more than other hospices to meet the face-to-face encounter requirement and be unable to guarantee face-to-face encounters for all hospice recertifications (Cerminara, 2011). Even though the concerns underlying the restrictive

regulations of face-to-face recertification are valid, the amplified challenges it could cause for rural hospices might become critically detrimental to their operations.

Theoretical Formulation

The review of the literature in this section will first provide a general overview of systems and ecological theory, its roots and its contributors including the six fundamental principles and key concepts on which systems, ecological, and ecological systems theories are grounded. Second, the section will cover how these theories, principles, and concepts apply to social work and social work practice. Lastly, the section will close with an outline on how, for the purposes of this study, these concepts apply to end-of-life social work in the climate of United States health care reform.

General overview of systems theory and ecological theory. Systems theory and ecology theory both stem from comparable frameworks of describing human behavior; when integrated as co-theories they are sometimes called *ecosystems theory* or *ecological systems theory* (Langer & Lietz, 2015). In the 1960s, Ludwig von Bertalanffy was credited with establishing the initial concept for systems theory based on his understanding of biology as an organized system of interrelated parts of a whole (von Bertalanffy, 1968). In applying this theory to social work practice, Netting et al. (2012) described systems or entities as having multiple parts, whether as groups, organizations, or communities with interconnecting components and common principles. Langer and Lietz (2015) provide a definition of a system as “an organized entity of components that consists of interrelated and interdependent parts” with a common purpose or goal (p. 31). For example, a person’s body can represent a system; as a whole it depends on the functioning of several interrelated parts operating together to sustain life. Von Bertalanffy's key contribution to understanding systems in a way that differed from the popular

framework at the time was to view the system as a whole, conceptualizing its relationships and interactions with other systems as a mechanism for growth and change, rather than breaking down a system and looking at its separate parts (B. D. Friedman, 1997). His concept later expanded beyond biology to *any* entity with interacting parts.

Urie Bronfenbrenner is credited with adding the perspective of ecological theory to systems theory in the 1970s to better understand the concept of systems with living beings (1979, 1986, 2004). Where biologists examine how aspects of systems can be controlled in scientific conditions, ecologists study the organically conjoint relationships within ecosystems (Langer & Lietz, 2015). Ecological theorist Bronfenbrenner is reported to have taken issue with systems theorist von Bertalanffy's linear, cause-and-effect model (B. D. Friedman, 1997). He perceived that systems theory did not fully portray the complex interactions of numerous environmental factors happening between humans within the ecological environment of social systems (Bronfenbrenner, 1979). These complex dynamics reciprocally affect and are affected by one another.

Fundamental principles and key concepts. Together, systems theory and ecological theory are composed of six fundamental theoretical principles with key concepts to help explain human behavior (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gitterman & Germain, 2008; Langer & Lietz, 2015). This subsection will briefly describe the basic principles or assumptions of systems theory and ecological theory and include some of the key concepts in understanding these principles. The first principle, which helps to define the concept of a system, is that a system is an organized entity of components that consists of interrelated and interdependent parts (Langer & Lietz, 2015). Systems exist on many levels, which can be distinguished as *microsystems*, *mesosystems*, *exosystems*, *macrosystems*, and *chronosystems* (Bronfenbrenner,

1979). A *microsystem* is the system closest to a person and includes family members, friends, and other relationships that exert the most influence on an individual. A *mesosystem* consists of the relationships among the systems in an individual's environment or microsystem, stressing the importance of the interactional relationship between systems and how those relationships help or hinder the growth of the individual. An *exosystem* is a relationship between two systems that has an indirect effect on a third system. A *macrosystem* is a larger system that influences an individual's life, such as policies, administration of entitlement programs, and culture. A *chronosystem* is composed of significant life events and how those events can affect how well an individual grows and adapts (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gitterman & Germain, 2008; Langer & Lietz, 2015).

The second principle of systems theory and ecological theory is that a system is defined by its boundaries and rules. A boundary is a key concept in systems and ecological theory and is defined as a barrier that delineates, distinguishes, or separates a system from its environment; barriers can be real or socially constructed (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gitterman & Germain, 2008; Langer & Lietz, 2015). These barriers or boundaries are described in terms of being thick or thin (also referred to as diffuse), flexible or rigid, and permeable, which refers to how freely energy in the environment can flow in and out of a system affecting its cohesion or connectedness and its ability to adapt.

The third principle is that a system demonstrates predictable patterns of behavior. These patterns are described by the key concepts of homeostasis, reciprocal transactions, and feedback loops. Homeostasis is the tendency of a system to resist change and maintain status quo; reciprocal transactions are circular interactions mutually influencing one another that exist between two systems or between a person and his or her environment; and feedback loops are the

processes by which systems self-correct based on reactions from other systems in the environment that may need or require adjustment or change (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gitterman & Germain, 2008; Langer & Lietz, 2015).

The fourth principle is that a system is more than the sum of its parts. The fifth principle is that changing one part of a system not only affects other parts of the system, but also the system as a whole (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gitterman & Germain, 2008; Langer & Lietz, 2015). The sixth principle is that a system's "goodness of fit" with its environment leads to positive growth and adaptation. An individual's goodness of fit with his or her environment is related to the interactional relationships, with the various system levels of his/her environment. Adaptation is a key concept, defined by Langer and Lietz as the tendency of or the process by which "a system makes the changes needed to protect itself and grow to accomplish its goal" (2015, p. 32). A related concept to adaptation is *equifinality*, which is defined as the process of systems taking multiple paths to adapt over time (p. 32).

Systems and ecological theories and social work. The literature argues that because von Bertalanffy's original conception of systems theory is a method of organizing the interactions between component parts of a larger system, rather than explaining observations, it is easily adaptable to various scientific fields, including psychology, psychiatry, sociology, and social work (B. D. Friedman, 1997). Systems theory requires an appreciation of the interdependent nature of a system. As the aforementioned principles of systems theory and ecological theory assert, these tenets embrace "a holistic look that recognizes that changing one component of the system affects not only the other components of that system but the system as a whole" (Langer & Lietz, 2015, p. 29). These tenets offer frameworks to considering social systems, such as families, communities, and organizations, as entities that are maintained by interrelated parts and

help social science disciplines in describing how these systems function. With the addition of ecological theory to an understanding of systems theory, social scientists have asserted that humans are organisms that maintain helpful or unhelpful interactions with their environment.

As previously mentioned in this section, ecological theory is most associated with the work of Bronfenbrenner, which includes his application of the theory to social work (Langer & Lietz, 2015). With his studies in child development, Bronfenbrenner (1979) applied ecological theory by describing the multiple systems (*microsystem*, *mesosystem*, *exosystem*, *macrosystem*, and *chronosystem*) that affect the growth and adaptation of a child. Bronfenbrenner argued that early social science practices, based on systems theory, focused assessments and interventions either on the behavior of the person or on the environment, but not the complex interaction between the two (Bronfenbrenner, 1979). Furthermore, these systems are interacting and the child who is affected by these interacting systems is also affecting the systems with which he or she interacts (Langer & Lietz, 2015).

From the mid-1960s to mid-1970s, family therapists Bowen (1966,1976) and Minuchin (1974) presented the application of systems theory to social work practice with families, often referred to as *family systems theory*. Family systems theory understands the family as a system or entity, comprised of multiple parts or subsystems, maintained through rules, boundaries, relationships (both within the system and with other systems), and established interaction patterns. These interaction patterns function in the service of enforcing the system's homeostasis, or maintenance of the status quo, but contributes to a family systems' tendency to resist change. In addition, Netting et al. (2012) add that family systems need resources in order to function; these resources may come in the form of people, equipment, funding, knowledge, legitimacy, or some other form.

Ecological systems theory. C. B. Germain (1991), a social work theorist, adapted the two theoretical models of systems theory and ecological theory into what is known as an *ecological systems perspective*, which has a specific application to social work. In contrast to previous theoretical frameworks, “the ecological systems perspective is specifically concerned with the nature of interactions between the individual (or group, family, community) and the greater environment” (B. D. Friedman, 1997, p. 4). Germain (1991) focused on the *nature of relationships* between systems and the *transactions* or reciprocal exchanges between entities or between their elements or components. Drawing from systems theory, Netting et al. describe entities as “systems with interconnecting components and certain common principles, whether they are as large as an international corporation or as small as a family” (2012, p. 10). Similar to Bronfenbrenner, Germain regarded these interactions between systems as inherently changing the elements of each system or influencing the other over time (1991). The relationships between systems are not characterized by a linear nature, but in their circularity, where all systems in the interaction are affecting one other. The literature indicates that Germain strongly advocated for a biopsychosocial perspective and viewed the development of individuals and families within cultural, historical, communal, and societal contexts (B. D. Friedman, 1997).

The theoretical frameworks of systems theory, ecological theory, and ecological systems theory advocate that social workers approach their comprehension of how their clients interact with the social, physical, and cultural elements of their environments (Langer & Lietz, 2015). Understanding these frameworks helps social workers take a holistic person-in-environment view of a client, a lens offering full consideration of how people, places, policies, and physical environment can affect an individual’s (or group’s, family’s, community’s) development. In order for social workers to make an accurate and comprehensive assessment, they must evaluate

the environment outside of the individual and consider public policy, practice, and research in their appraisal of all factors contributing to the environment.

Foundational to social work, as outlined in the preamble of the National Association of Social Work Code of Ethics (NASW, 2008), is the person in environment perspective, which is informed by both systems and ecological theories (Langer & Lietz, 2015). The NASW preamble states, “A historic and defining feature of social work is the profession’s focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living” (NASW, 2008, para. 1). These environmental influences include reciprocal relationships with family, friends, peers, coworkers, and community members, the areas in which people live, the health and social services that may or may not be available in those communities, the surrounding physical environment, culture and the beliefs and traditions that inform daily living, and macrosystem influences, such as local or federal policies, that may help or hinder a person’s potential (Langer & Lietz, 2015). Social workers also consider the environmental effects of racism, sexism, and other oppressive beliefs and practices when ascribing to a person-in-environment understanding of their clients.

Implications for social work practice. Social work practice is a broadly defined concept that allows for both microsystem (e.g., individual, domestic unit, or group) and macrosystem interventions (e.g., organization, community, or policy) (Netting et al., 2012). Systems can include individuals, couples, families, social groups, communities, organizations, and structural systems, such as local, state, and federal policies (Friedman & Allen, 2011). Depending on the system’s size and complexity, social work interventions occur on three levels, termed micro, mezzo, and macro practice. The stages of micro, mezzo, and macro social work practice are

listed as engagement, assessment, goal setting, intervention, termination, and evaluation (Langer & Lietz, 2015). Instrumental in social work practice is a person-in environment perspective, rooted in ecological systems theory, which “requires seeing the client as part of multiple, overlapping systems that comprise the person’s social and physical environment” (Netting et al., 2012, p. 8). Hospice social work also includes an ecological systems perspective in all levels of practice, which highlights the unique challenges inherent in this subspecialty of the health care social work field.

The three practices involve direct practice with clients and their immediate surroundings (micro), mid-level practice with communities or organizations (mezzo), and intervening to change policies and practices that can affect the members of a society (macro) (Langer & Lietz, 2015). The incorporation of microsystem, mesosystem, and macrosystem interventions bears a broad responsibility for all practicing social workers. Netting et al. (2012) describe how micro practice informs macro practice:

Workers in micro-level roles are often the first to recognize patterns indicating the need for change. If one or two persons present a particular problem, a logical response is to deal with them as individuals. However, as more individuals present the same situation, it may become evident that something is awry in the systems with which these clients are interacting. The social worker must then assume the responsibility for identifying the system(s) in need of change and the type of change needed. (p. 6)

Once these systems in need of change are identified by the micro-level social worker(s), a process of informing and outlining these needs to macro-level practitioners ensues and triggers activities towards macrosystem change. As Netting et al. explained, “Macro activities go beyond

individual interventions but are often based on needs, problems, issues, and concerns identified in the course of working one-to-one with service recipients” (p. 5); likewise, social workers in “macro practice must understand what is involved in the provision of direct services to clients at the individual, domestic unit, or group level” (p. 8). An interactive relationship exists between these systems of social work practice, as neither microsystems nor macrosystems social work practice exists on its own; one informs the other. Netting et al. warn, “Without this understanding, macro practice may occur without an adequate grounding in understanding client problems and needs” (p. 8)

In all systems of social work intervention (micro, mezzo, and macro), there are six stages of practice: *engagement*, *assessment*, *goal setting*, *intervention*, *termination*, and *evaluation* (Langer & Lietz, 2015). In the practice stage of *engagement*, the social worker develops a professional relationship with a client necessary for working together. Ideally, these relationships are built on trust and authenticity and will help the clients to invest themselves in the services they are receiving. In the stage of *assessment*, the social worker collects information, using interviewing micro skills and observational data and by reviewing past records and reports or other relevant data, that helps the social worker formulate a clear understanding of the client and the presenting problems. The purpose of the stage of *goal setting* is to connect the information that was disclosed in the assessment with the objectives the client wants to accomplish through involvement with the social worker. In the practice of *goal setting*, the social worker and the client participate in a formal process of writing a case or treatment plan together which they both sign or an informal verbal agreement between them regarding a plan of action. The practice stage of *intervention* can be on a micro-, meso-, or macro-system level and comprises action that pursues enrichment of the client’s functioning. The practice stage of *termination* is when the

relationship between the social worker and client ends. And the final stage of social work practice is *evaluation*, which determines the degree to which the client's goals were accomplished and whether the social work practice intervention helped facilitate change or enhanced functioning for the client.

When considering ecological systems theory in the application of the six stages of social work practice, each stage has specific functions to improve the clients' relationships with their environment(s) (Langer & Lietz, 2015). In the first three stages of social work practice—*engagement*, *assessment*, and *goal setting*— a person-in-environment framework for *engagement* means the social worker builds relationships with the systems surrounding the client, not the client only. The social worker looks for opportunities to enhance the “goodness of fit” (the sixth principle of systems theory) between the systems (or client) and the environment (Langer & Lietz, 2015, p. 40). In the second stage of *assessment*, information is collected about the client's interactions with their environment. Oftentimes, an ecomap is created to illustrate how the client interacts with the systems within his or her environment. In *goal setting* a social worker looks for ways to increase the “goodness of fit” between the environment and the client; in some cases, they set a goal to change the way a client interacts with a system in the environment, or the goal may involve changing the environment to better fit the client (Langer & Lietz, 2015).

Similar to the first three stages of social work practice, the last three stages of social work practice—*intervention*, *termination*, and *evaluation*— have specific applications in an ecological systems theoretical framework (Langer & Lietz, 2015). First, the person-in-environment perspective for the *intervention* stage is similar to *goal setting*, where the social worker is looking to change how clients interact with their environments or change their environments. *Intervention* from a person-in-environment perspective covers a broad scope of activities, such as

counseling to help foster communication and connection; psychoeducation to enhance knowledge; community organization; advocating a change in policy; or seeking change in legislation. Ultimately, the intervention seeks to enhance the functioning of a system (client) by improving the “goodness of fit” between client and the systems within which they interact. Second, because engagement in a person-in-environment perspective requires a social worker to build relationships with multiple systems in clients’ environments, *termination* will involve ending all of these interactions and relationships. And last, the *evaluation* stage determines the degree to which the social work practice intervention aided the clients in improving the “goodness of fit” between them and the systems embedded in their environments. *Evaluation* will consider the clients’ interactions with those systems and any changes to those systems.

Depending on the agency and its policies or work culture, social workers usually engage in all stages of social work practice and levels of intervention in some capacity. For example, even though a social worker may only be assigned to discharge planning, which may be considered a termination stage of practice, the social worker still needs to engage with the client and family to assess their discharge needs and goals. Later, the social worker will need to evaluate the appropriateness of the discharge plan, after discharge was completed, and make adjustments if necessary.

The following quote illustrates the complex nature of overlapping micro and macro systems specifically in hospice care and how it impacts the client as well as the hospice social workers providing direct services. Netting et al. (2012) cite a hospice social worker reflecting how policy impacts her work:

With all of this talk about outcome based measurement and evidence based practice, I am having a hard time connecting the dots. All of my clients die, and if

they don't, we have to discharge them from our program because they have lived more than their allotted six months. Ironic, isn't it? Policy demands that we discharge them, and then without the services we provide, you can rest assured that they will decline. I suppose a good intermediate outcome for our program is one in which patients steadily decline because if they get better, we can't serve them anymore. To add insult to injury, it's hard to measure our ultimate outcomes when everyone eventually dies. I suppose that a 'good death' is our outcome, but how do you measure that concept? (p. 3)

In some cases, a hospice social worker conducting discharge planning is responsible for supporting a patient's transition from an environment within the hospice system back to a home environment without the support of hospice services. A macrosystems practice approach would encourage the social worker to consider the roles state and federal policies employ in regards to discharge planning. If a patient no longer meets the eligibility criteria for services or is discharged prematurely due to a lack of appropriate insurance coverage, social work might evaluate the need to advocate for systems level change (Langer & Lietz, 2015).

Theoretical framework

This study uses an ecological systems theory framework to better understand the relationship between macro system policy and the mesosystem of direct service workers on their microsystem practice work with clients. Specifically, this study examines the interaction between macro system changes in United States health care policy via the PPACA and the mesosystem practice of hospice social workers by looking at the time and effort hospice social workers spend on five work-related categories of microsystems practice in hospice. Not only are direct service

health care social workers managing the micro practice demands of their clients' needs, but they are practicing in health care settings largely influenced by policy decisions at the federal and state levels (Stein & Sherman, 2005). Moreover, hospice social workers providing end-of-life care are influenced by these same federal and state level health care policies.

Ecological systems theory principles convey that systems consist of interrelated and interdependent parts, are defined by their boundaries and rules, and are affected when another part of a system changes; thus, the whole system is affected by one systemic level of change. The PPACA (2010), the largest and most recent health care policy reformation since Medicaid, has transformed the macrosystem level of health care in the United States. As a result of this reform, the entire health care system currently is in flux. Thus, on theoretical principle, the micro-, meso-, and macro- systems practice of hospice social work—hospice care policy, end-of life care agencies, direct service providers of end-of life care, the patients and families receiving end of life services— are all affected by the interacting relationships within the changing health care environment. The existing question is: *How is hospice social work affected by the PPACA?*

To explore how hospice social work practice has changed since the PPACA was enacted, this researcher focused on the following microsystem practices of social work-related responsibilities: clinical and counseling, case management, management and administration, advocacy, and spiritual and cultural competence. This study explored how the time and effort hospice social workers spend on these five categories of work-related responsibilities has changed during the period of PPACA health care reform.

CHAPTER III

Methodology

The purpose of this study was to explore how social workers based at hospice agencies in the United States perceive changes in their work responsibilities in relation to the Patient Protection and Affordable Care Act, within a climate of new rules and a growing number of Medicaid recipients. This mixed methods study was both exploratory and descriptive. The research design included an anonymous Internet-based survey instrument that collected quantitative data through Likert-scale questions, and qualitative data through comment boxes that allowed participants to elaborate on their responses.

Before conducting the study, the researcher received approval from the Smith College School for Social Work Human Subjects Review Committee (see Appendix A) and approval for a subsequent change in protocol (see Appendix B). The researcher recruited participants who met the eligibility criteria through online social and professional networking groups and forums, as well as by snowball sampling methods. Participants were self-selected and their eligibility for participation in the study confirmed by using a screening question in the online study instrument. After participants electronically provided their informed consent (see Appendix C), the instrument directed the participants to the 20-question study instrument (see Appendix D). Following the data collection phase, the researcher analyzed the data.

Eligibility Criteria

Participants self-identified as meeting eligibility criteria through a screening question in the anonymous online survey tool. Specifically, participant eligibility criteria required that participants: a) have a social work degree (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program); b) were currently working for a United States-based agency providing hospice care; and c) had worked for a United States-based agency providing hospice care before March 23, 2010, when the PPACA became law. Other eligibility criteria not explicitly stated required that participants have access to a computer with Internet access, be capable of using a computer, and be able to read and write in English.

Recruitment

A nonprobability sample of availability was used to find research participants who matched the above criteria. The researcher primarily relied on LinkedIn professional groups, Facebook, word of mouth discussions, and snowball sampling (referrals for participation made by friends, family, current participants, etc.) to recruit participants for the study.

LinkedIn. The primary tool used to recruit participants for this study was the online professional networking website, LinkedIn (URL: <https://www.linkedin.com>). The researcher shared the recruitment post on her professional LinkedIn profile, which accrued 69 views (see Appendix E). One member of the researcher's LinkedIn network stated she re-posted the recruitment request on her Facebook profile, while another member suggested contacting a United States-based hospice agency with which he had previously worked and permitted the researcher to reach out to the agency using his name as a reference. Two other members sent the

researcher a personal message indicating they knew individuals in hospice and offered to make an introduction.

The researcher actively sought out and joined hospice-related LinkedIn professional groups and selected professional groups with which she already was a member. Prior to posting in these groups, the researcher contacted either the group owner or a group manager to express her intent to post to the group and clarify group guidelines for posting research participant requests (see Appendix F). Of the eight hospice-related groups and two other professional groups, seven owners/managers responded indicating permission to post and specifying in which section of the group forums to post. Collectively, these groups had a potential to reach approximately 15,000 LinkedIn members.

The researcher also sent a personal message to 17 hospice social workers in her greater LinkedIn professional network who appeared to meet the eligibility criteria. Six people responded that they would participate.

Facebook. The researcher posted a recruitment message on her Facebook profile, which led to 12 people in her network sharing the information with their networks (see Appendix G). The researcher also posted to Facebook community groups. Collectively, these recruitment efforts had the potential to reach approximately 1,500 Facebook members.

Forty-six people clicked on the study link to take the survey. Of those 46 people, 29 indicated that they met the eligibility criteria to be a candidate to participate in the survey. Of the 29 eligible candidates, 22 people consented to participate in the study. Fourteen of the remaining 22 people completed the questionnaire.

Informed Consent

After the self-screened participants verified their eligibility to participate in the study, the researcher obtained electronic informed consents through the survey instrument on a separate informed consent page (see Appendix B). Participants were informed that the focus of the research was to explore changes in the hospice social worker's work-related responsibilities since the PPACA was enacted.

The researcher electronically explained to each participant the purpose and design of the research project, including the benefits and risks of participation. The researcher informed all participants that their involvement was voluntary and that all information gathered would be held with strict measures of confidentiality per federal guidelines. Participants were assured anonymity of the information collected, including that data would be linked to neither the participant identities nor their computer's IP addresses. The researcher informed the participants that, while unlikely, they might feel some discomfort or distress as a result of answering anonymous survey questions related to changes in their work. Furthermore, the researcher informed participants that they could withdraw from the study at any time, without penalty, by choosing to not complete the survey.

Participants were informed that there would be no financial compensation for their participation in this study. They also were informed that although there may not be direct benefit from taking part, their personal perspective might provide a valuable contribution to the overall growing body of knowledge on hospice social work. Their participation might aid in building an identity for, and defining the role of, hospice social work, especially within interdisciplinary treatment teams. This information might also inform future hospice practices and strategies for service, recruitment, and policy making. Potential participants also were informed that

information provided might enlighten future hospice practices as well as provide new insight into their practice as a hospice social worker and how their practice has shifted since the PPACA was enacted.

Participants could ask the researcher questions about the study via email and phone, using contact information provided in the informed consent, and through the communication tools available on the social and professional networking platforms. The researcher did not meet or interact with participants unless they contacted the researcher by email, phone, or through the social media platforms. Three participants contacted the researcher through LinkedIn and one participant contacted the researcher by email.

Data Collection

The data were collected through an anonymous online survey instrument hosted by SurveyMonkey. Participants spent 15 to 20 minutes completing the survey, depending on the extent to which they answered open-ended questions. The first 13 questions were demographic and related to the participant's personal identity, professional and educational experience, and information about their United States-based hospice agencies. Five questions were quantitative, each using a Likert scale and a qualitative text box asking participants to explain their scale response. Lastly, three questions were strictly qualitative and pertained to participant's opinions on, observations of, and additional comments they would like to offer on the PPACA. A copy of the study instrument is included in Appendix C.

Data Analysis

The researcher manually coded and analyzed participants' responses to the open-ended questions from the study instrument, grouped by emergent themes and organized by question. The researcher then determined the frequency and means of the quantitative responses.

Ethics and Safeguards

In keeping with federal regulations and the ethics of the social work profession, the findings of this study do not reveal the identity of study participants. A numerical code was assigned to each participant and no identifying information was presented. No relationship existed between the participants and the researcher that might lead to the appearance of coercion. All quotes were written in a manner that does not reveal information that could identify participants. Following federal guidelines, all research materials including recordings, transcriptions, analyses, and consent documents will be stored in a secure location for three years, with access only by the researcher and her research advisor. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data has been and will continue to be password-protected during the storage period.

CHAPTER IV

Findings

The purpose of this study was to explore how hospice social workers based at hospice agencies in the United States perceive changes in their work responsibilities in relation to the Patient Protection and Affordable Care Act (PPACA), particularly within a climate of new rules and a growing number of Medicaid recipients. A major finding was that study participants did not identify any substantial changes in their work-related duties after the PPACA took effect. Within the five categories examined—clinical and counseling, case management, management and administration, advocacy, and spiritual and cultural competence— which vary widely in the amount of perceived change, participants reported experiencing the most increase and overall change in case management duties. The study also found that overall, hospice social workers who responded to the survey supported the PPACA.

Before presenting each of the study's findings, demographic data for the participant sample are presented.

Demographic Information

The study participants ranged in age from 25 to 74, with a mean age between 55 and 64. Six participants (43%) were between the ages of 55 and 64; four (29%) were between 45 and 54; two (14%) were between 65 and 74; and one participant each (7%) fell within the ranges of 25 to 34 and 65 to 74.

Twelve female and two male social workers participated in the study; no participants indicated they were transgender. With regards to race and ethnicity, 86% ($n = 12$) reported their race/ethnicity as white, 7% ($n = 1$) identified as African American, 7% ($n = 1$) identified as “other,” and one participant chose not to disclose their race or ethnicity. As seen in Table 1, participants hailed from 11 of the 52 states and territories, with California and Minnesota having the highest number of participants at 21% ($n = 3$) and 14% ($n = 2$), respectively.

Table 1

<i>States Represented by Survey Participants</i>		
<u>State</u>	<u>n</u>	<u>%</u>
California	3	21
Minnesota	2	14
Connecticut	1	7
Illinois	1	7
Massachusetts	1	7
Michigan	1	7
New Jersey	1	7
New York	1	7
North Carolina	1	7
Vermont	1	7
Virginia	1	7
Total	14	

Professional experience. Participants’ total years of professional social work experience ranged from 1 to 40 years (mean = 16.5, median = 14.5). Total years of hospice social work experience ranged from 1 to 19 years (mean = 10.5, median = 10.5, mode = 11) (see Table 2).

All 14 participants completed a master’s degree in social work as their highest level of social work education, not including Continuing Education Units (CEUs). With respect to advanced training, one participant (7%) completed an end-of-life care certification/fellowship, another participant (7%) was in the process of completing an end-of-life care certification/fellowship, and none of the remaining 12 participants (86%) had further training in end-of-life care. Nine participants (64%) stated they were working full-time, while the remaining five participants (36%) indicated they were employed part-time. None of the participants were

employed on a temporary contract basis or reported having any other employment status. Twelve participants (86%) identified their job level as a direct service provider, while two participants (14%) considered themselves middle management. None of the participants identified their job level as senior management.

Table 2

Years of Professional Experience in Social Work and in Hospice

<u>Years</u>	<u>Social Work (n)</u>	<u>Hospice (n)</u>
1-5	1	2
6-10	3	5
11-15	4	5
16-20	3	2
21-25	0	0
26-30	1	0
31-35	1	0
36-40	1	0
Mean*	16.5	10.5

* One participant had only one year of professional experience, and it was in consulting. The next lowest number of years of professional experience by any of the participants was six years. If the means were calculated without including the participant with only one year of consulting experience, they would be 18 years of social work experience and 11 years of hospice social work experience.

Hospice agencies. Seventy-one percent ($n = 10$) of study participants stated their hospice agency was a non-profit, while 29% ($n = 4$) categorized their agency as for-profit. None of the participants worked for a hospice agency owned by the federal government. Seventy-one percent ($n = 10$) stated their hospice agency serves a city, urban, and/or suburban community, while only 36% ($n = 5$) stated their agency serves a rural community. This question was open; participants could select more than one response, the results suggesting that either one of the agencies served more than one geographic service area or one of the respondents worked for more than one hospice.

Half of the participants ($n = 7$) worked for a freestanding or independent hospice agency, while 29% of the participants ($n = 4$) worked for agencies that were part of a hospital or health system. Twenty-one percent ($n = 3$) worked for an organization that was part of a home health agency, while 14% ($n = 2$) worked for an agency that was part of a chain of hospices. None of the participants worked for a hospice agency that was part of a nursing home. Again, this question was open and participants could select more than one response.

Changes in Work-related Responsibilities

Overall, 76% of participants surveyed (mean $n = 10.6$) stated that they did not experience a change in time spent on any of the five identified categories of work-related responsibilities—clinical and counseling, case management, administrative and management, advocacy, and spiritual and cultural competence—since the PPACA became law (see Graph 1).

Participants provided general comments about changes in their work-related responsibilities as a result of the PPACA that illustrated different themes. These themes included: participants not noticing any changes to their work; increased access to health care insurance resulting in an increase in the number of clients served at participants' agencies; the quality of service being compromised; and Medicare being an influencer on client care.

Some participants reported noticing an increase in time and effort spent on the areas of clinical/counseling and spiritual and cultural competence, while others reported a decrease in these areas. For the categories of case management, administrative and management, and advocacy-related work responsibilities, an increase in time spent on these responsibilities was reflected in the data, but no decrease was reported.

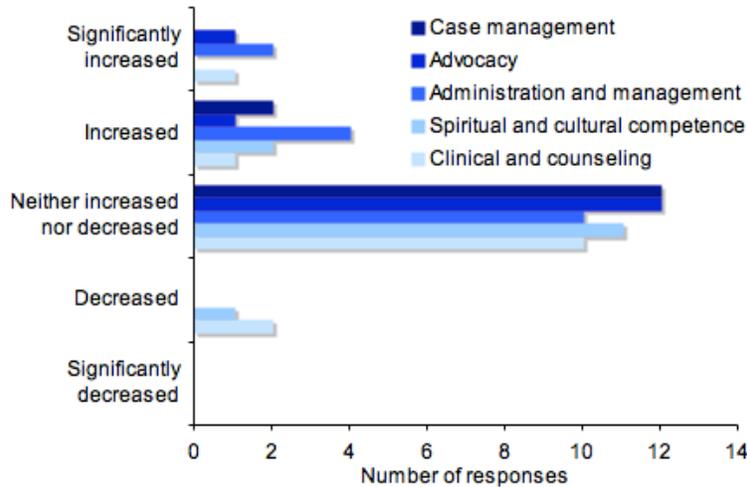


Figure 1. Change in time spent on work-related responsibilities . This figure illustrates hospice social workers' perceptions of changes in their time spent on different categories of work responsibilities since the Patient Protection and Affordable Care Act.

Clinical and counseling work. Participant responses revealed an equal percentage of participants who saw an increase in time spent working on clinical and counseling responsibilities as those who saw a decrease in time spent working in these areas. Fourteen percent of respondents ($n = 2$) stated that their clinical and counseling duties increased (7%, $n = 1$) or significantly increased (7%, $n = 1$) since the PPACA was enacted. A similar percentage of participants (14%, $n = 2$) stated that their work in these areas decreased. The vast majority of participants (71%, $n = 10$) stated that time spent on clinical and counseling work neither increased nor decreased. Given the distribution of these quantities, when rounded up to the nearest percent and even the nearest tenth of a percent, they do not add up to 100% (percent distribution: 7.14, 7.14, 14.29, and 71.43) (see Figure 2).

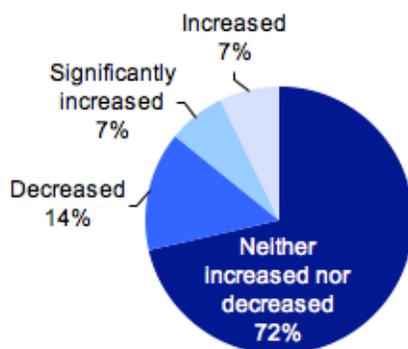


Figure 2. Clinical and counseling-related work responsibilities. This figure illustrates hospice social workers' perceptions of changes in their time spent on clinical and counseling-related work responsibilities since the Patient Protection and Affordable Care Act. Total does not equal 100% due to rounding.

One theme highlighted in participants' qualitative responses was uncertainty around whether the PPACA had any bearing on changes to their work in clinical- and counseling-related responsibilities. One participant stated, "We have no way of telling, however, if our patients were prior members of our health plan, or if they came into our health plan under the Affordable Care Act."

Another theme highlighted the priority of focusing on the needs of clients and their families relative to a lack of resources, rather than clinical- and counseling-related needs. One participated stated that there is a "... greater responsibility for clarifying insurance issues."

Spiritual and cultural support work. Similarly, in the category of spiritual and cultural support-related work responsibilities, the vast majority of respondents (79%, $n = 11$) experienced neither an increase nor decrease in their time spent on these work-related responsibilities. But for those who did experience a change in the time spent on work-related responsibilities, the data provided conflicting responses. Though 14% ($n = 2$) experienced some increase in time spent on spiritual and cultural support-related work responsibilities, 7% of participants ($n = 1$) experienced a decrease in these responsibilities. No participants, however, experienced

significant change in the time spent in this category of work-related responsibilities (see Figure 3).

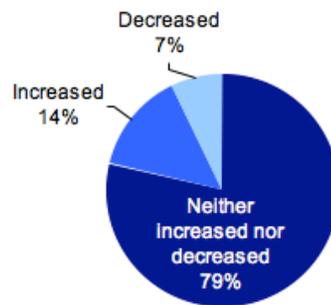


Figure 3. Spiritual and cultural competence-related work responsibilities. This figure illustrates hospice social workers' perceptions of changes in their time spent on spiritual and cultural competence-related work responsibilities since the Patient Protection and Affordable Care Act.

Themes in the qualitative data suggested that a decrease in spiritual and cultural support-related work responsibilities might be associated with changes in the participant's job position, with one participant stating, "Change has to do with change[s] in my job responsibilities. [It] has nothing to do with Obamacare." Another participant suggests a different perspective on why there has been a decrease in the time and effort spent on spiritual and cultural support-related responsibilities. This participant said she has "less time available to spend with each patient and less able to commit resources to them out of concern that I can't get back to them in a timely fashion if we start meaningful work." Another participant stated that spiritual and cultural support comes with the calling of social work: "If we are doing our job as social workers, cultural awareness is in the forefront of every evaluation and client/patient exchange."

Case management. In case management-related work responsibilities, 43% ($n = 6$) of survey participants stated that their time spent on case management-related work responsibilities had either increased (14%, $n = 2$) or significantly increased (29%, $n = 4$) since the PPACA was enacted. In contrast, more than half (57%, $n = 8$) stated that time spent on case management-related work responsibilities neither increased nor decreased (see Figure 4).

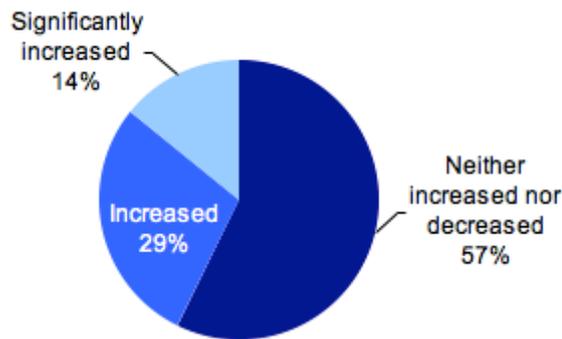


Figure 4. Case management-related work responsibilities. This figure illustrates hospice social workers' perceptions of changes in their time spent on case management-related work responsibilities since the Patient Protection and Affordable Care Act.

The major theme present in the qualitative data for increased case management-related responsibilities pertains to the need for client education on rights related to their hospice care. One participant stated that because she is informed on client rights she feels it is her responsibility to educate the client. She wrote, “I personally understand available program options better and therefore share the knowledge.” Another participant pointed to rights related specifically to transitioning from one service to another: “Families are not aware of their rights regarding discharge from facilities or from skilled days to hospice . . .”

Administrative and management duties. In the domain of administrative- and management-related work responsibilities, an equal percentage of survey participants stated that their time spent on these responsibilities increased (7%, $n = 1$) or significantly increased (7%, $n = 1$) since the PPACA was passed into law, for a total of 14% of participants ($n = 2$) seeing an increase. At the same time, no participants reported a decrease in their administrative- and management-related work responsibilities. A large majority (86%, $n = 12$) stated that their time spent on administrative- and management-related work responsibilities had neither increased nor decreased since the PPACA was enacted (see Figure 5).

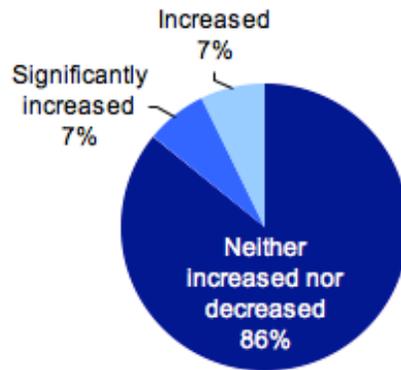


Figure 5. Administrative and management-related work responsibilities. This figure illustrates hospice social workers' perceptions of changes in their time spent on administrative and management-related work responsibilities since the Patient Protection and Affordable Care Act.

The qualitative data offer a broad range of explanations for understanding the changes to study participants' management- and administrative-related work responsibilities. Again, one participant pointed to her move from a direct service position to a management position as the reason for an increase in management and administrative work. Other participants pointed to a shift in their agencies' being focused on controlling the types of clients served, stating a "decision to keep as many of our 'commercial patients' (health plan / non-Medicare patients) as possible—therefore, our patient population has been getting younger (younger adults with children—we do not provide pediatric care and we refer about 3/4 of our members to outside Hospice programs)." While another participant explained a swing in client needs being more complex and thus resulting in additional supervision, she stated that "MSWs seeking increased consultation / support related to complex cases . . . placing more emphasis on communication and case consultation as part of changes in our department."

Advocacy work. A similar breakdown was reflected in advocacy-related work responsibilities. While the majority of respondents (86%, $n = 12$) indicated that they have neither experienced an increase nor a decrease in advocacy-related work responsibilities, 14% ($n = 2$)

noted experiencing an increase in these responsibilities since the PPACA was enacted. Although none of the respondents reported a substantial increase in time spent on advocacy-related work responsibilities, they also did not indicate any decrease (see Figure 6).

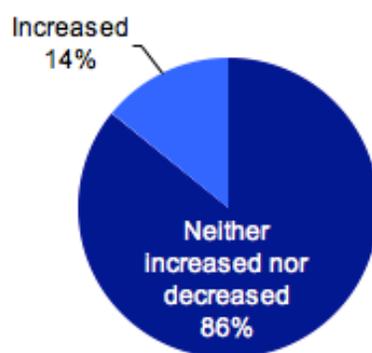


Figure 6. Advocacy-related work responsibilities. This figure illustrates hospice social workers' perceptions of changes in their time spent on advocacy-related work responsibilities since the Patient Protection and Affordable Care Act.

Little qualitative data was offered to help understand the changes or stability in advocacy-related work. One participant suggested that limited resources for the services offered in hospice could be related to an increase in time and effort spent on advocacy-related responsibilities. She states that, “More people [are] needing respite because of lack of finances/caregivers supports; and [I am] not always able to find available beds.” Another participant stated that advocacy is one of social work’s tenets and that it is “. . . what we do as social workers, no change in what I do or how I do it.”

Support of PPACA. Though there was overwhelming support of the PPACA by survey participants, many couched their support with qualitative statements that this health care reform is not “by any means perfect.” Some participants pointed to the implementation of the PPACA as an issue, while another pointed to the need for reimbursement of all services, not just some. Others said they believe the new rules need tweaking before the legislation can be considered

“ethical” and “socially responsible.” Some of the qualitative responses reflected a theme that the respondents preferred a “health care for all” or single-payer model.

CHAPTER V

Discussion

First, I will discuss the findings based on the literature reviewed in Chapter II, highlighting areas congruent, incongruent, and unrelated to the prior literature. Then I will review the limitations of the study and suggest ideas for further research. Last, I will explore the implications of the findings on the field of hospice social work and provide recommendations for future social work research and practice.

Findings congruent and incongruent with existing literature

Educating clients on policies and their rights. The literature also supports that client knowledge was often a barrier to receiving hospice services and resulted in a delayed referral to hospice (Friedman, Harwood, & Shields, 2002; Meier, 2011; Nelson et al., 2014). Participants expressed that changes in their work-related responsibilities were associated with clients and families not knowing their rights. For participants who experienced a decrease in time and effort spent on clinical and counseling support-related work responsibilities and for those who experienced an increase in case management work-related responsibilities supported these changes with the need for client education.

As one participant explained, “Families are not aware of their rights regarding discharge from facilities or from skilled days to hospice, so they go home and have inadequate support to care for a patient.” The literature supports the role of hospice social workers as helping clients and their families build agency by educating them on their options and rights in health care

(Blacker, 2004; Blum et al., 2001; Hedlund & Clark, 2001; Kramer, 2013; Kulys & Davis, 1987; Reese, 2011). As social workers see a need for client education, it is their role as hospice social workers to inform their clients. One participant identified her role as an educator, saying, “I personally understand available program options better [than my clients] and therefore share the knowledge [with them].”

Shift in quantity and complexity of caseloads at United States-based hospice agencies. The literature supports that an increase focus on health care spending could potentially lead to shrinking hospital budgets resulting in increases in caseloads or growing workload requirements (Reisch, 2012; Zabora, 2011). Several participants noted that their agencies experienced an increase of clients in their programs, in their caseloads, or in the complexity of the cases they were seeing. One participant commented on when staff caseloads increase, customization of care decreases: “We are no longer able to provide the quality personalized care we once did. [We have] much more discharge planning. Productivity is tightly monitored as caseloads increase.” Another participant cited a lack of time and resources for starting “meaningful” spiritual and cultural support work with clients out of fear that she wouldn’t be able to get back to the client and her other work. And a third participant stated, “Larger caseloads, shorter length of stay (on service—patients come on much sicker and die before much counseling work can be done), greater responsibility for clarifying insurance issues.”

While the literature supports an anticipated workforce shortage for physicians in hospice and palliative medicine (Lupu, 2010), and general workforce shortages in rural areas (Casey et al., 2005; Cerminara, 2011; Reese, 2013) in the post-PPACA era, a dearth of literature exists describing the workforce demands of other interdisciplinary team members, such as social workers. Also lacking are studies that explore how workforce shortages or increased demands on

non-social work team members may be impacting the direct service work of hospice social workers and their caseloads.

One study participant touched upon the workforce shortage of staff in her agency and how it affects her patients:

Due to decreases in Medicare payments, which resulted from changes to Medicare when the Affordable Care Act became law, we have seen a lot of changes in the number of staff our hospice has been able to hire. Thus we always work on skeleton staffing which has resulted in a lower level of care hours for our patients.

The qualitative findings in this study pertaining to shifts in service delivery could serve to inform further research exploring the connection between hospice staffing shortages and the delivery of quality end-of-life care. In the mission of advocacy work, direct service social workers are professionally called upon to intervene at a macro-level when they observe widespread concerns. “Issues in the workplace, such as the quality of service to clients, may surface and require an organized intervention” (Netting et al., 2012, p. 7).

No change in work-related responsibilities. Overall, participants did not endorse seeing a change in the time and effort they spent on their hospice social work-related responsibilities as categorized in this study. Possible explanations for the reported lack of change in work-related responsibilities could be derived from comments of study participants. As one participant stated, “I haven't noticed any changes but that does not mean there haven't been any. The biggest influence remains to be Medicare.” Or from another participant who stated, “I do not feel that the [Patient Protection and Affordable Care Act] has changed my work in hospice care in any particular way. There are constantly changes to policies and I know we certainly have had some

since the [PPACA], as a direct result of it, but any changes to my role as a direct service provider are minimal.”

One explanation for hospice social workers not seeing a change in the time and effort spent on their work related responsibilities since the PPACA could be based on the complexity of a person-in-environment systems perspective, especially when evaluating oneself. As will be discussed later in this chapter on the limitations of ecological and systems theories in evaluating practice, the literature supports that these frameworks are difficult to measure social work interventions, even when they are supported by these theories (Langer & Lietz, 2015). Additionally, given the subjective nature of the survey format of the research design, it is difficult for the participant to provide completely objective data (Anastas, 1999) and thus participants might not have been able to objectively review and assess how their time and effort spent on hospice social work related responsibilities had change.

New findings

Support of the Patient Protection and Affordable Care Act. The NASW supports “a national health care policy that ensures the right to universal access to a continuum of health and mental health care throughout all stages of the life cycle” (NASW, 2012). Though the PPACA is not considered universal access health care, the NASW endorsed passage of the legislation prior to its signing into law. In a 2009 press release, the NASW stated that it “strongly supports this historic legislation and urges the Senate to pass health care reform for Americans now. If passed, differences with a separate House version of health reform legislation will still need to be resolved” (NASW, 2009, para. 1).

Overall, study participants echoed their support of the PPACA, with some reservations. One participant stated their support of the PPACA, while also stating their preference, similar to the NASW's, for universal access health care:

I think [the PPACA] is great—and way overdue. I think it is one of Obama's greatest accomplishments. It should go even further than it does, and will need some tweaking and amendments to fix defects and cover more people. I believe in a single payer, Universal Health Care system—it is the practical, logical and ethical thing to do.

Of the 93% of participants who responded to this survey question, 46% endorsed their support of the legislation, while only 14% expressed disapproval. The remaining 33% of participants expressed ambivalence or stated their preference for a different health care policy. Ambivalent participants cited disappointment in the PPACA roll out, ineffectiveness, universal access, limited reimbursements, public insurance involvement, and social irresponsibility as reasons for their objectionable support of the legislation.

Administrative shift for funding. A minor finding was that three participants noted a shift in funding-related focus. The first participant, who works for a non-profit agency, expressed that the PPACA has helped their agency to expand their fundraising dollars to cover more clients. The participant noted that the agency does not turn patients away for lack of funds, thus additional publicly insured clients would help to subsidize some of the cost.

A second participant expressed concern that a funding-related focus could compromise the quality of service delivery. “Patient care is no longer the prime focus of management; it now is on the ‘bottom line.’ It is my experience from speaking to patients that the Affordable Care Act may give you ‘coverage’ but that service is another issue entirely.” The literature supports

that an increase focus on health care spending could potentially lead to shrinking hospital budgets resulting in staffing cuts, increases in caseloads, or growing workload requirements (Reisch, 2012; Zabora, 2011).

A third participant stated that the agency is focused to “keep as many of [their] ‘commercial clients’ (health plan/ non-Medicare patients)... as possible.” Without the opportunity to follow up with the participants directly, it is difficult to clarify the exact meaning behind this statement. However, a commercial client would imply a client with private health care insurance, which is defined as “usually any insurance for hospital or medical care which has the objective of making a profit” (World Health Organization, 2004, p. 59). In cases of for-profit insurance, the longer the commercial client stays in hospice the lower the costs to the hospice overall (Perry & Stone, 2011). The literature raises concerns about the ethical conflicts inherent in the for-profit model of health care delivery.

Limitations and Suggestions for Further Research

Theoretical framework. Although ecological and systems theories are essential to multilevel social work practice, as a theoretical framework for research they are limited in their conceptualization in two ways (Langer & Lietz, 2015). First, ecological and systems theories are difficult to measure. Social work has become increasingly interested in using, and pressured to use, evidence based practices. Systems and ecological theories are complex and difficult to measure social work interventions that are supported by these theories. And “although a person-in-environment perspective is consistent with social work’s mission and is referenced in NASW’s preamble, these practices are not identified as being empirically supported” (p. 53-54). Systems and ecological theories recognize the complex and highly dynamic forces of the human

experience; while acknowledging the complexity of these theories as a strength, it can be challenging when evaluating social work practice from a person-in-environment perspective.

Second, in addition to being difficult to measure for empirical research, ecological and systems theories are broad and do not offer much direction for specific interventions (Langer & Lietz, 2015). One of the strengths of these theories is it offers application in a multitude of social work settings and to a multilevel practice. However, some degree of specificity can be lost when theories can be so broadly applied; thus, theoretical strengths can also serve as limitations.

Recruitment and sample size. The small sample size prevented analysis of statistical significance on the data, including subsamples. Examples of subsamples that would have contributed to a richer analysis are gender, age range, years of experience, and states that opted into the Medicaid Hospice Benefit. This researcher intended to survey 50 or more hospice social workers who met the eligibility criteria, but due to time constraints, limited recruitment locations, and other factors, only 14 social workers participated.

Social media may not have been the most efficient mode of recruiting participants. One cause for low response rates may have been that some LinkedIn group administrators appeared to have mistaken research participant recruitment for headhunting or job recruitment and requested the post be placed in the Jobs forum. This miscategorization may have decreased visibility of the participant recruitment post within these groups. Additionally, by primarily using LinkedIn and Facebook as recruitment venues for the sample, the posts might have only attracted active users of social media. Perhaps the more active users of the LinkedIn hospice groups were younger and thus might have had less experience in the field; hence, they may not have been eligible to participate in the study.

In general, the eligibility criteria may have also posed limitations to recruitment. Eligibility requirements were that participants had to have had professional experience working in hospice for a United States-based agency both before the PPACA was enacted and at the time of the study. This requirement could be one explanation for disparity between the number of people who clicked on the survey link ($n = 46$) but did not meet eligibility criteria ($n = 17$), versus those who met eligibility ($n = 29$) and also consented to participate ($n = 22$). Two hospice social workers who did not participate in the study reached out to the researcher stating that they practice hospice social work but did not meet the eligibility criteria because they either worked in a different country or because they were not working in hospice prior to the PPACA's enactment.

Data collection. As a mixed methods questionnaire/survey, all data were self-reported. Though it was a mixed methods survey (or questionnaire), where many of the self-reported/self-administered questions utilized a scale format, several portions of the survey asked open-ended questions. Literature regarding best practices in research cautions against asking respondents to write in their answers, as it could pose a burden to the participants. In the book *Research Design for Social Work and the Human Services*, the author explains that “Open-ended questions, especially those requiring the respondents to reply at length in writing, are difficult and tiring for most respondents to questionnaires” (Anastas, 1999, p. 376). Thus, the open-ended question portion of the survey, despite being listed as optional, might have dissuaded some of the eligible, consenting participants from either completing the survey or providing useful qualitative data.

Since the survey was anonymous, nonresponse rates were predictably high as it was easy for eligible, participant candidates to disregard the survey, partially complete it, or begin the survey but not finish or submit their answers. In order to maintain the participants' anonymity,

no follow up channels existed through which the researcher could contact participants to pursue further clarification of their answers. Without a means to follow up with the anonymous survey participants, qualitative data were solely available for face value interpretation and speculation.

Last, since the researcher did not conduct a pilot of the survey, feedback on the survey questions did not inform the wording of the survey; potential misunderstandings of the intent of the questions were not ruled out. For example, as discussed earlier, overall, participants did not see a change in the time and effort spent on their work-related responsibilities as categorized in this study. The intent of the question was to have clients reflect on how their work has changed since the point of time when the Patient Protection and Affordable Care Act passed, not necessarily attribute the cause of any work-related changes to the PPACA. Some participants mentioned in the qualitative data that they could not determine if changes in their work-related responsibilities were associated with the PPACA. This response implied that participants seemed to have made an assumption that the question was asking about how they thought the PPACA changed their work. Piloting the study might have helped avoid this miscommunication; the responses illustrate a potential need for rewording the questions.

Ideas for further research

Explore changes in a different or more specific social work mesosystem practice.

The categories outlined as work-related responsibilities were clinical and counseling, case management, management and administration, advocacy, and spiritual and cultural support. However, very few PPACA measures and provisions changed the way hospice social workers conduct these direct service tasks. The primary PPACA changes to hospice were specifically related to concurrent care for children on SCHIP (PPACA, §2302), increased reporting measures for hospices that receive Medicare and Medicaid funding (PPACA, §§3004, 3006), and

physicians' and nurse practitioners' 180-day recertifications (PPACA, §3132). Questions related to the three primary PPACA changes to hospice care may have solicited different responses. For example, the researcher could have asked a question about the age range of the population with which the participants work and whether the age range has changed since the PPACA's enactment.

Another question related to direct changes in hospice as a result of the PPACA could have been about the size of caseloads in comparison to prior to the PPACA's enactment. For example, one participant stated in response to how the PPACA has changed her work in hospice, "We are no longer able to provide the quality personalized care we once did. Much more discharge planning. Productivity is tightly monitored as caseloads increase." Another participant provided an explanation for changes to her time and effort spent on clinical and counseling work-related responsibilities, "Larger caseloads, shorter length of stay (on service— patients come on much sicker and die before much counseling work can be done), greater responsibility for clarifying insurance issues."

And last, another question related to the hospice social worker's agency inquiring about changes in administrative focus on reporting or specific kinds of documentation, might have provided more information directly linking back to the PPACA.

Improving sample size. Given the limited data in this study as a result of the small sample size, the researcher might have approached sampling differently. Still using a nonprobability sample technique, but targeting specific agencies using a communication method other than social media discussion platforms, such as email or contacting a representative listed on the agency's website, might have improved the response rate. Additionally, providing the

option of confidential phone surveys versus anonymous electronic surveys might have provided a more reliable response rate and the opportunity to clarify participant answers.

Looking Ahead

Hospice care and chronic illness. When hospice was initially founded in the United States, it was to treat patients dying of cancer. However, today, more and more patients who elect into hospice have other chronic illnesses, where prognosis is more difficult to predict leading to multiple hospice stays and recertifications beyond 180 days. According to the Centers for Disease Control and Prevention ([CDC], 2011), by 2030 the number of Americans aged 65 or older is predicted to approach 71 million, with 80% of these individuals having at least one chronic condition and 50% having two or more. Chronic conditions include cancer, heart failure, and chronic respiratory conditions with significant symptom related morbidity and functional morbidity, which are in the sphere of palliative care.

The literature endorses warnings of hospice overuse and increased public spending for use of hospice services for chronic illness patients (Jennings & Morrissey, 2011; Meier, 2011). The Medicare Payment Advisory Commission (2010a) expands on these alarms regarding public insurance, “Concerns about the overuse of hospice focus on Medicare beneficiaries with multiple chronic conditions and functional impairment who are not imminently dying and may survive beyond the initial six-month prognostic eligibility criterion set in statute” (as cited in Meier, 2011, p. 351-52). However, research results regarding whether or not the Medicare Hospice Benefit decreases Medicare spending are mixed. Despite data pointing to overall Medicare savings associated with the use of hospice (Taylor Jr. et al., 2007), the recent rise in hospice spending has led to mandate and consistent government review by both the Medicare Payment Advisory Commission (MedPAC, 2009; MedPAC 2010a) and the Department of Health and

Human Services. The Patient Protection and Affordable Care Act (2010) includes a requirement examining the appropriate use of the Medicare Hospice Benefit (PPACA, §3132). Hospital-based (Morrison et al., 2008) and community-based (Kamal, Currow, Ritchie, Bull, & Abernethy, 2013) nonhospice palliative care models are demonstrating to have more effective results for the chronically ill.

Palliative care and concurrent care. Prior to the last decade, palliative care services were only available to patients enrolled in hospice, with few exceptions (National Consensus Project for Quality Palliative Care, 2013). For patients not meeting the hospice eligibility requirement of a prognosis of six months or less, few options have existed to meet their needs for improved quality of life standards, otherwise known as palliative care. These patients consist of those with serious or chronic illness who are not in immediate threat of death. This need for palliative care has led to the recent rapid growth in hospital palliative care teams in the United States in the last one-and-a-half decades (Meier, 2011). Though, one study indicated that the term palliative care is still difficult to define based on a review of palliative care, hospice, and end of life literature (Hui et al., 2012).

Unique to the United States, the distinction between hospice and palliative care is that eligibility for services is prognosis-based; while palliative care eligibility is based on need without a prognostic restriction (Hui et al., 2012). Hospice care eligibility is based on a terminally ill patient having a prognosis of less than six months remaining to live. Palliative care, although often used synonymously with hospice care, can simply refer to palliation of symptoms, such as pain, nausea, anxiety, and other biopsychosocial factors (Reese et al., 2006) including emotional social and spiritual comfort. Palliative care can be given concurrently with life-sustaining treatment, regardless of whether or not a patient has a prognosis of living less than six

months, such as with hospice care. Traditionally there has been a clear boundary that separates life-sustaining treatment from hospice care. Patients have to wait until life-sustaining treatment has been determined by the medical team to be futile before the patient can receive the valuable wraparound services offered by hospice, such as aggressive symptom management, home health nursing, family support and pastoral counseling. As previously mentioned, the requirement that a patient must agree to abandon life-sustaining treatment before accepting hospice care often leads to delays in a patient being referred to hospice (Friedman et al., 2002), even though the patient and his or her family could greatly benefit from receiving hospice services.

In other countries, hospice and palliative care are in large part interchangeable and in the last decade the United States has slowly begun to join this international standard. For example, in February 2000, the United States' largest national organization for hospice care changed its name from the National Hospice Care Organization to the National Hospice and Palliative Care Organization (NHPCO, n.d., para. 4), illustrating the cultural shift from hospice to include palliative care beyond hospice services. In addition, given the stringent terms for hospice eligibility, a move towards reforming end-of-life care in U.S. health care policy to incorporate nonhospice palliative care with curative, life-prolonging care exists in the current climate of health care reform. Some of the legislative measures in the PPACA illustrates this shift in end of life care to include palliative and hospice services with curative treatment, or concurrent care, by allowing federal coverage for SCHIP patients (PPACA, §2302) and the provision for support of demonstration projects to test the viability of similar concurrent care services for adult Medicare patients (PPACA, §3140). However, few participants in the study provided qualitative data to support this shift.

One of the major challenges with concurrent care is that the government and health insurers are concerned that it will likely reduce the cost savings of hospice care because concurrent care does not require the patient to forgo expensive therapies in order to receive hospice benefits. However, as mentioned in a previous section of this chapter, given that patients experience referral delays to hospice (Friedman et al., 2002), preventing them from taking full advantage of hospice care services, what could happen if a patient is not required to make the binary choice between life-sustaining therapy and hospice care?

One potential outcome could be that the patient might be able to benefit from hospice and accept his or her prognosis sooner. Concurrent and palliative care could be a burgeoning area of end-of-life care that may end up decreasing the utilization of more expensive treatments than necessary at the end of life and changing services for the country's terminally and chronically ill patients. More research is needed to determine the full benefits of this model of care.

Education and specialization. The literature illustrates the lack of education and training on hospice and palliative care in graduate education (Berzoff et al., 2005; Christ & Sormanti, 2000; Dickinson et al., 1992; Kovacs & Bronstein, 1999; Kramer, 1998; Sormanti, 1994). Specifically, MSW students receive a dearth of instruction on death, bereavement, and terminal care in their course work and fieldwork. Though the field of end-of-life care has made advancements in social work education curriculum, especially for post-Master's education, certification, and fellowships, only one survey participant identified having completed a certification/fellowship in end-of-life care. Only one other participant stated being in the process of working towards this certification/fellowship.

As outlined in the literature review chapter, the end-of life social work profession has developed multiple specialties. This evolution in social work professional specialization has

arisen as human service organizations have become larger and more bureaucratized (Netting et al., 2012). However, sociologist, Sullivan (2005) warns against becoming too professionally specialized in any profession as it can become a barrier from maintaining a shared vision and detract from the values of a professional identity. Netting, Kettner, McMurty, and Thomas explain that though, “specialization offers attractive organizational efficiencies and it can allow social workers to develop greater skill and expertise in particular areas of practice...it can also lead to tunnel vision, in which one begins to work within narrowly defined limits at the expense of a broader awareness of client needs” (2012, p. 28-29). The risk Netting et al. argue is:

As the nation’s health and human service delivery systems have become more and more complex, as new actors enter the arenas, and as professionals specialize, it becomes rare for the practitioner to see an intervention from beginning to end. Many tasks have become more standardized and routinized; thus, social workers may feel bound by rules rather than directed by flexible guidelines that facilitate discretion and judgment. These changes can jeopardize the maintenance of a professional vision that transcends individual organizations and communities (2012, p. 29).

The need for additional training through education, certification, or specialization is important for preparing social workers entering the field of end-of-life care to be knowledgeable and skilled. Social workers have secured a seat as a skilled member of the interdisciplinary team and preparation maintains their viability in the field. However, in times of policy change, funding pressures, bureaucratization, and changing credential requirements, competition for job security and decreased quality of patient care could contribute to losing sight of the profession’s role and responsibilities for macro level interventions. And yet, on an organizational macro level, a

systems approach highlights the intricacies involved in understanding multiple groups (e.g., professional staff, clerical staff, management, administration, board, clients funding sources, neighbors, and others in the community) that are invested in what that organization does and whom it serves.

Research opportunities for social work in the future of hospice. Social workers can play a significant role in hospice in the future of further health care reform. Given that one of the goals of the PPACA is to reduce overall health care costs (PPACA, 2010), hospice social workers could promote social work involvement outcomes by building on existing research. For example, literature currently exists supporting social work involvement in hospice as associated with reduced costs (Cherin, 1997; Mahar, Eickman, & Bushfield, 1997; Paquette, 1997) and that reducing social worker involvement does not reduce hospice care costs (Reese & Raymer, 2004).

Some literature indicates that the future of end-of-life care research appears to be in the micro-practice interventions (Blacker, 2004; E. Clark, 2001). Social work can seize a major area of opportunity by participating in the empirical validation of specific interventions focused on reduction of distress and enhancement of quality of life (E. Clark, 2001). For example, wider implementation of the Social Work Assessment Tool (SWAT) (Reese et al., 2006), which is already under way and was discussed previously in this chapter, could be one way to provide measurable outcomes, evaluate aggregate data, and to benchmark end-of-life care (Reese, 2013). In addition, further development and implementation of a new hospice comprehensive documentation system that links assessment findings to the plan of care of hospice patients, called the Social Work Assessment Notes (SWAN), based on SWAT, could also be useful in future measurable outcomes based research (Hansen, Martin, Jones, & Pomeroy, 2015). Regardless, one key barrier to ensuring access to quality care for all Americans with advanced or

chronic illness is inadequate research to develop an evidence base guiding and measuring quality end-of-life care (Gelfman & Morrison, 2008).

Conclusion. It is unclear what the future of hospice will be in a new era of health care reform. Beyond access to health insurance, which the PPACA begins to mediate, many barriers still exist that limit patients' abilities to receive quality end-of-life care. These barriers include, rules within the hospice system that determine who is eligible for hospice care; caseload management for consistent delivery of quality care; racial, cultural, and geographic disparities; managing funds to remain operative; adequate staffing; and staff retention.

The vision of social work is "built on a commitment to serve diverse people within a society in which basic human needs are not always met and that at times actually denies support to some populations. The challenge is to work toward the development of comprehensive, effectiveness-oriented health and human service systems" (Netting et al., 2012, p. 29). As more than one-third of the participants of this study ambivalently commented, the PPACA is overall a positive move towards ethical health care reform, but it still falls short in meeting the needs of their clients. As one participant stated, "I think that all people are entitled to appropriate health care. However, it seems that the Affordable Care Act needs a lot of tweaking to achieve that goal in a way that provides quality care while remaining socially responsible."

Furthermore, as the role of social work "often requires the practitioner to... skillfully use a macro-practice model to change 'what is' to 'what could be'" (Netting et al., 2012, p. 29), social workers appear to be faced with an ethical dilemma. This ethical dilemma of delivering inadequate services within a health care model that does not meet the needs of end-of-life care recipients across all barriers requires the social worker to have an ethical response to envision

alternatives to the existing status quo and create change. In the era of PPACA full implementation, advocacy work remains a forefront in achieving this goal.

References

- Altilio, T. (2004). Pain and symptom management: An essential role for social work. In J. Berzoff & P. R. Silverman (Eds.), *Living with dying: A handbook for end of life healthcare practitioners* (pp. 380-408). New York, NY: Columbia University Press.
- Anastas, J. W. (1999). *Research design for social work and the human services*. New York, NY: Columbia University Press.
- Anderson, G. F., & Squires, D. A. (2010). *Measuring the U.S. health care system: A cross-national comparison*. New York, NY: The Commonwealth Fund. Retrieved from http://www.commonwealthfund.org/~media/files/publications/issue-brief/2010/jun/1412_anderson_measuring_us_hlt_care_sys_intl_ib.pdf
- Association of Oncology Social Work. (2012). Standards of practice in oncology social work. Oakbrook Terrace, IL: Author. Retrieved from <http://www.aosw.org/professional-development/standards-of-practice>
- Bausewein, C., & Higginson, I. J. (2012). Challenges in defining 'palliative care' for the purposes of clinical trials. *Current Opinion in Supportive and Palliative Care*, 6(4), 471-482. <http://dx.doi.org/10.1097/SPC.0b013e32835998f5>
- Berzoff, J., Dane, B., & Cait, C. A. (2005). Innovative models for developing post-masters curriculum in end-of-life care. *Journal of Teaching in Social Work*, 25(3-4), 63-88. http://dx.doi.org/10.1300/J067v25n03_05
- Berzoff, J., Lucas, G., Deluca, D., Gerbino, S., Browning, D., Foster, Z., & Chatchkes, E. (2006). Clinical social work education in palliative and end-of-life care: Relational approaches for advanced practitioners. *Journal of Social Work in End-of-Life & Palliative Care*, 2(1), 45-63. doi:10.1300/J457v02n02_04

- Billings, J. A., & Block, S. (1997). Palliative care in undergraduate medical education: Status report and future directions. *Journal of the American Medical Association*, 278(9), 733-38. <http://dx.doi.org/10.1001/jama.1997.03550090057033>
- Blacker, S. (2004). Palliative care and social work. In J. Berzoff & P. R. Silverman (Eds.), *Living with dying: A handbook for end of life healthcare practitioners* (pp. 409-423). New York, NY: Columbia University Press.
- Blum, D., Clark, E. J., & Marcusen, C. P. (2001). Oncology social work in the 21st century. In M. M. Lauria, E. J. Clark, J. F. Hermann, & N. M. Stearns (Eds.), *Social work in oncology: Supporting survivors, families and caregivers* (pp. 45-71). Atlanta, GA: American Cancer Society.
- Bosma, H., Johnston, M., Cadell, S., Wainwright, W., Abernethy, N., Feron, A., . . . Nelson, F. (2010). Creating social work competencies for practice in hospice palliative care. *Palliative Medicine*, 24(1), 79-87. <http://dx.doi.org/10.1177/0269216309346596>
- Brandsen, C. K. (2005). Social work and end-of-life care: reviewing the past and moving forward. *Journal of Social Work in End-of-Life & Palliative Care*, 1(2), 45-70. http://dx.doi.org/10.1300/J457v01n02_05
- Brenner, P. R. (1997). Issues of access in a diverse society. *Hospice Journal* 12(2), 9-17.
- Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, 7(5), 343-374. [http://dx.doi.org/10.1016/S0010-440X\(66\)80065-2](http://dx.doi.org/10.1016/S0010-440X(66)80065-2)
- Bowen, M. (1976). Theory in practice of psychotherapy. In P. J. Guerin (Ed.), *Family therapy: Theory and practice* (pp. 42-90). New York, NY: Gardner Press.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723-742. <http://dx.doi.org/10.1037/0012-1649.22.6.723>
- Bronfenbrenner, U. (2004). *Making humans human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage.
- Carlson, M. A., Bradley, E. H., Du, Q., & Morrison, R. S. (2010). Geographic access to hospice in the United States. *Journal of Palliative Medicine*, 13(11), 1331-1338. <http://dx.doi.org/10.1089/jpm.2010.0209>
- Casey, M. M., Moscovice, I. S., Virnig, B. A., & Durham, S. B. (2005). Providing hospice care in rural areas: Challenges and strategies. *The American Journal of Hospice & Palliative Care*, 22(5), 363-368. <http://dx.doi.org/10.1177/104990910502200509>
- Centers for Disease Control and Prevention. (2011). Healthy aging at a glance. Atlanta, GA. Retrieved at http://www.giaging.org/documents/CDC_Healthy_Aging_AAG_508.pdf
- Centers for Medicare & Medicaid Services. (2008). Medicare and Medicaid Programs: Hospice Conditions of Participation; final rule. Federal Register 73(109): 32088-32220
- Centers for Medicare & Medicaid Services. (2016). Medicare & you 2016. Retrieved from <https://www.medicare.gov/pubs/pdf/10050.pdf>
- Cerminara, K. L. (2011). Hospice and health care reform: Improving care at the end of life. *Widener Law Review*, 17(2), 443-473. Retrieved from <http://widenerlawreview.org/files/2011/07/05-cerminara2.pdf>
- Cherin, D. (1997). Saving services: Redefining end-stage home care for HIV/AIDS. *Innovations*, 26-27.

- Christ, G. H., & Sormanti, M. (2000). Advancing social work practice in end-of-life care. *Social Work in Health Care, 30*(2), 81–99. http://dx.doi.org/10.1300/J010v30n02_05
- Clark, D. (2001). A special relationship: Cicely Saunders, the United States, and the early foundations of the modern hospice movement. *Illness, Crisis & Loss, 9*(1), 15.
- Clark, E. J. (2001). The importance of research in oncology social work. In M. M. Lauria, E. J. Clark, J. F. Hermann, & N. M. Stearns (Eds.), *Social work in oncology: Supporting survivors, families and caregivers* (pp. 194-211). Atlanta, GA: American Cancer Society.
- Clark, L., Leedy, S., McDonald, L., Muller, B., Lamb, C., Mendez, T., . . . Schonwetter, R. (2007). Spirituality and job satisfaction among hospice interdisciplinary team members. *Journal Of Palliative Medicine, 10*(6), 1321-1328. <http://dx.doi.org/10.1089/jpm.2007.0035>
- Coluzzi, P. H., Grant, M., & Doroshov, J. H. (1995). Survey of the provision of supportive care services at the National Cancer Institute-designated cancer centers. *Journal of Clinical Oncology, 13*(3), 756-764.
- Connor, S. R. (2007). Development of hospice and palliative care in the United States. *Omega, 56*(1), 89-99. <http://dx.doi.org/10.2190/OM.56.1.h>
- Connor, S. R., Elwert, F., Spence, C., & Christakis, N. A. (2007). Geographic variation in hospice use in the United States in 2002. *Journal of Pain and Symptom Management, 34*(3), 277-285. <http://dx.doi.org/10.1016/j.jpainsymman.2007.03.007>
- Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. 99-272, 100 Stat. 208, as codified as amended at 42 U.S.C. §§1395-1396. (1986).

- Contro, N., Davies, B., Larson, J., & Sourkes, B. (2010). Away from home: experiences of Mexican American families in pediatric palliative care. *Journal of Social Work in End-of-Life & Palliative Care*, 6(3), 185–204. <http://dx.doi.org/10.1080/15524256.2010.529020>
- Csikai, E. L. (1997). Social workers' participation on hospital ethics committees: An assessment of involvement and satisfaction. *Arete*, 22(1), 1-13.
- Csikai E. L. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health Social Work*, 29(1): 67-76. <http://dx.doi.org/10.1093/hsw/29.1.67>
- Csikai, E. L., & Bass, K. (2000). Health care social worker's views of ethical issues, practice, and policy in end-of-life care. *Social Work in Health Care*, 32(2), 1-22. http://dx.doi.org/10.1300/J010v32n02_01
- Csikai, E. L., & Raymer, M. (2005). Social workers' educational needs in end-of-life care. *Social Work in Health Care*, 41(1), 53-72. http://dx.doi.org/10.1300/J010v41n01_04
- Dartmouth Institute for Health Policy and Clinical Practice. (2015a). [Table, interactive map and graph illustration of hospice days per decedent during last six months of life]. *The Dartmouth atlas of health care*. Retrieved December 12, 2015 from <http://www.dartmouthatlas.org/data/table.aspx?ind=4>
- Dartmouth Institute for Health Policy and Clinical Practice. (2015b). [Table, interactive map and graph illustration of percent of decedents enrolled in hospice during the last six months of life]. *The Dartmouth atlas of health care*. Retrieved December 12, 2015 from <http://www.dartmouthatlas.org/data/table.aspx?ind=16>
- Davidson, K. W. (1978). Evolving social work roles in health care: The case of discharge planning. *Social Work in Health Care*, 4(1), 43–54. http://dx.doi.org/10.1300/J010v04n01_05

- Del Rio, N. (2004). A framework for multicultural end-of-life care: Enhancing social work practice. In J. Berzoff & P. R. Silverman (Eds.), *Living with dying: A handbook for end of life healthcare practitioners* (pp. 439-461). New York, NY: Columbia University Press.
- Dickinson, G. E., Sumner, E., & Frederick, L. (1992). Death education in selected health professions. *Death Studies, 16*(3), 281-289.
<http://dx.doi.org/10.1080/07481189208252575>
- Dinger, E. (2005). *Massachusetts end of life survey*. Washington, DC: AARP. Retrieved from http://assets.aarp.org/rgcenter/health/ma_eol.pdf
- Fisher, E. S., Bynum, J. P., & Skinner, J. S. (2009). Slowing the growth of health care costs—lessons from regional variation. *The New England Journal of Medicine 360*(9), 849-852.
<http://dx.doi.org/10.1056/NEJMp0809794>
- Forsyth, J. (1999). Volunteer management strategies: balancing risk and reward. *Nonprofit World, 17*(3), 40-43.
- Friedman, B. D. (1997). System theory. In J. Brandell (Ed.), *Theory & practice in clinical social work* (pp. 3-17). Los Angeles, CA: Sage.
- Friedman, B. D. & Allen, K.N. (2011). System theory. In J. Brandell (Ed.), *Theory & practice in clinical social work* (2nd ed., pp. 3-22). Los Angeles, CA: Sage.
- Friedman, B. T., Harwood, M. K., & Shields, M. (2002). Barriers and enablers to hospice referrals: an expert overview. *Journal of Palliative Medicine, 5*(1), 73-84.
<http://dx.doi.org/10.1089/10966210252785033>
- Gelfman, L. P., & Morrison, R. S. (2008). Research funding for palliative medicine. *Journal of Palliative Medicine 11*(1), 36-43. <http://dx.doi.org/10.1089/jpm.2006.0231>

- Germain, C. B. (1991). *Human behavior in the social environment: An ecological view*. New York, NY: Columbia University Press.
- Germain, C. B., & Bloom, M. (1999). *Human behavior in the social environment* (2nd ed.). New York, NY: Columbia University Press.
- Gitterman, A., & Germain, C. (2008). *The life model of social work practice: Advances in theory and practice*. New York, NY: Columbia University Press.
- Goldsmith, B., Dietrich, J., Du, Q., & Morrison, R. S. (2008). Variability in access to hospital palliative care in the United States. *Journal of Palliative Medicine*, *11*(8), 1094-1102. <http://dx.doi.org/10.1089/jpm.2008.0053>
- Gordon, A. K. (1996). Hospice and minorities: A national study of organizational access and practice. *Hospice Journal*, *11*(1), 49-69.
- Gustafson, J. M. (1982). Professions as “callings.” *Social Service Review*, *56*(4), 501-515.
- Hansen, A. G., Martin, E., Jones, B. L., & Pomeroy, E. C. (2015). Social Work Assessment Notes: A Comprehensive Outcomes-Based Hospice Documentation System. *Health & Social Work*, *40*(3), 191-200. <http://dx.doi.org/10.1093/hsw/hlv033>
- Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the ‘good death.’ *Mortality*, *3*(1), 65-77.
- Health Care and Education Reconciliation Act, Pub. L. No. 111-152, 124 Stat. 1029 (2010).
- Hedlund, S., & Clark, E. J. (2001). End of life issues. In M. M. Lauria, E. J. Clark, J. F. Hermann & N. M. Stearns (Eds.), *Social work in oncology: Supporting survivors, families and caregivers* (pp. 299-316). Atlanta, GA: American Cancer Society.
- Heller, J. M. (1998). The role of the social worker on a stroke rehabilitation unit. *Loss, Grief & Care*, *8*(1-2), 143-147. http://dx.doi.org/10.1300/J132v08n01_19

- Himmelstein, D. U., Thorne, D., Warren, E., & Woolhandler, S. (2009). Medical bankruptcy in the United States, 2007: Results of a national study. *The American Journal of Medicine*, *122*(8), 741-746. <http://doi.org/10.1016/j.amjmed.2009.04.012>
- Hodgson, H., Segal, S., Weidinger, M., & Linde, M. B. (2004). Being there: Contributions of the nurse, social worker, and chaplain during and after a death. *Generations*, *28*(2), 47-52.
- Huff, M. B., Weisenfluh, S., Murphy, M., & Black, P. J. (2006). End-of-life care and social work education: What do students need to know? *Journal of Gerontological Social Work*, *48*(1-2), 219–231. http://dx.doi.org/10.1300/J083v48n01_15
- Hui, D., Mori, M., Parsons, H. A., Kim, S. H., Li, Z., Damani, S., & Bruera, E. (2012). The lack of standard definitions in the supportive and palliative oncology literature. *Journal of Pain and Symptom Management*, *43*(3), 582-592.
<http://dx.doi.org/10.1016/j.jpainsymman.2011.04.016>
- Jennings, B., & Morrissey, M.B. (2011). Health care costs in end-of-life and palliative care: The quest for ethical reform. *Journal of Social Work in End-Of-Life & Palliative Care*, *7*(4), 300-317. <http://dx.doi.org/10.1080/15524256.2011.623458>
- Jennings, B., Ryndes, T., D’Onofrio, C., & Baily, M. A. (2003). *Access to hospice care: Expanding boundaries, overcoming barriers*. Garrison, NY: The Hastings Center.
Retrieved from
http://www.thehastingscenter.org/uploadedFiles/Publications/Special_Reports/access_hospice_care.pdf
- Jimenez, J. (2010). *Social policy and social change: Toward the creation of social and economic justice*. Thousand Oaks, CA: SAGE Publications, Inc.

- Jones, B. L. (2005). Pediatric palliative and end-of-life care: The role of social work in pediatric oncology. *Journal of Social Work in End-of-Life & Palliative Care*, 1(4), 35–62.
http://dx.doi.org/10.1300/J457v01n04_04
- Kaiser Family Foundation. (2012). *Disparities in health and health care: Five key questions and answers*. Menlo Park, CA: Author. Retrieved from <http://kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers>
- Kaiser Family Foundation. (2014). *How will the uninsured fare under the affordable care act?* Menlo Park, CA: Author. Retrieved from <https://kaiserfamilyfoundation.files.wordpress.com/2014/04/8531-how-will-the-uninsured-fare-under-the-aca.pdf>
- Kaiser Family Foundation. (2015). *Status of state action on the Medicaid expansion decision* (Data file). Retrieved on November 13, 2015 from <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/#>
- Kamal, A. H., Currow, D. C., Ritchie, C. S., Bull, J., & Abernethy, A. P. (2013). Community-based palliative care: The natural evolution for palliative care delivery in the U.S. *Journal Of Pain And Symptom Management*, 46(2), 254-264.
<http://dx.doi.org/10.1016/j.jpainsymman.2012.07.018>
- Kovacs, P. J., & Bronstein, L. R. (1999). Preparation for oncology settings: What hospice social workers say they need. *Social Work in Health Care*, 24(1), 57-64.
<http://dx.doi.org/10.1093/hsw/24.1.57>
- Kramer, B. J. (1998). Preparing social workers for the inevitable: A preliminary investigation of a course on grief, death, and loss. *Journal of Social Work Education*, 34(2), 211-227.

- Kramer, B. J. (2013). Social workers' roles in addressing the complex end-of-life care needs of elders with advanced chronic disease. *Journal of Social Work in End-Of-Life & Palliative Care*, 9(4), 308-330. <http://dx.doi.org/10.1080/15524256.2013.846887>
- Kramer, B. J., Hovland-Scafe, C., & Pacourek, L. (2003). Analysis of end-of-life content in social work textbooks. *Journal of Social Work Education*, 39(2), 299-320.
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.
- Kumagai, A. K., & Lyson, M. L. (2009). Beyond cultural competence: Critical consciousness, social justice, and multicultural education. *Academic Medicine*, 84(6), 782-787. <http://dx.doi.org/10.1097/ACM.0b013e3181a42398>
- Kulys, R., & Davis, M. A. (1987). Nurses and social workers: Rivals in the provision of social services? *Health & Social Work*, 12(2), 101-112.
- Landau, R. (2000). Ethical dilemmas in general hospitals: Social workers' contribution to ethical decision-making. *Social Work in Health Care*, 32(2), 75-92. doi:10.1300/j010v32n02_05
- Langer, C. L., & Lietz, C. A. (2015). *Applying theory to generalist social work practice: A case study approach*. Hoboken, NJ: John Wiley & Sons, Inc.
- Laungani, P. (1996). Death and bereavement in India and England: A comparative analysis. *Mortality*, 1(2), 191-212. <http://dx.doi.org/10.1080/713685836>
- Levetown, M. (1998). Palliative care in the intensive care unit. *New Horizons: The Science and Practice of Acute Medicine*, 6(4): 383-397.
- Lister, L. (1980). Role expectations of social workers and other health professionals. *Health & Social Work*, 5(2), 41-49.
- Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health Social Work*, 29(1), 7-15. <http://dx.doi.org/10.1093/hsw/29.1.7>

- Lupu, D. (2010). Estimate of current hospice and palliative medicine physician workforce shortage. *Journal of Pain and Symptom Management*, 40(6), 899-911.
<http://dx.doi.org/10.1016/j.jpainsymman.2010.07.004>
- Mahar, T., Eickman, L., & Bushfield, S. (1997, May). *Efficacy of early social work intervention*. Paper presented at the National Hospice and Palliative Care Organization's 11th Management and Leadership Conference, Washington, DC.
- Maison, D. (2010). Workforce shortages: A staggering need and a call to action. *Journal of Pain and Symptom Management*, 40(6), 912-913.
<http://dx.doi.org/10.1016/j.jpainsymman.2010.09.011>
- Mason, S. (2013). The Affordable Care Act and social work. *Families In Society*, 94(2), 67-68.
<http://dx.doi.org/10.1606/1044-3894.4297>
- Medicare Payment Advisory Commission. (2004, June). Hospice care in Medicare: recent trends and a review of the issues. In *Report to the Congress: New approaches in Medicare* (pp. 139-152). Retrieved from
http://medpac.gov/documents/reports/June04_Entire_Report.pdf?sfvrsn=0
- Medicare Payment Advisory Commission. (2009, March). Reforming the Medicare Hospice Benefit. In *Report to the Congress: Medicare Payment Policy* (pp. 347-373). Retrieved from <http://medpac.gov/documents/reports/march-2009-report-to-congress-medicare-payment-policy.pdf?sfvrsn=0>
- Medicare Payment Advisory Commission. (2010a). Report to the Congress: Aligning Incentives in Medicare. June. Washington, DC: Author. Retrieved from
http://www.medpac.gov/documents/reports/Jun10_EntireReport.pdf?sfvrsn=0

- Medicare Payment Advisory Commission. (2010b). Report to the Congress: Medicare Payment Policy. March. Washington, DC: Author. Retrieved from http://medpac.gov/documents/reports/Mar10_EntireReport.pdf?sfvrsn=0
- Medicare Payment Advisory Commission. (2015). Spending in the last year of life and the impact of hospice on Medicare outlays. Washington, DC: Author. Retrieved from <http://medpac.gov/documents/contractor-reports/spending-in-the-last-year-of-life-and-the-impact-of-hospice-on-medicare-outlays-rev.pdf>
- Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *The Milbank Quarterly*, 89(3), 343-380. <http://dx.doi.org/10.1111/j.1468-0009.2011.00632.x>
- Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.
- Morrison, R. S. (2013). Models of palliative care delivery in the United States. *Current Opinion in Supportive and Palliative Care*, 7(2), 201-206. <http://dx.doi.org/10.1097/SPC.0b013e32836103e5>
- National Association of Social Workers. (2003). Client Self-Determination in End-of-Life Decisions. In *Social work speaks: NASW policy statements, 2003–2006* (6th ed., pp. 46-49). Washington, DC: NASW Press.
- National Association of Social Workers. (2004). NASW Standards for Social Work Practice in Palliative and End of Life Care. Washington, DC: NASW Press. Retrieved from <http://www.socialworkers.org/practice/bereavement/standards/standards0504New.pdf>
- National Association of Social Workers. (2008). *Code of ethics of the National Association of Social Workers*. Washington, DC: NASW Press. Retrieved on November 16, 2015 from <https://www.socialworkers.org/pubs/code/code.asp>

- National Association of Social Workers. (2009, December 10). NASW supports the Patient Protection and Affordable Care Act [Press Release]. Retrieved from <https://www.socialworkers.org/pressroom/2009/121009.asp>
- National Association of Social Workers. (2012). Health care policy. In *Social work speaks: NASW policy statements, 2009–2012* (8th ed., pp. 167-170). Washington, DC: NASW Press.
- National Consensus Project for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Pittsburgh, PA: HPNA. Retrieved from http://www.nationalconsensusproject.org/guidelines_download2.aspx
- National Federation of Independent Business v. Sebelius, 567 U.S. ____ , 132 S.Ct 2566 (2012).
- National Hospice and Palliative Care Organization. (n.d.). About us. Retrieved November 15, 2015 from <http://www.nhpco.org/nhpco-0>
- National Hospice and Palliative Care Organization (2001). *Competency-based education for social workers*. Arlington, VA: Author.
- National Hospice and Palliative Care Organization. (2010). NHPCO facts and figures: Hospice care in America (2010 ed.). Alexandria, VA: Author.
- National Hospice and Palliative Care Organization. (2014). NHPCO's facts and figures: Hospice care in America (2014 ed.). Alexandria, VA: Author. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf
- National Hospice and Palliative Care Organization. (2015). NHPCO's facts and figures: Hospice care in America (2015 ed.). Alexandria, VA: Author. Retrieved from

http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

National Quality Forum. (2006). A national framework and preferred practice for palliative and hospice care quality. Washington, DC: Author. Retrieved from

<https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=22041>

Netting, F. E., Kettner, P. M., McMurtry, S. L., & Thomas, M. L. (2012). *Social work macro practice* (5th ed.). Boston, MA: Pearson Education.

Nelson, M., Gale, R. C., Naierman, N., & DeViney, M. (2014). A descriptive study of California hospice providers' perceptions of public reporting of quality data using the family evaluation of hospice care survey. *American Journal of Hospice & Palliative Medicine*, 31(4), 428-434. <http://dx.doi.org/10.1177/1049909113497418>

Oliviere, D. (2001). The social worker in palliative care: the "eccentric" role. *Progressive Palliative Care*, 9(6), 237-241.

Olsen, K. M., & Olsen, M. E. (1967). Role expectations and perceptions for social workers in medical settings. *Social Work*, 12(3), 70-78.

Paquette, S. (1997, May). *Social work intervention and program cost reduction outcomes*. Paper presented at the National Hospice and Palliative Care Organization's 11th Management and Leadership Conference, Washington, DC.

Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

Perry, J. E., & Stone, R. C. (2011). In the business of dying: Questioning the commercialization of hospice. *Journal Of Law, Medicine & Ethics*, 39(2), 224-234. doi:10.1111/j.1748-720X.2011.00591.x

- Reardon, C. (2011). The health care reform puzzle: How does social work fit? *Social Work Today*, 11(1), 18-21. Retrieved from <http://www.socialworktoday.com/archive/020911p18.shtml>
- Reese, D. J. (2011). Interdisciplinary perceptions of the social work role in hospice: Building upon the classic Kulys and Davis study. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(4), 383-406. <http://dx.doi.org/10.1080/15524256.2011.623474>
- Reese, D. J. (2013). *Hospice social work*. New York, NY: Columbia University Press.
- Reese, D. J., & Raymer, M. (2004). Relationships between social work involvement and hospice outcomes: Results of the National Hospice Social Work Survey. *Social Work*, 49(30), 415-422. <http://dx.doi.org/10.1093/sw/49.3.415>
- Reese, D. J., Raymer, M., Orloff, S. F., Gerbino, S., Valade, R., Dawson, S., ... Huber, R. (2006). The Social Work Assessment Tool (SWAT). *Journal Of Social Work in End-Of-Life & Palliative Care*, 2(2), 65-95. http://dx.doi.org/10.1300/J457v02n02_05
- Reisch, M. (2012). The challenges of health care reform for hospital social work in the United States. *Social Work In Health Care*, 51(10), 873-893. <http://dx.doi.org/10.1080/00981389.2012.721492>
- Rosenberg, C. E. (1987). *The care of strangers: The rise of America's hospital system*. New York, NY: Basic Books.
- Ross, J. W. (1995). Hospital social work. In R.L. Edwards (Ed.), *Encyclopedia of Social Work* (19th ed., pp. 1365-1376). Washington, DC: NASW Press.
- Sentell, T. (2012). Implications for reform: Survey of California adults suggests low health literacy predicts likelihood of being uninsured. *Health Affairs*, 31(5), 1039-1048. <https://dx.doi.org/10.1377/hlthaff.2011.0954>

- Sheldon, F. M. (2000). Dimensions of the role of the social worker in palliative care. *Palliative Medicine*, 14(6), 491-498. <http://dx.doi.org/10.1191/026921600701536417>
- Skinner, K. (1991). A national survey of social workers on institutional ethics committees: Patterns of participation and roles (Unpublished doctoral dissertation). State University of New York at Albany, Albany, NY.
- Skoglund, A. G. (2006). Do not forget about your volunteers: A qualitative analysis of factors influencing volunteer turnover. *Health & Social Work*, 31(3), 217-220. <http://dx.doi.org/10.1093/hsw/31.3.217>
- Sofaer, S., Hopper, S. S., Firminger, K., Naierman, N., & Nelson, M. (2009). Addressing the need for public reporting of comparative hospice quality: a focus group study. *The Joint Commission Journal on Quality and Patient Safety*, 35(8), 422-429.
- Sormanti, M. (1994). Fieldwork instruction in oncology social work: Supervisory issues. *Journal of Psychosocial Oncology*, 12(3), 73-87. http://dx.doi.org/10.1300/J077V12N03_05
- Stein, G. L., & Sherman, P. A. (2005). Promoting effective social work policy in end-of-life and palliative care. *Journal of Palliative Medicine*, 8(6), 1271-1281. <http://dx.doi.org/10.1089/jpm.2005.8.1271>
- Sullivan, W. M. (2005). *Work and integrity: The crisis and promise of professionalism in America* (2nd ed.). San Francisco, CA: Jossey-Bass.
- Surbone, A. (2008). Cultural aspects of communication in cancer care. *Supportive Care in Cancer*, 16(3), 235-240. <http://dx.doi.org/10.1007/s00520-007-0366-0>
- Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. 97-248, 96 Stat. 324, codified as amended at 42 U.S.C. §1395. (1982).

- Taylor, J. S. (2003). Confronting “culture” in medicine’s “culture of not culture”. *Academic Medicine*, 78(6), 555-559.
- Taylor Jr., J. H., Ostermann, J., Van Houtven, C. H., Tulskey, J. A., & Steinhauser, K. (2007). What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? *Social Science & Medicine*, 65(7),1466-1478.
doi:10.1016/j.socscimed.2007.05.028
- Taylor-Brown, S., Blacker, S., Walsh-Burke, K., Altilio, T., & Christ, G. (2001). *Care at the end-of-life*. Philadelphia, PA: Society of Social Work Leadership in Health Care.
- Thompson, M., Rose, C., Wainwright, W., Mattar, L., & Scanlan, M. (2001). Activities of counsellors in a hospice/palliative care environment. *Journal of Palliative Care*, 17(4), 229–235.
- Tsui, M. S. (1997). Empirical research of social work supervision: The state of the art (1970-1995). *Journal of Social Service Research*, 23(2), 39-54.
http://dx.doi.org/10.1300/J079v23n02_03
- United States Census Bureau. (2010). Income, poverty, and health insurance coverage in the United States: 2009. (Consumer Income Reports P60-238). Washington, DC: U.S. Government Printing Office. Retrieved from
<https://www.census.gov/prod/2010pubs/p60-238.pdf>
- United States Census Bureau. (2015). Health insurance coverage in the United States: 2014. (Consumer Income Reports P60-253). Washington, DC: U.S. Government Printing Office. Retrieved from
<https://www.census.gov/content/dam/Census/library/publications/2015/demo/p60-253.pdf>

- United States General Accounting Office. (2000). Medicare: More beneficiaries use hospice, but for fewer days of care (GAO Publication No. GAO/HEHS-00-182). Washington, DC: U.S. Government Printing Office. Retrieved from <http://www.gao.gov/new.items/he00182.pdf>
- Unroe, K. T., & Meier, D. E. (2011). Palliative care and hospice: Opportunities to improve care for the sickest patients. *Notre Dame Journal of Law, Ethics & Public Policy*, 25(2), 413-428. Retrieved from <http://scholarship.law.nd.edu/ndjlepp/vol25/iss2/10/>
- von Bertalanffy, L. (1968). *General system theory: Foundations, development, application*. New York, NY: George Braziller.
- Weissman, D. E., & Blust, L. (2005). Education in palliative care. *Clinics in Geriatric Medicine*, 21(1), 165-175. <http://dx.doi.org/10.1016/j.cger.2004.08.004>
- Weissman, D. E., Mullan, P.B., Ambuel, B. & von Gunten, C. (2002). End-of-life curriculum reform: Outcomes and impact in a follow-up study of internal medicine residency programs. *Journal of Palliative Medicine*, 5(4), 497–506. <http://dx.doi.org/10.1089/109662102760269733>
- Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67. <http://dx.doi.org/10.1017/S1478951511001027>
- World Health Organization. (2004). *A glossary of terms for community health care and services for older persons*. (Ageing and Health Technical Report, Volume 5). Geneva, Switzerland: Author. Retrieved from http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf

Zabora, J. R. (2011). How can social work affect health care reform? *Health & Social Work*, 36(3), 231–232. <http://dx.doi.org/10.1093/hsw/36.3.231>

Zilberfein, F., & Hurwitz, E. (2004). Clinical social work practice at the end of life. In J. Berzoff & P. R. Silverman (Eds.), *Living with dying: A handbook for end of life healthcare practitioners* (pp. 297-317). New York, NY: Columbia University Press.

Appendix A

Smith College School for Social Work Human Subjects Review Application



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 2, 2015

Christine Couture

Dear Christine,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Mary Beth Averill, Research Advisor

Smith College School for Social Work
Human Subjects Review Application

Project title: Hospice Social Work and the Patient Protection and Affordable Care Act (PPACA)

Name of researcher: Christine Couture

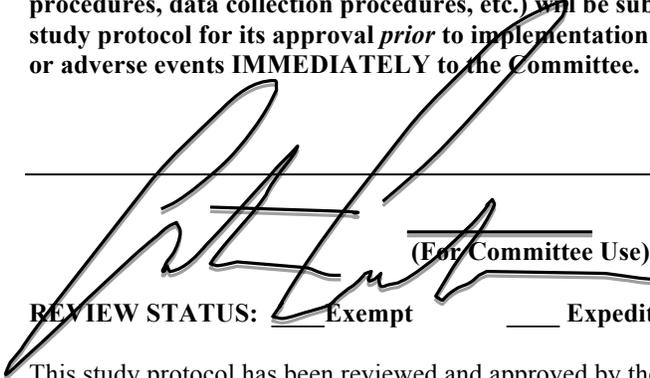
Check one: MSW PhD

Home phone: xxx-xxx-xxxx Email: ccouture@smith.edu

Research advisor: Mary Beth Averill

The signature below testifies that I, as the researcher, pledge to conform to the following: As one engaged in research utilizing human subjects, I acknowledge the rights and welfare of the participants involved. I acknowledge my responsibility as a researcher to secure the informed consent of the participants by explaining the procedures and by describing the risks and benefits of the study. I assure the Committee that all procedures performed under the study will be conducted in accordance with those federal regulations and Smith School for Social Work policies that govern research involving human subjects.

Any deviation from the study (e.g.: change in researcher, research methodology, participant recruitment procedures, data collection procedures, etc.) will be submitted to the Committee in the form of a change of the study protocol for its approval *prior* to implementation. I agree to report all deviations to the study protocol or adverse events IMMEDIATELY to the Committee.



(For Committee Use)

REVIEW STATUS: Exempt Expedited Full Not Approved

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Board (HSRB).

Chair, Smith College SSW HSRB

Date

IN THE SECTIONS BELOW WHERE DESCRIPTIONS ARE REQUESTED, BE SURE TO PROVIDE SUFFICIENT DETAIL TO ENABLE THE COMMITTEE TO EVALUATE YOUR PROCEDURES AND RESPONSES.

DESCRIPTION OF RESEARCH PROJECT INVOLVING HUMAN PARTICIPANTS

Briefly summarize:

1. The purpose of the study,

The purpose of this study is to explore the perceptions of U.S.-based hospice social workers of the changing responsibilities of providing hospice services in the climate of changing regulation and increased Medicaid recipients as a result of the Patient Protection and Affordable Care Act.

2. The over-arching research question,

How have hospice service responsibilities changed for U.S.-based hospice social workers in the climate of changing regulation and increased Medicaid recipients as a result of the Patient Protection and Affordable Care Act?

3. Brief literature review with citations,

The purpose of this study is to explore how hospice social workers working for U.S.-based hospice agencies are perceiving changes in their work responsibilities in relation to the Patient Protection and Affordable

Care Act and explore the relationship of these changes to hospice social workers working in for-profit agencies and those working in not-for-profit agencies, states that accepted the Medicaid expansion and states that did not, states that offer the optional Medicaid Hospice Benefit and those that do not.

The Patient Protection and Affordable Care Act (PPACA) HR-3590 (2010), or Affordable Care Act for short, is the health care reform federal statute signed into law in 2010 by President Barack Obama. Often called by its nickname, Obamacare, this reform act refers to two separate pieces of legislation: the Patient Protection and Affordable Care Act (Public Law 111-148, 2010) and the Health Care and Education Reconciliation Act of 2010 (Public Law 111-152, 2010). This historical and highly controversial legislation expanded Medicaid coverage to millions of low-income Americans and made numerous improved changes to both Medicaid and the Children's Health Insurance Program (CHIP). It also includes amendments to other laws like the Food, Drug and Cosmetics Act and the Health and Public Services Act.

Several provisions of the Patient Protection and Affordable Care Act (2010) that were enacted into law are directly relevant to hospice care. These provisions require hospice to report quality measures to The Center for Medicare and Medicaid Services (CMS) of the U.S. Department of Health and Human Services or receive a reduction in Medicare and Medicaid payments.

Additionally, provisions allowing research on a new model of reimbursable care permits adult Medicare recipients access to both hospice and “curative/life-prolonging care”, also known as “concurrent care,” will be evaluated for potential expansion (Meier, 2011). Currently, individuals cannot access concurrent care through the highly standardized Medicare Hospice Benefit. Patients and their caregivers may only elect to access “curative/life-prolonging care” or hospice. Furthermore, under the PPACA, children enrolled in Medicare or Children’s Health Insurance Program (CHIP) will now be allowed to elect access to concurrent care.

Unlike many terms used to describe phases of end-of-life care, a general consensus exists on what constitutes “hospice care,” which can be defined as a predominantly community-based program that provides interdisciplinary multidimensional care for patients with terminal illness (i.e., expected survival fewer than six months) and their families, working in conjunction with volunteers to provide services ranging from symptom management to bereavement care. “Hospice care” is considered to be under the spectrum of “palliative care” and the two are often paired together as “hospice and palliative care” in end-of-life literature (Bausewein & Higginson, 2012; Billings & Block, 1997; Hui, Mori, Parsons, Kwon, Torres-Vigil, & Bruera, 2013). Information about the

current quality measures of palliative care and hospice programs is limited, but both the United States and other nations are investing in outcomes measures for quality improvement and public reporting (Anderson & Squires, 2010). In fact, PPACA provisions increase the quality measure reporting requirements for hospice agencies that accept Medicaid and CHIP funding.

Many experts have made projections on the impact of health care services as a result of the changes dictated by the PPACA provisions, including to the hospice and palliative care workforce. In the last fifteen years, the number of hospice programs in the United States has grown by forty-seven percent (Medicare Payment Advisory Commission, 2009, 2010b; National Hospice and Palliative Care Organization, 2010). This growth in hospice programs, as well as a seventy-four percent increase in the number of persons served by hospice (Medicare Payment Advisory Commission, 2009, 2010b; National Hospice and Palliative Care Organization, 2010), illustrates a rising demand for hospice care services. Additionally, due to increased regulatory requirements, forecasters have anticipated a large increase in work responsibilities for hospice physicians in a field that has already demonstrated a need for more resources (Maison, 2010), as revealed by a report commissioned by the Health Resources and Services Administration (HRSA) in 2002 that projected significant shortfalls in the nation's number of palliative medicine specialists (Conner et al., 2007). The 2002 report also called for an examination of the appropriate role of non-physician professionals (such as nurse practitioners, clinical social workers, and physician assistants) in strengthening access to palliative care across health care settings.

The role of social work is still being defined within modern healthcare, and specifically with regard to facing advanced illness and end-of-life care (Brandsen, 2005; Institute of Medicine; Brown et al., 2001; Jones, 2005). Bosma et al. (2010) stated that, "The lack of a clearly defined [social work] identity has contributed to other professionals' confusion about what social workers actually do in hospice palliative care, and, consequently, other professions often have inadequate knowledge about the complexity and value of social work practice in this area (Oliviere, 2001; Thompson, Rose, Wainwright, Mattar & Scanlan, 2001; Christ & Sormanti, 2000)."

4. Type of study design/approach i.e. internet based survey, in person survey; phone interview; in person interview.

Internet based survey

PARTICIPANTS:

a). How many participants will be involved in the study?

12-15 ≥ 50 Other (how many do you anticipate)

b). List specific eligibility requirements for participants, including inclusionary criteria and any specific exclusion criteria. For example, if including only male participants, *explain why*.

- *Social Workers (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program)*
- *Currently working for a U.S.-based agency providing hospice care*
- *Worked for a U.S.-based agency providing hospice care before March 23, 2010*

c). Describe how participants will be recruited:

Participants will be recruited through the following methods:

1) Recruitment Letter/Email to friends, family, and professional contacts and their referrals:

“Dear Friends, Family, and Colleagues,

My name is Christine Couture and I am a graduate student studying social work at Smith College. For my master’s thesis, I am conducting a mixed methods study exploring hospice social workers’ perceptions of changes in their work responsibilities since the Patient Protection and Affordable Care Act (PPACA) was passed into law. Very little research has been done on the subject of hospice social work and the PPACA. I am interested in gaining a better understanding of how hospice social workers responsibilities have changed since the PPACA and in exploring how other variables - such as states which accepted the Medicaid expansion, for-profit and not-for-profit agencies, full-time and part-time, and other demographic information – impact these perceived changes to hospice social worker responsibilities, if at all.

Will you please help me find participants to complete a brief online survey for my study?

I am seeking social workers (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program) who are currently working for a U.S.-based hospice service provider, and who worked for a U.S.-based hospice service provider prior to March 23, 2010 when the Patient Protection and Affordable Care Act (PPACA) was passed into law.

The online survey consists of 20 questions, and will take 15-20 minutes to complete. The survey has been set up in a manner that ensures that participation is anonymous.

Please forward this email to anyone you know who might be interested in completing the survey or if you are interested, please [click here](#) or copy and paste the following URL into your browser

<https://www.surveymonkey.com/s/hospiceswppaca>.

If you have any questions, please contact me at christine.a.couture@gmail.com.

Thank you for your time and assistance,

Christine Couture

--

Christine Couture

Master’s of Social Work Candidate

Smith College School for Social Work”

2) LinkedIn.com - hospice and palliative care related professional networking groups

On LinkedIn.com, you are allowed to post to a group’s discussion forum if you are a member of that group and the post is in accordance to each group’s participation guidelines. Prior to posting to the hospice and palliative care related LinkedIn groups, I will contact the group manager/administrator. In this correspondence, I will formally notify the group manager/administrator that I will be posting to recruit for my study and request for the group manager/administrator to specify in which forum section they would prefer I recruit. I will then proceed as directed. Otherwise, if I do not hear from the group manager/administrator, one week from my correspondence date, I will notify the group manager/administrator the forum under which I will be posting my recruitment post and that if they would prefer I move my recruitment post to a different section than I will do so once instructed. The post will read as follows:

“Post Header: Seeking hospice social workers for my master’s thesis

Post Body: I am a graduate student studying social work at Smith College. For my master’s thesis, I am conducting a mixed methods study exploring hospice social workers’ perceptions of changes in their work-related responsibilities since the U.S. government passed the Patient Protection and Affordable Care Act (PPACA) into law. I am interested in gaining a better understanding of how hospice social workers responsibilities have changed since the PPACA and explore other variables that may impact these perceived changes, if at all.

Please share this post with anyone you know who might be interested in completing the survey or if you are interested, please [click here](#) or copy and paste the following URL into your web browser

<https://www.surveymonkey.com/s/hospiceswppaca>. Thank you for your time and assistance.”

3) Hospice and palliative care related professional organizations’ member discussion forums

Prior to posting to the organization's discussion forum, I will contact the Executive Director of the organization expressing my interest in posting a recruitment request for my study to the organization's discussion forum. After obtaining verbal consent I will notify them that I will send them the Template for an Agency or Institution Approval Letter (along with an addressed and stamped envelope) requiring a written signature and printed copy of their consent for me to proceed. Once I have obtained the signed letter from the organization, I will scan them and email them to the HSR Committee, while maintaining files of the original documents.

Please see Appendix A attached for the Template for an Agency or Institution Approval Letter obtained from the Smith Moodle > Thesis Advising Resources SSW997 (2014-2015) > HSR Forms 2014-15.

1. How you identify participant pool – if you have others helping with participant identification, please describe. Participants will self-identify as a social worker (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program), currently working for a U.S.-based hospice service provider, and worked for a U.S.-based hospice service provider prior to March 23, 2010.

2. How you will contact these people

Please see part c above for recruitment plan. Additionally, if participants choose to contact me, I will respond to them either by email or phone.

3. How you will screen

I will screen participants through the anonymous online SurveyMonkey survey link, by including the following screening question into the study instrument:

Do you qualify to participate in this study?

- Yes, I am a social worker (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program), I am currently working for a U.S.-based hospice service provider, and I worked for a U.S.-based hospice service provider prior to March 23, 2010.
- No, I do not meet the aforementioned criteria for inclusion in this study.

If the self-screening participant selects "No, I do not meet the aforementioned criteria for inclusion in this study." the survey link will redirect the interested participant to a survey webpage stating:

"Unfortunately, you do not meet the eligibility criteria to be included as a participant in this study. Thank you for your interest in participating."

If the self-screening participant selects "Yes, I am a social worker (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program), I am currently working for a U.S.-based hospice service provider, and I worked for a U.S.-based hospice service provider prior to March 23, 2010." the survey link will redirect the interested participant to the informed consent page.

4. How you will obtain informed consents

I will obtain informed consent electronically through the survey instrument on the informed consent page, after the screened participants verify their eligibility to participate in this study.

Please see Appendix C for the electronic informed consent.

5. How you will provide opportunities for asking questions

I will provide my email in the Recruitment Letter to Professional Colleagues and Friends, the Recruitment Post in online LinkedIn Groups and in the survey instrument itself.

6. Include copies of flyers, letters, announcements, email messages etc. that will be used to recruit.

Please see c1, c2, and c3 above.

d). Is there any relationship between you as the researcher and the participants (e.g. teacher/student, superintendent/principal/teacher; supervisor/clinician; clinician/client, etc.) that might lead to the appearance of coercion? If so, what steps will you take to avoid this situation. For example: "I will not interview individuals who have been direct clients."

No. There is no relationship between the participants and me (the researcher) that might lead to the appearance of coercion.

e). Are study target populations any of the following federally defined vulnerable populations?

Yes No

If 'Yes', check all that apply:

minors (under 18 years of age)

prisoners

- pregnant women
- persons with physical disabilities
- persons with mental disabilities
- economically disadvantaged
- educationally disadvantaged

If any of the above are anticipated participants in this study, state the necessity for doing so. Please indicate the approximate age range of minors to be involved. Participants under age 18 require participant assent AND written consent from the parent/legal guardian. Please use relevant forms.

RESEARCH METHODS:

(Check which applies)

- Interview, focus group, non-anonymous questionnaire
- Anonymous questionnaire/survey
- Observation of public behavior
- Analysis of de-identified data collected elsewhere
- () Where did these data come from originally?

Did this original research get IRB approval? Yes No

(Skip to BENEFITS section)

Other (describe) _____

Describe the nature of the interaction between you and the participants. Additionally, if applicable, include a description of the ways in which different subjects or groups of participants will receive different treatment (e.g., control group vs comparison group, etc.).

a). Please describe, with sufficient detail, the procedure/plan to be followed in your research (e.g. what participants will do).

Participants will complete the anonymous online SurveyMonkey survey, which will take approximately 15-20 minutes.

b). How many times will you meet/interact with participants? (If you are only observing public behavior, SKIP to question d in this section.)

I do not expect to meet or interact with participants unless they contact me by email.

c). How much total time will be required of each participant?

15-20 minutes.

d). Where will the data collection occur (please provide sufficient detail)?

On an anonymous online SurveyMonkey survey

e). If you are conducting surveys, attach a copy of the survey instrument to this application. If you are conducting individual interviews or focus groups, including ethnographies or oral histories, attach a list of the interview questions as an "Attachment". Label attachments alphabetically, with descriptive titles (e.g.:

Attachment A: Interview Questions).

Please see Appendix B attached.

INFORMED CONSENT: (If you are only observing public behavior, SKIP to next section)

a). What categories of consent documentation will you be obtaining from your participants? (Check all that apply)

- written participant consent through the anonymous online SurveyMonkey survey
- written parent/guardian consent
- Child assent 14-17
- Child assent, assent 6-13
- Adult with guardian assent

b). Attach original consent documents. *note: be advised that, once the study begins, ALL consents/assents *except those collected in connection with anonymous surveys* will require [wet] signatures – no faxed or email/electronically signed copies.

N/A. Consents will be collected electronically through the study instrument (an anonymous online SurveyMonkey survey).

COLLECTION /RETENTION OF INFORMATION:

a). With sufficient detail, describe the method(s) of recording participant responses (e.g., audiotape, videotape, written notes, surveys, etc.)

An anonymous online SurveyMonkey survey.

b). Include the following statement to describe where and for how long will these materials will be stored and the precautions being taken to ensure the security and safety of the materials:

All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period.

c). Will the recordings of participant responses be coded for subsequent analysis? *If you are only observing public behavior, SKIP to next section.*

Yes

No – I will not have audio or video recordings of participant responses. However, I will have participant written records from the survey, which I may be coding for analysis.

CONFIDENTIALITY:

a). What assurances about maintaining privacy will be given to participants about the information collected?

1. Anonymity is assured (data cannot be linked to participant identities, including IP addresses)

2. Confidentiality is assured (names and identifying information are protected, i.e., stored separately from data).

3. Neither anonymity nor confidentiality is assured

b). If you checked (2) above, describe methods to protect confidentiality with sufficient detail. Describe how you will maintain privacy of the participant as well as the data

c). If you checked (3) above, explain, with sufficient detail, why confidentiality is not assured.

d). If you checked (3) above, provide sufficient detail that describes measures you will take to assure participants understand how their information will be used. Describe and attach any permissions/releases that will be requested from participants.

RISKS:

a). Could participation in this study cause participants to feel uncomfortable or distressed?

Yes

No – Participants will be answering anonymous survey questions related to changes in their work

If yes, provide a detailed description of *what steps* you will take to protect them.

b). Are there any other risks associated with participation (e.g. financial, social, legal, etc.)?

Yes

No

If yes, provide a detailed description of the measures you will take to mitigate these additional risks.

COMPENSATION: (If you are only observing public behavior, SKIP to the next section)

Describe any cash or ‘gifts’ (e.g.: coffee shop gift card) that participants will receive for participating in this research (see guidance about payment/gift compensation in the Smith School for Social Work Human Subjects Review Guideline, at the HSR site in the SSW website).

There will be no compensation for participation in this study.

BENEFITS:

a). Describe the potential benefits for the researcher (you).

This research will support the researcher’s completion of the MSW research requirement.

b). Describe the potential or guaranteed benefits for participants, EXCLUDING payment/gift compensations.

The participants may gain new insight into their practice as a hospice social worker and how their practice has shifted since the Patient Protection and Affordable Care Act was enacted.

c). What are the potential benefits to social work/society from this research?

The participants’ feedback may contribute to the growing body of knowledge on hospice social work, as well as aid in building an identity and defining the role of hospice social work especially working within interdisciplinary teams. This information may also inform future hospice practices and strategies for service, recruitment and policy making.

FINAL APPLICATION ELEMENTS:

a. Include the following statement to describe the intended uses of the data:

The data collected from this study will be used to complete my Master’s in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

b. If there are Co- Researchers, cooperating departments, and/or cooperating institutions, follow the following instructions:

N/A

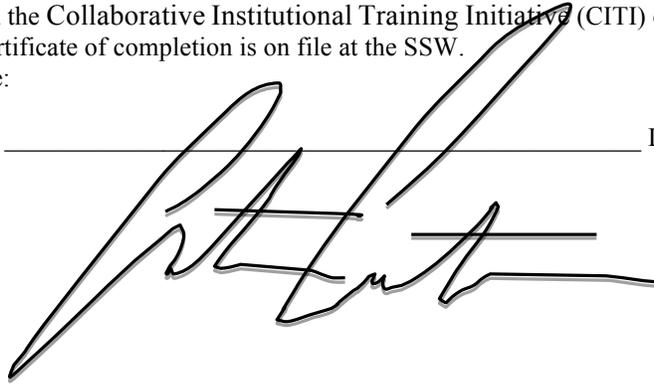
c. TRAINING:

I have completed the Collaborative Institutional Training Initiative (CITI) on line training course prior to HSR approval. The certificate of completion is on file at the SSW.

d. Your signature:

RESEARCHER: _____ DATE: 2/27/15

Updated 8-6-14

A handwritten signature in black ink, appearing to be 'R. H. Smith', written over a horizontal line. The signature is stylized and cursive.

Appendix B

Research Project Change of Protocol Submission



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 11, 2015

Christine Couture

Dear Christine,

I have reviewed your amendments and they look fine. These amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Mary Beth Averill, Research Advisor

RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

**Hospice Social Work and the Patient Protection and Affordable Care Act (PPACA)
Christine Couture
Mary Beth Averill, PhD**

.....

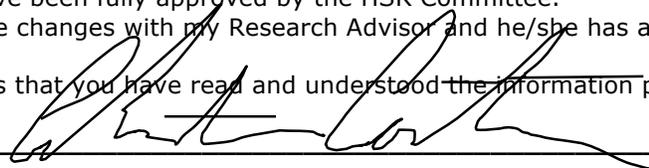
I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

1. *To the participant recruitment section, I will **add** the following:*
 - a. *Facebook recruitment– I will post a recruitment message on my personal Timeline/News Feed, in Smith SSW student-organized groups and other personal and professional groups of which I am an active member.*
 - b. *LinkedIn recruitment – in addition to the hospice and palliative care related professional groups of which I am a member, I will also post recruitment messages to other social work related groups, Smith College School for Social Work groups, and other personal and professional groups of which I am an active member.*
2. *To the participant recruitment section, I will **delete** the first sentence of the approved Recruitment Letter/Email to friends, family, and professional contacts and their referrals, (which reads: “My name is Christine Couture and I am a graduate student studying social work at Smith College.”). And I will replace it with “I am pursuing my graduate degree in clinical social work at Smith College School for Social Work and could use your help with my research project. Would you please take a moment to read this email/letter to see if you or someone you know may be able to assist me? [¶]”*

.....

- I understand that these proposed changes in protocol will be reviewed by the Committee.
- I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
- I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: 

Name of Researcher (PLEASE PRINT): Christine Couture **Date:** 03/09/15

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

***Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.

.....

Appendix C

Electronic Informed Consent to Participate in a Research Study

Title of Study: Hospice Social Work and the Patient Protection and Affordable Care Act (PPACA)

Investigator(s): Christine Couture, Smith College School for Social Work, (xxx) xxx-xxxx

.....

Introduction

You are being asked to participate in a research study on U.S.-based hospice social work. You were selected as a possible participant because you identify as a social worker (BSW, MSW, and/or PhD or DSW in Social Work from a Council on Social Work Education (CSWE) accredited program), you currently work for a U.S.-based hospice service provider, and you worked for a U.S.-based hospice service provider prior to March 23, 2010.

We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

The purpose of the study is to explore hospice social workers' perceptions of changes in their work responsibilities since the Patient Protection and Affordable Care Act (PPACA) was passed into law. This study is being conducted as a research requirement for my master's in social work degree. Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

If you agree to be in this study, you will be asked to do the following things:

You will be asked to take a brief survey that will take 15-20 minutes to complete. You will be asked to complete 20 survey items - consisting of several multiple-choice questions, as well as questions where you will be asked to write in your responses. Participants are encouraged to answer each question with the response that best fits the question.

Risks/Discomforts of Being in this Study

The study has the following risk:

Emotions can arise as you reflect on your social work-related responsibilities in your U.S.-based hospice service, which you may or may not want to explore. The likelihood of this potential risk of participating in this study is minimal.

Benefits of Being in the Study

You may benefit from gaining new insight into and having the opportunity to write about your practice as a hospice social worker and how your practice has shifted since the Patient Protection and Affordable Care Act was enacted. You may also benefit from contributing to the growing body of knowledge on hospice social work, as well as aiding in building an identity and defining the current role of hospice social.

This information may benefit social work and society by informing future hospice practices and strategies for service, hospice recruitment, and hospice policy.

Confidentiality

This study is anonymous. We will not be collecting or retaining any information about your identity.

As an online data collection platform, Survey Monkey encodes the data, and the data sent to the researcher is unidentifiable. Therefore, while my research advisor, the statistical consultant, and I will have access to the data, we will only be able to view the answers to the survey with no identifiable information of the participants. The data collected in this study will be presented in the aggregate in presentations and/or publications, which will further minimize the risks of identification. Data from this survey will be kept in a secure location for a period of three years as required by Federal guidelines and data stored electronically will be protected. Data will be destroyed when it is no longer needed.

Payments/gift

You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time - by simply closing your survey window or the tab in your web browser and not complete the survey - without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely from this study at any time during the survey. If you choose to withdraw by not completing the survey, your data will not be included in the research. Only completed surveys in which all questions are answered will be used for the study. Once the survey is completed and your

answers are submitted, you can no longer withdraw. I will have no way to exclude your answers, as there is no way to identify which answers are yours.

Right to Ask Questions and Report Concerns

You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Christine Couture at ccouture@smith.edu or by telephone at (xxx) xxx-xxxx. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

BY SELECTING “I CONSENT” BELOW YOU ARE INDICATING THAT YOU HAVE READ AND UNDERSTAND THE INFORMATION ABOVE AND THAT YOU HAVE HAD AN OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Please print a copy of this consent for your personal records.

[The following are radio buttons in the survey, from which the participant is required to select in order to advance to the survey questions and can only select one]

- I consent.

- I do not consent.

Appendix D
Study Instrument

1. What is your age?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

2. What is your gender?

- Female
- Male
- Transgender
- Other

3. What is your race/ethnicity? (check all that apply)

Please choose the best answer(s).

- Asian
- Black or African-American
- Hispanic or Latin(a/o)
- Middle-Eastern
- Native American or Alaskan Native
- Native Hawaiian or Pacific Islander
- White
- Multi-racial
- Choose not to disclose
- Other

4. How many years of professional social work experience do you have?

Please enter a whole number.

5. How many years of professional hospice experience do you have?

Please enter a whole number.

6. Which of the following best describes your current job level?

Please choose the best answer.

- Top management
- Middle management
- Direct service provider

7. Not including your Continuing Education Units (CEUs), what is the highest level of social work education you have completed? (check all that apply)

Please choose the best answer.

- Bachelor's degree in Social Work
- Master's degree in Social Work
- Doctor of Philosophy in Social Work or Doctor of Social Work

8. Have you completed or are you currently working towards a certification or fellowship as an end-of-life care provider?

Please choose the best answer.

- Yes. I have completed an end-of-life care certification/fellowship.
- Yes. I am currently working towards an end-of-life care certification/fellowship.
- No. I have not completed nor am I currently working towards an end-of-life care certification/fellowship.

9. Which of the following categories best describes your hospice employment status?

- Employed, working full-time
- Employed, working part-time
- Working on temporary contract
- Other (please specify):

10. In what state or U.S. territory do you currently work?

11. Is the U.S.-based hospice agency for which you work a nonprofit, for-profit, or government owned organization?

Please choose the best answer.

- A nonprofit
- For-profit
- Government owned
- Unsure

12. What type of community does your U.S.-based hospice serve? (check all that apply)

Please choose the best answer(s).

City or urban community

Rural community

Suburban community

13. Is your hospice? (check all that apply)

Please choose the best answer(s).

Free-standing/independent

Part of a hospital/health system

Part of a home health agency

Part of a nursing home

Part of a chain of hospices

14. How do you think the Patient Protection and Affordable Care Act (a.k.a. Affordable Care Act, Obamacare) - which was signed enacted into law on March 23, 2010 - has changed your work in hospice care, if at all?



In questions numbered 15-19, please reflect on the time and effort you spend working in the following categories of hospice social work-related responsibilities since the Patient Protection and Affordable Care Act (PPACA) was enacted into law on March 23, 2010:

CATEGORIES:

- **CLINICAL AND COUNSELING** - assessment of psychosocial issues, crisis intervention, counseling in the areas of suicide or wanting to hasten death, denial, anticipatory grief, bereavement, death anxiety, safety issues, on-call responsibilities, caregiver support, family counseling, etc.
- **CASE MANAGEMENT** - financial counseling, insurance navigation, referrals, discharge planning, facilitating social supports, community outreach, case coordination, intake interviews, etc.
- **MANAGEMENT AND ADMINISTRATION** - supervising hospice social workers, directing the agency, planning, program assessment and management, creating agency policy, data reporting, training, volunteer management, etc.
- **ADVOCACY** - civil and legal assistance, upholding preference of environment, advocating on behalf of the client, research, ethical dilemmas, etc.
- **CULTURAL AND SPIRITUAL SUPPORT** - cultural competence, ensuring culturally competent end of life decisions, supporting direct spiritual experience, discussing the meaning of life, etc.

15. How has the time and effort you spend working on CLINICAL AND COUNSELING-related responsibilities at your U.S.-based hospice agency changed since the Affordable Care Act was enacted into law?

CLINICAL AND COUNSELING - assessment of psychosocial issues, crisis intervention, counseling in the areas of suicide or wanting to hasten death, denial, anticipatory grief, bereavement, death anxiety, safety issues, on-call responsibilities, caregiver support, family counseling, etc.

- Significantly increased
- Increased
- Neither increased nor decreased
- Decreased
- Significantly decreased

How do you explain this change?

16. How has the time and effort you spend working on CASE MANAGEMENT-related responsibilities at your U.S.-based hospice agency changed since the Affordable Care Act was enacted into law?

CASE MANAGEMENT - financial counseling, insurance navigation, referrals, discharge planning, facilitating social supports, community outreach, case coordination, intake interviews, etc.

- Significantly increased
- Increased
- Neither increased nor decreased
- Decreased
- Significantly decreased

How do you explain this change?

17. How has your time and effort spent working on MANAGEMENT AND ADMINISTRATION-related responsibilities at your U.S.-based hospice agency changed since the Affordable Care Act was enacted into law?

MANAGEMENT AND ADMINISTRATION - supervising hospice social workers, directing the agency, planning, program assessment and management, creating agency policy, data reporting, training, volunteer management, etc.

- Significantly increased
- Increased
- Neither increased nor decreased
- Decreased
- Significantly decreased

How do you explain this change?

18. How has your time and effort spent working on **ADVOCACY related responsibilities at your U.S.-based hospice agency changed since the Affordable Care Act was enacted into law?**

ADVOCACY - civil and legal assistance, upholding preference of environment, advocating on behalf of the client, research, ethical dilemmas, etc.

- Significantly increased
- Increased
- Neither increased nor decreased
- Decreased
- Significantly decreased

How do you explain this change?

19. How has the time and effort you spend working on **CULTURAL AND SPIRITUAL SUPPORT-related responsibilities at your U.S.-based hospice agency changed since the Affordable Care Act was enacted into law?**

CULTURAL AND SPIRITUAL SUPPORT - cultural competence, ensuring culturally competent end of life decisions, supporting direct spiritual experience, discussing the meaning of life, etc.

- Significantly increased
- Increased
- Neither increased nor decreased
- Decreased
- Significantly decreased

How do you explain this change?

20. Some people are in strong support of the Affordable Care Act, while others are unwaveringly opposed to the legislation. Some people have ambivalent or indifferent thoughts and feelings about the Affordable Care Act. How would you describe your support of the Affordable Care Act?

A large, empty rectangular text input area with a light blue background. It has a small upward-pointing arrow in the top right corner and a small downward-pointing arrow in the bottom right corner, indicating it is a scrollable text field.

Please use this space to provide any additional comments about the Affordable Care Act's effect on your hospice work:

A small, empty rectangular text input area with a light blue background. It has a small upward-pointing arrow in the top right corner and a small downward-pointing arrow in the bottom right corner, indicating it is a scrollable text field.

Appendix E

LinkedIn Recruitment Post

Seeking hospice social workers for my master's thesis

Mar 7, 2015 | 72 views | 6 likes | 2 comments | [in](#) [f](#) [g+](#) [t](#)

I am a graduate student studying social work at Smith College. For my master's thesis, I am conducting a mixed methods study exploring hospice social workers' perceptions of changes in their work-related responsibilities since the U.S. government passed the Patient Protection and Affordable Care Act (PPACA) into law. I am interested in gaining a better understanding of how hospice social workers responsibilities have changed since the PPACA and explore other variables that may impact these perceived changes, if at all.

Please share this post with anyone you know who might be interested in completing the survey or if you are interested, please [click here](https://www.surveymonkey.com/s/hospiceswppaca) or copy and paste the following URL into your web browser <https://www.surveymonkey.com/s/hospiceswppaca>.

Thank you for your time and assistance.

[in](#) [f](#) [g+](#) [t](#) ...

Appendix F

LinkedIn Group Owner/Manager Correspondence



InMail |

Posting to Social Work Hospice & Palliative Care
Network Group

March 6, 2015, 10:03 PM

[Name of Group Owner/Manager]

I hope this email finds you well. I understand you are one of the LinkedIn group managers for [Name of Group], a group of which I am a member.

I am a graduate social work student conducting research for my master's thesis on hospice social work and the Patient Protection and Affordable Care Act. I will be posting in the group to recruit participants for my study.

Please let me know your preference as to which forum section (Discussions, Promotions, or Jobs) in which I should post a link to my study requesting participation. If you have no preference or if I do not hear back from you within a reasonable timeline, I will post in the Discussions section. Please let me know.

Thank you for your time.

Sincerely,
Christine Couture
Smith College School for Social Work

Appendix G

Facebook Recruitment Post

 **Christine A. Couture**
March 14 · 🌐 ▼

Questions for my FB community:

Do you currently work in hospice social work or know someone who does? Do you know someone who might know hospice social workers? If so, I could use your support!

I am conducting a study for my master's thesis on hospice social work and changes in the field's work-related responsibilities since the implementation of the Patient Protection and Affordable Care Act (a.k.a. Obamacare). I am currently seeking participants to take a 15-20 minute anonymous online survey. Eligibility criteria is: social workers (BSW, MSW, and/or PhD or DSW in Social Work from a Council for Social Work Education (CSWE) accredited program) who are currently working for a U.S.-based hospice service provider, and who worked for a U.S.-based hospice service provider prior to March 23, 2010 when the Patient Protection and Affordable Care Act (PPACA) was passed into law.

Please share this post with your network knowing you are contributing to research in end-of-life care and social work. For more information or to take the survey, click on the link below or copy and paste the following URL into your web browser: <https://www.surveymonkey.com/s/hospiceswppaca>.

Thank you for your help!

	<p>Hospice Social Work and The Patient Protection and Affordable Care Act (PPACA) Survey</p> <p>Web survey powered by SurveyMonkey.com. Create your own online survey now with SurveyMonkey's...</p> <p>SURVEYMONKEY.COM</p>
---	---